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Experienced emotional burden in caregivers: psychometric properties of the Involvement Evaluation Questionnaire in caregivers of brain injured patients

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Objective: To examine the psychometric properties (internal consistency, discriminant validity, and responsiveness) of the Involvement Evaluation Questionnaire for Brain Injury measuring emotional burden in caregivers of patients with chronic acquired brain injury.

Design: Inception cohort study.

Subjects: Caregivers of chronic acquired brain injury patients.

Main measures: Besides the Involvement Evaluation Questionnaire for Brain Injury, the Family Assessment Device and the General Health Questionnaire were used.

Methods: Ninety-eight caregivers filled out all questionnaires, of which 41 caregivers did this twice, before and after the persons they cared for had started a residential community reintegration programme. Cronbach's alpha and Intra class Correlation Coefficient were calculated for internal consistency. Pearson correlation coefficients were used for discriminant validity and Intra class Correlation Coefficient and Cohen's *d* were calculated to determine responsiveness.

Results: The internal consistency of the Involvement Evaluation Questionnaire for Brain Injury was good ($\alpha = 0.73\text{--}0.84$; Intra class Correlation Coefficient = $0.69\text{--}0.76$). As expected, low correlations were found between the Involvement Evaluation Questionnaire for Brain Injury and either the General Health Questionnaire ($r = 0.11\text{--}0.40$) or the Family Assessment Device subscales ($r = -0.29\text{--}0.19$). Regarding responsiveness of the Involvement Evaluation Questionnaire for Brain Injury, a moderate effect size was found (Cohen's *d* = 0.36) while the Intra class Correlation Coefficient was good (0.80).

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Conclusions: The Involvement Evaluation Questionnaire for Brain Injury measures the experienced emotional burden in caregivers of patients with chronic acquired brain injury and seems to be a promising new instrument with good internal consistency, discriminant validity and responsiveness.

Introduction

Brain injury has considerable consequences for family and other caregivers of the patients. High levels of experienced burden can lead to deterioration in caregivers' health status, social life and well-being.^{1,2} Furthermore, a high degree of caregivers' burden can have negative effects on the well-being of persons with brain injury and on the outcome of their rehabilitation.² Not so much caring for the patient, but the continuous sense of responsibility for and concerns about the brain injured person lead to experienced burden. In this perspective, experienced burden is to a large extent an emotional construct.

Rehabilitation programmes addressing the patients' level of functioning and participation can reduce the level of emotional burden on the caregiver.³ In order to evaluate the effectiveness of treatment on the caregivers we need valid and responsive measures for caregivers' emotional burden. However, such measures are lacking.⁴ In contrast, several questionnaires have been developed to evaluate the practical burden of care, for instance the Caregiver Strain Index, the Caregiver Reaction Assessment and the Sense of Competence Questionnaire.⁵ Moreover, proof of responsiveness is lacking in most of these caregivers' questionnaires,^{5,6} such as the Sense of Competence Questionnaire and the Caregiver Strain Index, or has not been conclusively demonstrated, such as for the Caregiver Reaction Assessment.⁵

Only in mental illness populations was a valid and reliable questionnaire developed, the Involvement Evaluation Questionnaire,⁷ as a self-report scale to measure emotional burden. Therefore, we decided to test the Involvement Evaluation Questionnaire in the brain injury population. For this purpose we slightly adapted the Involvement Evaluation Questionnaire into the Involvement Evaluation Questionnaire for Brain Injury. However, one cannot assume that the psychometric characteristics of the original

Involvement Evaluation Questionnaire, as established in mental illness populations, are the same in brain injured patients. Therefore, the goal of this study was to determine the internal consistency, validity and responsiveness of the Involvement Evaluation Questionnaire for Brain Injury in caregivers of patients with chronic acquired brain injury.

As in the mental illness populations,⁴ it is not possible to test concurrent validity of the Involvement Evaluation Questionnaire for Brain Injury, because no other instruments measure the same construct. Hence, in the present study, we have chosen to test discriminant validity using related constructs such as family functioning and caregivers' mental health. The first construct relates to healthy or unhealthy functioning.⁸ According to many researchers, family functioning is a rather stable characteristic which is related to both physical and psychiatric disorders.⁸⁻¹⁰ Yet, unhealthy family functioning can lead to a diminished tolerance of family problems, which may indirectly influence caregivers' burden. Therefore, we hypothesized that family functioning would show only a low association with experienced emotional burden ($r < 0.50$).

Caregivers' mental health problems can have several causes.¹¹ Wijngaarden *et al.*¹² found significant mental health problems only in a subgroup of caregivers of schizophrenic patients who experienced a high degree of burden. This finding is in accordance with the recently published study by Davis *et al.*,¹³ who found that mental health and practical burden are different constructs in caregivers of brain injured patients. Therefore, we hypothesized that caregivers' mental health would show merely a low association with emotional burden ($r < 0.50$).

In clinical practice and research, responsiveness of an outcome measure is one of its most important properties. To this end, we tested the Involvement Evaluation Questionnaire for Brain Injury in a group of patients with acquired brain injury who

had been admitted to a residential community integration programme.¹⁴ We expected that their caregivers would show at least some relief of emotional burden after the patients had started the programme, when compared to the moment of inclusion, as a result of feelings of hope and expectations of treatment effects.

Methods

The Brain Integration Programme is a residential community integration programme for patients with chronic acquired brain injury who show behavioural problems, severe problems in social and emotional functioning, and who experience great difficulties in their vocational integration.¹⁴ The inclusion criteria for the treatment are: (1) having sustained acquired brain injury (traumatic, stroke, tumour, encephalitis, hypoxia); (2) having problems in social areas, emotional disturbances, and labour/work integration; (3) unsuitability for other (outpatient) cognitive rehabilitation programmes.¹⁴

In ongoing studies on the effects of this programme, the principal caregivers of all patients who participated between the years 2004 and 2009 were included. In one part of the ongoing studies, concerning the admission period 2004–2007, the caregivers filled out the questionnaires twice: once after inclusion and the second time after a waiting list period of three months, which served as a control period in the effectiveness study.¹⁵ In this study 41 caregivers filled out the same questionnaires a second time, within two weeks after the start of the treatment programme.

The principal caregiver, who was at least 18 years old, was asked to fill out the questionnaires. No additional inclusion criteria were used. Each caregiver filled out the questionnaires immediately when the patient had been selected for the treatment programme. The study was approved by the regional medical-ethics committee.

Instruments

The Involvement Evaluation Questionnaire for Brain Injury (see appendix for the questionnaire items) is a slightly adapted version of the Involvement Evaluation Questionnaire.¹⁰

The Involvement Evaluation Questionnaire is an originally Dutch self report questionnaire with 31 items and has been developed to measure caregivers' worries, coping and emotional burden as a consequence of mental illness of patients. The Involvement Evaluation Questionnaire and the Involvement Evaluation Questionnaire for Brain Injury are both scored on a 5-point Likert scale (never, sometimes, regularly, often, [almost] always). The questions concern a period of four weeks prior to the assessment. It takes about 20 minutes to complete the Involvement Evaluation Questionnaire for Brain Injury. Two items contribute to two subscales. The Involvement Evaluation Questionnaire has a sum score based on 27 items and comprises four subscales:

- 1) Tension (9 items) refers to a possibly strained interpersonal atmosphere.
- 2) Supervision (6 items) by caregivers of patients' medicine intake, sleep, dangerous behaviours, etc.
- 3) Worrying (6 items), which covers painful interpersonal cognitions, for instance on patient's safety, health and health care.
- 4) Urging (8 items), which refers to activities such as stimulating the patient to take care of himself, eat appropriately and undertake sufficient activities.

The subscales were established through a factor analytic study.⁴ The Involvement Evaluation Questionnaire has been validated in several countries and is available in eleven European languages and in two non-European languages. The original Dutch version of the Involvement Evaluation Questionnaire has good internal consistency, test-retest reliability^{4,7,16} and is sensitive to change.¹⁷

The Involvement Evaluation Questionnaire for Brain Injury is essentially the same as the Involvement Evaluation Questionnaire, however, the term 'mental health problem' was replaced by 'brain injury problem' in four of the 31 items. This adaptation was made in collaboration with the developer of the original Involvement Evaluation Questionnaire.⁷

The Family Assessment Device^{9,18} is a widely used self report questionnaire¹⁹ and often applied in brain injury research.^{8,20,21} The Family

Assessment Device comprises 60 items and is based on the McMaster model of family functioning and family dynamics. The Family Assessment Device contains seven subscales: (1) problem solving, (2) communication, (3) roles, (4) affective responsiveness, (5) affective involvement, (6) culture and (7) general functioning. The concurrent and discriminant validity were good⁸ and the internal consistency of the subscales was moderate.²⁰ Furthermore, the one week test-retest reliability was moderate as well.¹⁰ Cut-off scores were determined per subscale to differentiate healthy from unhealthy families.¹⁰ The diagnostic confidence, being the proportion of correctly identified cases compared with expert opinion, was between 0.68 and 0.89.¹⁰

The 12 item version of the General Health Questionnaire^{11,22} is a widely used self report screening instrument for psychological health in general health care. The General Health Questionnaire is used as case-detector for mental health problems. The General Health Questionnaire had a high sensitivity and high specificity with a Receiver Operating Curve area of 0.88 in 5438 general health care patients.¹¹

Statistical analyses

Descriptive statistics were used for caregivers' and patients' characteristics. For internal consistency, Cronbach's alpha and one way Intra class Correlation Coefficients were determined, as was done in the study of the original Involvement Evaluation Questionnaire.⁴ Internal consistency was considered to be good if Cronbach's alpha and Intra class Correlation Coefficient were between 0.70 and 0.90.²³ Discriminant validity was tested by calculating Pearson correlation coefficients between the Involvement Evaluation Questionnaire for Brain Injury on the one hand and the Family Assessment Device subscales and the General Health Questionnaire on the other hand. To assess the responsiveness of the Involvement Evaluation Questionnaire for Brain Injury, one way Intra class Correlation Coefficients were calculated using a General Linear Model with repeated measures. In addition, responsiveness was expressed in terms of effect size, using Cohen's *d*, which was calculated by $(\mu_1 - \mu_2)/\sigma$, where $\mu_1 - \mu_2$ are the mean scores at

inclusion and at start of treatment, respectively, and σ is the standard deviation at inclusion. Values from 0.20 to 0.30 were considered a 'small' effect, between 0.30 and 0.80 a 'moderate' effect and greater than 0.80 a 'large' effect.²³ All analyses were performed with SPSS16.

Results

Ninety-eight caregivers of patients with acquired brain injury were included simultaneously with the patients that were included in the trial. All caregivers were willing to participate. The caregivers were predominantly female (67.3%; $n = 66$), their mean age was 48 (9.3) years, and most caregivers (80.6%; $n = 79$) were parents (Table 1a). Fifty-nine (60.2%) patients had sustained traumatic brain injury; 14 (14.3%), a brain tumour; 11 (11.2%), a stroke; 10 (10.2%), encephalitis; and 4 patients (4.1%), a hypoxia. Patients were predominantly male (69.4%; $n = 68$) and their mean age was 25 (7.8) years (Table 1b). Of the patients with traumatic brain injury, 86% had sustained a severe injury (Glasgow Coma Scale 3–8), 5% a moderate injury (Glasgow Coma Scale 9–12) and 9% a mild injury (Glasgow Coma Scale 13–15).

Regarding the sum score of the Involvement Evaluation Questionnaire for Brain Injury, Cronbach's alpha was 0.89 and the Intra class Correlation Coefficient 0.85. As for the subscales of the Involvement Evaluation Questionnaire for Brain Injury, Cronbach's alpha ranged from 0.73–0.84 and the Intra class Correlation Coefficient from 0.69–0.76 (Table 2). These values were slightly lower than those of the original Involvement Evaluation Questionnaire.⁷

Low correlations were found between the Involvement Evaluation Questionnaire for Brain Injury scales and the Family Assessment Device subscales ($r = -0.29$ – 0.19). Only two of the thirty-five tested correlations were statistically significant, namely Involvement Evaluation Questionnaire-Tension on the one hand and Family Assessment Device Problem solving and General functioning on the other hand. Similar results were found for the Involvement Evaluation Questionnaire for Brain Injury and the General Health Questionnaire ($r = 0.11$ – 0.40). Four of the five scales of the Involvement Evaluation Questionnaire for Brain

Table 1a Caregivers' characteristics: all caregivers (N=98) and responsiveness sample (N=41)

Caregivers		N=98		N=41	
Age in years	(SD; range)	48	(9.3; 22–71)	47.9	(8.2; 25–61)
Relation: Parent	(%)	79	(80.6)	33	(80.5)
Spouse		13	(13.3)	6	(14.6)
Child		1	(1.0)	0	(0)
Sibling		3	(3.1)	2	(4.8)
Other family member		1	(1.0)	0	(0)
Friend		1	(1.0)	0	(0)

Table 1b Patient characteristics (N=98)

Patients			
Age in years		(SD; range)	25 (7.8; 15–49)
Time since onset in years		(SD; range)	5.7 (6.2; 0.2–26.3)
Lowest GCS score for TBI patients within 24 hours		(SD; range)	6.6 (3.6; 3–15)
Coma duration in days		(SD; range)	24.1 (30.4; 0–14)

SD, standard deviation; GCS, Glasgow Coma Scale; TBI, traumatic brain injury.

Table 2 Internal consistency of the Involvement Evaluation Questionnaire for Brain Injury (N=98)

Subscale	n items	Cronbach's α	Intra class Correlation
Tension	9	0.84	0.76
Supervision	6	0.78	0.76
Worrying	6	0.79	0.73
Urging	8	0.73	0.69
Sum score	27	0.89	0.85

Injury showed low, but statistically significant correlations with the General Health Questionnaire ($r=0.33-0.40$).

Forty-one caregivers filled out the Involvement Evaluation Questionnaire for Brain Injury for a second time within two weeks after the start of the residential treatment programme, which was three months after the assessment at inclusion. The one way Intra class Correlation Coefficient was 0.80 (95% CI = 0.68–0.88), indicating a good reliability of the change score. Cohen's d effect size was 0.36. The raw scores at the start of treatment were lower, meaning less emotional burden, compared to the assessment at inclusion for treatment on the subscales Tension, Worrying, Urging and for the sum score (Table 3).

Discussion

The results of this study indicate that the internal consistency of the Involvement Evaluation Questionnaire for Brain Injury subscales was good and comparable to the internal consistency of the original Involvement Evaluation Questionnaire for mental illness populations.⁴ Furthermore, the responsiveness and (discriminant) validity of the Involvement Evaluation Questionnaire for Brain Injury seem to be good as well. The low correlations between the Involvement Evaluation Questionnaire for Brain Injury and either the General Health Questionnaire or the Family Assessment Device subscales indicate that family functioning and mental health are truly other constructs than experienced emotional burden of caregivers. The Family Assessment Device showed almost no association at all with the Involvement Evaluation Questionnaire for Brain Injury, suggesting that emotional burden is very different from a 'stable' construct such as family functioning.^{8,9} Emotional burden is determined by the worries and concerns of the caregiver about the patient. Indeed, a caregiver has to cope with the deficits of the patient as well as with his or her own worries about current and future

Table 3 Raw mean scores Involvement Evaluation Questionnaire for Brain Injury (N=41)

Scale	Mean at inclusion	(SD)	Mean at start	(SD)	Cohen's d
Tension	8.02	(4.91)	6.12	(4.36)	0.39
Supervision	2.00	(2.99)	2.12	(2.87)	-0.04
Worrying	9.12	(4.32)	8.17	(4.68)	0.22
Urging	7.73	(5.76)	5.76	(5.22)	0.34
Sum score ¹⁾	25.32	(14.11)	20.27	(13.50)	0.36

¹⁾Two items are used in more than one scale. The total score therefore differs from the sum of the subscales. SD, standard deviation.

functioning of the patient. In this perspective, emotional burden may be an 'anticipatory' measure, sensitive to expected changes rather than actual changes in functioning and participation of the patient. The General Health Questionnaire identifies persons with mental health problems.¹¹ Although many caregivers experienced mental health problems, the General Health Questionnaire showed only low correlations with caregivers' emotional burden. These low correlations were statistically significant, however, not clinically relevant. This result is in accordance with the study by Davis *et al.*,¹³ who found that caregivers' mental health was not associated with caregivers' practical burden.

As for the responsiveness of the Involvement Evaluation Questionnaire for Brain Injury, the observed moderate effect size corresponds to our expectations, as the start of the treatment programme probably led to feelings of hope, expectation and emotional relief in the caregivers of the patients, irrespective of the (future) changes in patients' functioning. On the subscale Supervision, the initial score was already low at inclusion, so that this subscale could hardly show improvement at the start of treatment. However, for the subscales Tension, Worrying, and Urging, the observed improvements all exceeded a 10% change, while the sum score showed a 20% improvement. The results of the current study are comparable to those of Stam and Cuijpers¹⁷ on the original Involvement Evaluation Questionnaire. Hence, the responsiveness of the Involvement Evaluation Questionnaire for Brain Injury seems to be a valuable psychometric quality, especially because data on the responsiveness of existing questionnaires of practical burden of care^{5,6} are still lacking or inconclusive.⁵

A limitation of this study is that it did not determine the test-retest reliability of the Involvement Evaluation Questionnaire for Brain Injury. Although this test property was found to be moderate to high for the original Involvement Evaluation Questionnaire,⁴ we have planned to perform a test-retest reliability study of the Involvement Evaluation Questionnaire for Brain Injury to confirm this finding in the brain injury population. After establishing the test-retest reliability, the responsiveness of the Involvement Evaluation Questionnaire for Brain Injury needs to be further supported by intervention studies. In addition, its construct validity should be further substantiated, for instance by testing the Involvement Evaluation Questionnaire for Brain Injury in different brain injury populations.

This study is a first indication that the Involvement Evaluation Questionnaire for Brain Injury has good internal consistency, discriminant validity and responsiveness, making it a potentially sound tool for the assessment of emotional burden of caregivers of patients with chronic brain injury.

Clinical messages

- Emotional burden seems to be a different construct than practical burden in caregivers of patients with acquired brain injury. Both aspects of caregivers' burden need to be addressed in interventions studies.
- The Involvement Evaluation Questionnaire for Brain Injury is as yet the only available instrument to assess emotional burden in caregivers of patients with acquired brain injury with potentially good validity, internal consistency and responsiveness.

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Contributors

GJG designed the study, supervised the collection of the data, supervised data-entry, performed data-analysis and interpretation, conducted the writing of the article and approved the final version of the article. RM provided clinimetric advice, performed data-analysis and interpretation, conducted the writing of the article and approved the final version of the article. JDM designed the study, conducted the writing of the article and approved the final version of the article. CVH performed data interpretation, conducted the writing of the article and approved the final version of the article. ACHG designed the study, conducted the writing of the article and approved the final version of the article.

Competing interests

None declared.

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Appendix – Involvement Evaluation Questionnaire for Brain Injury core item list

How often during the past four weeks (never, sometimes, regularly, often, [almost] always):

- 1) have you **encouraged** your relative/friend to take proper care of her/himself (e.g. washing, bathing, brushing teeth, dressing, combing hair etc.)?
- 2) have you **helped** your relative/friend to take proper care of her/himself?
- 3) have you **encouraged** your relative/friend to eat enough?
- 4) have you **encouraged** your relative/friend to undertake some kind of activity (e.g. go for a walk, have a chat, hobbies, household chores)?
- 5) have you **accompanied** your relative/friend on some kind of outside activity, because he/she did not dare to go alone?
- 6) have you **ensured** that your relative/friend has taken the required medicine?
- 7) have you **guarded** your relative/friend from committing dangerous acts (e.g. setting something alight, leaving the gas on, forgetting to stub cigarettes out)?
- 8) have you **guarded** your relative/friend from self-inflicted harm (e.g. cutting himself, excessive medicine intake, suicide attempt)?
- 9) have you **ensured** that your relative/friend received sufficient sleep?
- 10) have you **guarded** your relative/friend from drinking too much alcohol?
- 11) have you **guarded** your relative/friend from taking illegal drugs?
- 12) have you carried out tasks normally done by your relative/friend (e.g. household chores, financial matters, shopping, cooking)?
- 13) have you **encouraged** your relative/friend to get up in the morning?
- 14) has your relative/friend disturbed your sleep?*

- 15) has the atmosphere been strained between you both, as a result of your relative/friend's behaviour?
- 16) has your relative/friend caused a quarrel?
- 17) have you been annoyed by your relative/friend's behaviour?
- 18) have you heard from **others** that they have been annoyed by your relative/friend's behaviour?
- 19) have you felt threatened by your relative/friend?
- 20) have you thought of moving out, as a result of your relative/friend's behaviour?
- 21) have you been able to pursue your own activities and interests (e.g. work, hobbies, sports, visits to family and friends)?
- 22) have you **worried** about your relative/friend's **safety**?
- 23) have you **worried** about the kind of **help/treatment** your relative/friend is receiving?
- 24) have you **worried** about your relative/friend's **general health**?
- 25) have you **worried** about how your relative/friend would manage financially if you were no longer able to help?
- 26) have you **worried** about your relative/friend's **future**?
- 27) have you **worried** about **your own future**?
- 28) have your relative/friend's brain injury problems been a **burden** to you?*
- 29) have you got used to your relative/friend's brain injury problems?
- 30) have you felt able to cope with your relative/friend's brain injury problems?
- 31) Has your relationship with your relative/friend changed **since the onset** of the brain injury?

* Items used in more than one subscale.

Involvement Evaluation Questionnaire for Brain Injury subscale items

Subscale	<i>n</i> items	Item in scale
Tension	9	14, 15, 16, 17, 18, 19, 20, 27, 28
Supervision	6	7, 8, 9, 10, 11, 14
Worrying	6	22, 23, 24, 25, 26, 28
Urging	8	1, 2, 3, 4, 5, 6, 12, 13
Sumscore	27 ¹⁾	1 to 20, 22 to 28
Coping	4	21, 29 to 31

¹⁾items 14 and 28 are used in more than one scale.