

ORIGINAL REPORT

QUALITY OF LIFE AFTER TRAUMATIC BRAIN INJURY: FINNISH EXPERIENCE OF THE QOLIBRI IN RESIDENTIAL REHABILITATION

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Objective: To evaluate health-related quality of life of traumatic brain injury patients who have received intensive multidisciplinary residential rehabilitation. To examine the psychometric characteristics of the Finnish Quality of Life after Brain Injury (QOLIBRI) questionnaire.

Subjects: A total of 157 adults with TBI, up to 15 years post-injury, who had been treated in the Käpylä Rehabilitation Centre, Helsinki, Finland.

Methods: Functional status was assessed using the Extended Glasgow Outcome Scale. Emotional state was evaluated using the Hospital Anxiety and Depression Scale. Health-related quality of life was measured using a generic measure (Short Form-36) and the QOLIBRI.

Results: Quality of life was related to depression, amount of help needed, anxiety, education level and age at injury. Quality of life was not associated with time since injury, but a paradoxical relationship was found with injury severity. Internal consistency ($\alpha=0.79-0.95$) and test-retest reliability ($r_{tt}=0.75-0.87$) of the Finnish QOLIBRI met standard psychometric criteria.

Conclusion: Quality of life remained relatively stable in the long term. Milder injuries were associated with lower life satisfaction, and careful follow-up is recommended to target patients in special need. This study confirms the reliability and validity of the Finnish QOLIBRI.

Key words: health-related quality of life; traumatic brain injury; rehabilitation; outcome assessment; psychometrics.

J Rehabil Med 2013; 45: 835–842

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Accepted April 30, 2013

INTRODUCTION

Traumatic brain injury (TBI) affects many domains of life, and impacts the quality of life (QoL) experienced by the injured person (1). A central aspect of QoL is subjective well-being, and overall QoL is related to the person's individual expectations and achievements and their culture and value systems (1). Subjective health-related quality of life (HRQoL) refers to human life experiences, including health status, subjective

well-being and life satisfaction (2). Earlier studies have shown that HRQoL after TBI is linked to changes in emotional status (3–6), neurobehavioral disturbances (7, 8), cognitive impairments (9), sleep-wake disturbances and fatigue (10, 11), pain (12), loss of communication skills (13), loss of autonomy in advanced activities of daily living (ADL) (9), changes in the level of participation (14) and vocational status (3, 5).

In recent years HRQoL has become an important outcome variable after TBI (2, 15–18) alongside the more traditional outcome measures, such as physical independence and return to work. This reflects an underlying paradigm shift in the evaluation of outcomes in TBI: capturing the patient's own perspective has become increasingly essential (15). HRQoL is also viewed as a central end-point of rehabilitation, and appropriate measures are needed for the development and evaluation of effective treatments.

Generic HRQoL measures do not capture the full spectrum of effects of brain injury, and the need for a disease-specific measure was identified (16, 17). The Quality of Life after Brain Injury (QOLIBRI) was created to fill this gap. It is a HRQoL instrument specifically developed for persons after TBI (19–21). The validity and psychometric properties of the QOLIBRI have been investigated recently in a multi-centre international study with 795 adults with TBI (19–21). The use of the QOLIBRI in clinical settings has also been described previously in detail; the QOLIBRI provides information about the patient's subjective perception of his/her HRQoL, allows the identification of personal needs, and aids in the prioritization of therapeutic goals and evaluation of individual progress (21).

The Finnish version of the QOLIBRI questionnaire was originally translated in 2004 according to linguistic validation guidelines (20) and was revised in 2006. The Finnish QOLIBRI validation study presented here was conducted using a convenience sample of patients with TBI, who had all participated in residential rehabilitation. This strategy creates some limitations for the study, but simultaneously provides an opportunity to explore the HRQoL in a pure rehabilitation sample with its own distinctive characteristics. The present study also covers an exceptionally long follow-up time of up to 15 years after TBI. The aims of the present study were: (i) to examine the HRQoL of patients with TBI who have received residential rehabilitation; and (ii) to assess the psychometric properties and validity of the Finnish QOLIBRI.

MATERIAL AND METHODS

Participants

The Finnish sample of the international QOLIBRI validation study consisted of 157 patients with TBI who had received intensive multidisciplinary residential rehabilitation during 1993–2006 at the Käpylä Rehabilitation Centre, Helsinki. Patients are referred to the centre from all over Finland by the clinicians responsible for their care. They stay in the centre for 2–8 weeks depending on their individual needs and goals. The multidisciplinary rehabilitation consists of neuropsychological rehabilitation, physiotherapy, occupational therapy, speech and language therapy, as well as the services provided by social workers, nurses and medical doctors. The support provided by peers is essential. After the rehabilitation period the patients return to home. Inclusion criteria were: (i) diagnosis of traumatic brain injury according to ICD-10; (ii) Glasgow Coma Scale score (24 h worst) obtained; (iii) time since injury between 3 months and 15 years; (iv) aged 15 years or more at injury; (v) outpatient status; (vi) aged 17–69 years at interview; and (vii) able to give informed consent. Exclusion criteria were: (i) Extended Glasgow Outcome Scale (GOSE) <3; (ii) spinal cord injury; (iii) significant current or pre-injury psychiatric history; (iv) ongoing severe addiction; (v) inability to understand, cooperate and answer; and (vi) having terminal illness. The Finnish sample is part of the larger international QOLIBRI development and validation data (19, 20) and it was collected during 2006–2007.

Measures

The QOLIBRI (19–21) gives a profile of HRQoL in domains relevant to TBI, together with a total HRQoL score. The measure consists of 37 items which form 6 scales: Cognition; Self; Daily life and autonomy; Social relationships; Emotions; and Physical problems. Four of the scales contain “How satisfied are you with...” items, and two have “How bothered are you with...” items. Responses are given on a 5-point Likert scale, from “not at all” to “very”.

The GOSE was used as an assessment of functional status (22). Depression and anxiety were assessed using the Hospital Anxiety and Depression Scale (HADS) (23). The Short-Form 36 (SF-36) (24) was used as a patient-reported generic health outcome measure, which gives information on both physical and mental HRQoL (25). Data were also gathered concerning social and demographic information, including age, gender, relationship status, educational background, occupation, level of independence, number of social contacts, participation in leisure activities, and the use of alcohol and recreational drugs. A health questionnaire was used to assess health status and comorbid health conditions and problems. Information was also gathered concerning help needed in daily life. Clinicians collected clinical data, including level of consciousness after injury (the worst GCS score in the first 24 h), length of post-traumatic amnesia, location of injury, current medication, and a rating of disorders in 10 areas (epilepsy, hemiparesis, visual and auditory deficit, extra-cerebral injuries, communication problems, attention dysfunction, memory dysfunction, executive dysfunction, affective and behavioural disorders).

Ethical approval

The QOLIBRI study was approved by the ethical committee of the Käpylä Rehabilitation Centre.

Data analysis

The data was analysed using SPSS 18.0. Missing responses on the QOLIBRI-scale were imputed per participant by substituting the missing value by the scale mean rounded to an integer. The scale scores were transformed to 100-point scale (i.e. percentage scale).

RESULTS

Descriptives

A total of 157 participants were enrolled, 14 subjects were excluded due to missing GCS. Demographic and clinical characteristics of the sample are shown in Table I. Both age

Table I. Demographic and clinical characteristics of the sample

| Characteristics | n (%) |
|---------------------------------------|------------|
| Gender | |
| Male | 101 (64.3) |
| Female | 56 (35.7) |
| Age | |
| 20–30 years | 23 (14.6) |
| 31–44 years | 62 (39.5) |
| 45–63 years | 72 (45.9) |
| Employment status | |
| Employed full-time | 7 (4.5) |
| Employed part-time | 15 (9.6) |
| Self-employed | 13 (8.3) |
| Voluntary work | 22 (14.0) |
| Unemployed | 6 (3.8) |
| Retired | 100 (64.7) |
| Relationship status | |
| Single | 34 (21.7) |
| Married or partnered | 100 (63.7) |
| Separated/divorced or widowed | 23 (14.6) |
| Living arrangements | |
| Independent | 103 (65.6) |
| Supported | 54 (34.4) |
| Glasgow Coma Scale score (24 h worst) | |
| Severe: 3–8 | 93 (59.2) |
| Moderate: 9–12 | 8 (5.1) |
| Mild: 13–15 | 56 (35.7) |
| Time since injury | |
| <1 years | 5 (3.2) |
| 1 to <2 years | 4 (2.5) |
| 2 to <4 years | 19 (12.1) |
| 4–15 years | 129 (82.2) |
| Glasgow Outcome Scale Extended | |
| Severe disability | 19 (12.1) |
| Moderate disability | 136 (86.6) |
| Good recovery | 2 (1.3) |

(mean 43.10 years [SD 10.78]) and the years since injury (mean 8.03 years [SD 3.99]) were somewhat higher than in the international data (age: mean 39.0 years [SD 13.30]; years since injury: mean 5 years [SD 3.9]). Coma length (mean 3.90 days [SD 6.68]) was obtained from 149 participants

Table II. Regression model for Finnish Quality of Life after Brain Injury (QOLIBRI) questionnaire total score

| Variable | Standardized coefficient (beta) | Proportion of explained variance (cumulative adjusted R ²) | Change in R ² | Significance of change in R ² |
|-------------|---------------------------------|--|--------------------------|--|
| HADS | | | | |
| depression | −0.45 | 0.49 | 0.50 | <0.001 |
| Help needed | −0.21 | 0.55 | 0.06 | <0.001 |
| HADS | | | | |
| anxiety | −0.25 | 0.57 | 0.03 | 0.006 |
| Education | | | | |
| level | 0.14 | 0.59 | 0.02 | 0.030 |
| Age at TBI | −0.13 | 0.60 | 0.02 | 0.031 |

TBI: traumatic brain injury; HADS: Hospital Anxiety and Depression Scale.

and the length of post-traumatic amnesia (mean 26.42 days [SD 35.63]) was obtained from 150 participants. The highest education levels were: primary school (14.5%), secondary school (5.1%), trade or technical certificate (28.0%), college diploma or degree (33.1%), university degree (17.2%) and other (1.9%). Again compared with the international data, both lower primary school-group and higher college- and university groups were larger, and therefore the variance was greater (19). For further analysis, the education level "other", which was chosen by 3 participants, was replaced by mean rank (3.) of the 5 clearly ordinal education levels. This was also considered case by case to be the best match.

Predictors of health-related quality of life

Stepwise linear regression analysis was conducted to examine predictors of quality of life. The following variables were entered into the analysis: coma length, GCS, length of post-traumatic amnesia, GOSE, number of comorbid health conditions, number of clinical disorders, number of leisure activities, anxiety and depression measured by HADS, age, rounded age at TBI, rounded years since injury, alcohol use, education level, employment status and amount of received rehabilitation. Since most of the variables were skewed, the analysis was conducted using ranked data (26). Variables were excluded if they explained less than 1% of the variance. Five

Table III. Item characteristics

| Scale | Item | Mean | SD | Skewness | CITC | Cronbach's Alpha if item removed | <i>n</i> |
|-------------------------|------------------------------------|------|------|----------|------|----------------------------------|----------|
| Cognition | Concentrate | 2.96 | 1.16 | 0.76 | 0.74 | 0.91 | 156 |
| | Express yourself | 3.33 | 1.05 | -0.12 | 0.78 | 0.90 | 156 |
| | Remember | 2.86 | 1.23 | 0.06 | 0.73 | 0.91 | 156 |
| | Plan and problem solve | 3.42 | 1.20 | -0.24 | 0.81 | 0.90 | 156 |
| | Decisions | 3.28 | 1.13 | -0.24 | 0.75 | 0.90 | 156 |
| | Find way | 3.76 | 1.20 | -0.70 | 0.67 | 0.91 | 156 |
| | Speed of thinking | 3.12 | 1.24 | -0.15 | 0.75 | 0.90 | 156 |
| Self | Energy | 2.76 | 1.22 | 0.25 | 0.65 | 0.90 | 157 |
| | Motivation | 2.97 | 1.22 | -0.08 | 0.70 | 0.88 | 157 |
| | Self-esteem | 3.11 | 1.22 | -0.15 | 0.72 | 0.88 | 157 |
| | Way you look | 3.27 | 1.12 | -0.24 | 0.61 | 0.89 | 157 |
| | Achievements | 3.28 | 1.30 | -0.29 | 0.67 | 0.89 | 157 |
| | Self-perception | 3.15 | 1.07 | -0.25 | 0.82 | 0.87 | 157 |
| Daily life and autonomy | Own future | 3.10 | 1.24 | -0.10 | 0.76 | 0.88 | 157 |
| | Independence | 3.41 | 1.16 | -0.32 | 0.67 | 0.86 | 157 |
| | Get out and about | 3.59 | 1.20 | -0.34 | 0.74 | 0.85 | 157 |
| | Domestic activities | 3.52 | 1.22 | -0.47 | 0.70 | 0.85 | 157 |
| | Run personal finances | 3.80 | 1.30 | -0.89 | 0.63 | 0.86 | 157 |
| | Participation in work or education | 2.55 | 1.38 | 0.40 | 0.51 | 0.88 | 157 |
| Social relationships | Social-leisure activities | 3.15 | 1.35 | -0.11 | 0.66 | 0.86 | 157 |
| | In charge of life | 3.64 | 1.14 | -0.41 | 0.76 | 0.85 | 157 |
| | Affection towards others | 3.49 | 1.28 | -0.38 | 0.67 | 0.84 | 156 |
| | Family members | 3.86 | 1.08 | -0.74 | 0.73 | 0.84 | 155 |
| | Friends | 3.54 | 1.19 | -0.52 | 0.70 | 0.84 | 155 |
| | Partner | 3.53 | 1.43 | -0.57 | 0.66 | 0.85 | 155 |
| Emotions | Sex life | 2.94 | 1.47 | 0.09 | 0.70 | 0.84 | 155 |
| | Attitudes of others | 3.25 | 1.10 | -0.06 | 0.57 | 0.86 | 155 |
| | Loneliness | 4.01 | 1.14 | -1.19 | 0.48 | 0.84 | 156 |
| | Boredom | 3.76 | 1.13 | -0.83 | 0.65 | 0.79 | 156 |
| | Anxiety | 3.73 | 1.26 | -0.71 | 0.75 | 0.76 | 156 |
| | Depression | 3.58 | 1.24 | -0.59 | 0.73 | 0.77 | 156 |
| Physical problems | Anger/aggression | 3.88 | 1.23 | -0.91 | 0.55 | 0.82 | 156 |
| | Slowness/clumsy | 3.86 | 1.17 | -0.95 | 0.56 | 0.76 | 157 |
| | Other injuries | 3.41 | 1.39 | -0.46 | 0.61 | 0.74 | 157 |
| | Pain | 3.41 | 1.38 | -0.41 | 0.57 | 0.75 | 157 |
| | See/hear | 3.89 | 1.05 | -0.93 | 0.52 | 0.77 | 157 |
| | TBI-effects | 2.81 | 1.13 | -0.05 | 0.60 | 0.74 | 157 |

SD: standard deviation; TBI: traumatic brain injury; CITC: corrected item-total correlations.

Table IV. Scale properties

| | Mean, % | SD | Cronbach's alpha |
|-------------------------|---------|-------|------------------|
| Cognition | 56.11 | 23.20 | 0.92 |
| Self | 52.28 | 23.68 | 0.90 |
| Daily life and autonomy | 59.49 | 23.73 | 0.88 |
| Social relationships | 60.92 | 24.53 | 0.87 |
| Emotions | 69.84 | 23.23 | 0.83 |
| Physical problems | 61.89 | 22.71 | 0.79 |
| QOLIBRI total | 59.41 | 19.19 | 0.95 |

CITC: corrected item-total correlations; SD: standard deviation; QOLIBRI: Finnish Quality of Life after Brain Injury.

variables reached significance as predictors of the total QOLIBRI score: depression; the amount of help needed; anxiety; education level; and age at injury. These variables accounted for 60.1% of the variance (Table II).

Education level and age at injury were examined further, since these were specific predictors from the Finnish sample not found in the international study. A statistically significant correlation was found between the total QOLIBRI scale and age at TBI ($r=-0.177, p=0.027$). When examined more closely, two of the QOLIBRI subscales were significantly correlated with age at TBI: the Cognition scale ($r=-0.226, p=0.005$) and the Physical problems scale ($r=-0.162, p=0.043$). The association between the total QOLIBRI and education level, on the other hand, did not reach statistical significance when measured by Spearman's rho ($r=0.108, p=0.179$). However, the Physical problems ($r=0.206, p=0.010$) and Daily life and autonomy subscales ($r=0.163, p=0.041$) correlated significantly with education level.

Psychometric properties of the Finnish QOLIBRI

There were a maximum of 18.9% and a median of 6.1% missing responses per participant. Item characteristics of the QOLIBRI-items are shown in Table III. All of the corrected item-total correlations (CITCs) were 0.48 or greater: it is conventionally accepted that they should be greater than 0.4 (27). Internal consistency of the scales and the total score estimated by Cronbach's alpha met standard psychometric criteria (Table IV). An endorsement index was used for item frequency analysis: distributions were checked for frequency problems and no 2 adjacent response categories had a sum of less than 10% of the total number of responses (28).

Test-retest reliability. A total of 49 subjects completed the QOLIBRI again after a 2-week interval. The test-retest intra-class correlations (ICC) of the Finnish QOLIBRI, which have previously been reported by Steinbüchel et al. (20), ranged from 0.75 to 0.83 for separate scales. The ICC for the total QOLIBRI was 0.87. Test-retest change was examined by paired sample *t*-testing (Table V). Because most of the scale-variables were skewed, a square-root transformation was applied before carrying out the statistical comparisons. The total QOLIBRI score was consistent over the 2 measurements ($p=0.478$). Two of the scales ("Daily life and autonomy" and "Emotions") differed statistically between the 2 measurements ($p=0.035$; $p=0.032$), but the effect sizes were small (-0.176 ; -0.213).

Structure of the measure. To confirm the dimensionality and structure of the QOLIBRI, principal component analysis was conducted using oblique rotation (promax method with Kaiser Normalization based on the assumption of correlated scales). A forced 6-factor solution was produced to compare the structure of Finnish QOLIBRI with the international analysis. As shown in Table VI, most of the QOLIBRI scales load on appropriate factors and the PCA reproduces the overall structure of the QOLIBRI. The Daily life and autonomy scale had most cross loadings, and the reliability of this scale was therefore examined more closely. The overall alpha of the scale was good (0.877) and the corrected item total correlations were all 0.512 or greater.

Validity of the Finnish QOLIBRI

Construct validity was assessed by examining correlations between the QOLIBRI scale and other assessments (GOSE, HADS, SF-36) plus demographic and clinical factors. Since the variables were not normally distributed, Spearman correlations were used (Table VII). The results indicate that emotional state is strongly associated with the overall QOLIBRI. In addition, significant correlations were found between the QOLIBRI and the SF-36, a general HRQoL-measure; the mental scale of the SF-36 correlated most strongly with the Emotions-scale of the QOLIBRI, and the physical scale of the SF-36 correlated most strongly with the Physical scale as expected. No association between the years since injury and the QOLIBRI was found and there was no overall trend for change in HRQoL over the long follow-up. The QOLIBRI

Table V. Test-retest comparisons

| | Paired samples <i>n</i> | Test Mean (SD) | Re-test Mean (SD) | <i>t</i> -value | <i>p</i> -value | Effect size (Cohen's <i>d</i>) |
|-------------------------|----------------------------|-------------------|----------------------|-----------------|-----------------|---------------------------------|
| Cognition | 48 | 55.58 (21.45) | 54.19 (21.04) | 0.648 | 0.520 | 0.07 |
| Self | 49 | 53.18 (22.18) | 50.87 (21.45) | 1.263 | 0.213 | 0.11 |
| Daily life and autonomy | 49 | 55.83 (22.01) | 59.84 (23.49) | -2.165 | 0.035 | -0.18 |
| Social relationships | 49 | 58.95 (23.51) | 58.45 (24.22) | 0.202 | 0.841 | 0.02 |
| Emotions | 49 | 67.65 (22.66) | 72.47 (22.67) | -2.209 | 0.032 | -0.21 |
| Physical problems | 49 | 60.92 (21.47) | 62.65 (21.77) | -0.873 | 0.387 | -0.08 |
| QOLIBRI total | 49 | 58.16 (16.63) | 59.06 (17.19) | -0.715 | 0.478 | -0.05 |

QOLIBRI: Finnish Quality of Life after Brain Injury; SD: standard deviation.

Table VI. Principal component analysis of the Finnish Quality of Life after Brain Injury (QOLIBRI) items. Factor loadings ≥ 0.25 are shown

| Scale | Item | Communality | Factor 1 | Factor 2 | Factor 3 | Factor 4 | Factor 5 | Factor 6 |
|------------|-----------------------------|-------------|----------|----------|----------|----------|----------|----------|
| Cognition | | | | | | | | |
| | Concentrate | 0.66 | 0.75 | | | | | |
| | Express yourself | 0.72 | 0.83 | | | | | |
| | Remember | 0.66 | 0.70 | | | 0.25 | | |
| | Plan and problem solve | 0.76 | 0.81 | | | | | |
| | Decisions | 0.72 | 0.77 | | | -0.27 | | |
| | Find way | 0.58 | 0.90 | | | | | |
| | Speed of thinking | 0.68 | 0.88 | | | | | |
| Self | | | | | | | | |
| | Energy | 0.64 | | 0.55 | | 0.30 | | |
| | Motivation | 0.63 | | 0.67 | | | | |
| | Self-esteem | 0.70 | | 0.80 | | | | |
| | Way you look | 0.47 | | 0.68 | | | | |
| | Achievements | 0.55 | | 0.64 | | | | |
| | Self-perception | 0.75 | | 0.86 | | | | |
| | Own future | 0.67 | | 0.80 | | | | |
| Daily life | | | | | | | | |
| | Independence | 0.64 | | | | | | 0.57 |
| | Get out and about | 0.69 | | 0.25 | | | | 0.54 |
| | Domestic activities | 0.63 | | 0.25 | | 0.43 | | 0.31 |
| | Run personal finances | 0.69 | | | | | | 0.78 |
| | Participation work | 0.37 | | 0.38 | | | | |
| | Social & leisure activities | 0.66 | | 0.55 | | 0.26 | | |
| | In charge of life | 0.74 | | | | | | 0.64 |
| Social | | | | | | | | |
| | Affection towards others | 0.67 | | | 0.73 | 0.26 | | |
| | Family members | 0.69 | | | 0.77 | | | |
| | Friends | 0.70 | | 0.33 | 0.65 | | | |
| | Partner | 0.65 | | | 0.86 | | | |
| | Sex life | 0.61 | | | 0.72 | | | |
| | Attitudes of others | 0.54 | | 0.39 | 0.47 | | | |
| Emotions | | | | | | | | |
| | Loneliness | 0.63 | | | 0.54 | 0.32 | | -0.36 |
| | Boredom | 0.60 | | | | | 0.65 | |
| | Anxiety | 0.80 | | | | | 0.83 | |
| | Depression | 0.79 | | | | | 0.86 | |
| | Anger/aggression | 0.70 | | | -0.29 | | 0.80 | |
| Physical | | | | | | | | |
| | Slow/clumsiness | 0.57 | | | | 0.81 | | |
| | Other injuries | 0.59 | | | | 0.83 | | |
| | Pain | 0.64 | | | | 0.78 | | |
| | See/hear | 0.49 | | -0.42 | | 0.49 | | |
| | TBI effects | 0.64 | | | | 0.55 | | |

Table VII. Spearman correlations

| | Cognition | Self | Daily life | Social | Emotions | Physical problems | QOLIBRI total |
|--------------------|-----------|---------|------------|---------|----------|-------------------|---------------|
| Age | -0.18 | -0.10 | -0.09 | -0.01 | -0.01 | -0.13 | -0.12 |
| Education level | 0.13 | 0.07 | 0.16* | 0.08 | 0.12 | 0.21** | 0.15 |
| Glasgow Coma Scale | -0.25** | -0.17* | -0.23** | -0.08 | -0.10 | -0.24** | -0.21** |
| Time since injury | -0.02 | 0.02 | 0.02 | 0.08 | 0.06 | 0.10 | 0.01 |
| Age at injury | -0.23** | -0.14 | -0.15 | -0.06 | -0.04 | -0.16* | -0.18* |
| Coma length | 0.31** | 0.24** | 0.31** | 0.19* | 0.18* | 0.30** | 0.32** |
| GOSE | 0.22** | 0.17* | 0.28** | 0.17* | 0.23** | 0.27** | 0.27** |
| HADS depression | -0.57 | -0.64** | -0.65** | -0.59** | -0.61** | -0.55** | -0.74** |
| HADS anxiety | -0.48** | -0.51** | -0.50** | -0.39** | -0.64** | -0.48** | -0.60** |
| SF-36 MCS | 0.40** | 0.56** | 0.54** | 0.54** | 0.67** | 0.35** | 0.63 |
| SF-36 PCS | 0.38** | 0.27** | 0.30** | 0.15 | 0.15 | 0.62** | 0.39** |

* $p < 0.05$; ** $p < 0.01$.

QOLIBRI: Finnish Quality of Life after Brain Injury; GOSE: Extended Glasgow Outcome Scale; HADS: Hospital Anxiety and Depression Scale; SF-36: Short-Form 36; PCS: physical component summary scores; MCS: mental component summary scores.

total was 59.4 (SD=14.5) at 0 to <4 years ($n=28$), 58.1 (SD=19.5) at 4–9 years ($n=72$), and 61.0 (SD=21.0) at 10–15 years ($n=57$).

DISCUSSION

The first aim of this study was to evaluate HRQoL and its predictors in patients with TBI, who have received residential rehabilitation. In this group depression was found to be the strongest predictor of HRQoL. Other significant predictors were the amount of help needed, anxiety, age at injury, and education level. Time after injury was not related to reported HRQoL. Milder injuries were paradoxically associated with lower life satisfaction. The other main goal of this study was to assess the reliability and validity of the Finnish version of the QOLIBRI questionnaire. The results show that the psychometric properties of the Finnish QOLIBRI met standard psychometric criteria. The construct validity of the measure was confirmed by examining its relationship with other measures, including the HADS, SF-36 and GOSE; the relationships found are consistent with expectations for a HRQoL scale.

The strong association between the QOLIBRI and emotional state was expected on the basis of the theoretical model and the analysis of the international data (19) and from previous research (3–6). The association between the QOLIBRI and the amount of help needed has also been reported previously (19), whereas age at injury and education level were novel predictors of the QOLIBRI, which had a small, but significant, impact on reported HRQoL in this study. Both are recognized as factors contributing to outcome after TBI in the literature (29). Truelle et al. (2010) also found that patients with a lower level of education experienced lower quality of life in several domains measured by the QOLIBRI, which is consistent with our finding. Compared with the large international sample, the variance in education level was greater and the follow-up time after injury was longer in the Finnish sample, which could have made these phenomena more visible. Younger age is also consistently associated with better functional outcome after TBI (29, 30), but the literature concerning age and cognitive outcome after TBI is still rather limited. It has been shown in one longitudinal study, however, that most patients with TBI experience mild cognitive decline during follow-up, but this decline is influenced by gender and age at injury (31). Our finding, that age at TBI is related to the patient's subjective satisfaction with their cognitive functioning, complements these results nicely.

Time since TBI was not associated with quality of life in our sample. On the contrary, HRQoL remained relatively stable in the long-term in this rehabilitation group. Studies concerning life satisfaction several years after TBI are rare (32), and studies of long-term quality of life after rehabilitation are even rarer. Cicerone et al. (33) found that patients less than one year after TBI demonstrate significantly higher quality of life, whereas no significant differences were found later after injury; this can be interpreted as a result of early anosognosia. Jacobson et al. (32), on the other hand, found that life satisfaction

improved over time many years after injury. They concluded that perceived self-efficacy may mediate the relation between the individual expectations and achievements, and thereby contribute to overall subjective well-being. In our study, all of the participants had undergone an intensive multidisciplinary rehabilitation period, which could affect both their perceived self-efficacy and self-awareness.

The psychometric properties of the Finnish QOLIBRI proved to be good. Consistency of the measure was excellent for the total score ($\alpha=0.954$) and good or excellent for the separate scales ($\alpha=0.79$ to 0.92). Consistency was even slightly higher than in the multi-centre study, in which α varied between 0.75 and 0.89. Test-retest reliability of the QOLIBRI was considered acceptable. The overall structure of the measure was reproduced quite well by the principal component analysis, although one of the scales (Daily life and autonomy) loaded on several factors. This could have been due to the relatively small sample size for this type of analysis. Despite small differences, the results concerning the reliability of the Finnish QOLIBRI are well in line with previous QOLIBRI studies (19–21).

The validity of the QOLIBRI was examined by comparing it with other measures known to relate to the HRQoL. Significant correlations were found between the QOLIBRI and the SF-36, a general HRQoL-measure. The mental summary scale of the SF-36 was particularly associated with the Emotions-scale of the QOLIBRI and the physical summary scale of the SF-36 correlated most strongly with the Physical problems-scale of the QOLIBRI, which shows that the sub-scales of the QOLIBRI measure different concepts in a consistent manner. In addition, the measure of depression and anxiety (HADS) was strongly associated with the QOLIBRI, as noted previously. These findings confirm the construct validity of the QOLIBRI. Functional outcome measured by GOSE was moderately related to the QOLIBRI. It is noteworthy, however, that HRQoL is not strongly determined by functional outcome in this sample. A similar finding has been reported in some previous research (1, 21, 34) and suggests adjustment to disability caused by TBI.

A negative correlation was found between the QOLIBRI and injury severity measured by the GCS, which indicates lower HRQoL in the patients with milder TBI compared with more severe injuries. This was unexpected, since such an association was not found in the analysis of the international data. However, previous research has revealed that relationship between injury severity and HRQoL after brain injury is not straightforward; some studies have found no connection between injury severity and HRQoL or life satisfaction (34, 35, 20) and a few have revealed a similar relationship between these variables that we found (32, 36, 37), although this phenomenon has not been widely reported. One possible explanation for this finding in our study is that it is at least partially due to the selection of the sample. Patients classified as having mild traumatic brain injury, are in fact a heterogeneous group. There is, for example, discussion about whether GCS 13 should be considered as indicating mild TBI as the risk of intracranial lesions is considerably higher in this group than in patients with GCS 14–15 (38). Outcome after mild TBI is usually good, but this does not

apply to all cases; outcome is moderated by various pre-injury, injury related and post-injury factors (38). In our sample the vast majority (98.7%) had moderate or severe disabilities and only a few (1.3%) displayed good recovery assessed by the GOSE. It is therefore reasonable to conclude that patients who are referred to residential rehabilitation after TBI primarily classified as “mild”, are usually in need of special help and do not represent typical cases of mild TBI. These patients could also have had more difficulties in getting the help they need, and they may have had to struggle more with the consequences of their TBI.

It is likely, however, that selection is not the only factor affecting these results, since some similar findings have been reported previously. Jones et al. (37) present the interesting idea that a positive relationship between injury severity and life satisfaction is mediated by personal and social changes, in that severely injured patients have a greater sense of “survivorship” along with greater levels of social support. Such personal and social variables may play a part in our sample too, although they were not specifically measured. In addition, patients with low self-awareness might estimate their HRQoL higher (39), although divergent results have also been reported (34). Lower self-awareness has also been found to associate with more severe injuries (39, 40), and therefore lack of self-awareness could also be a mediating factor in our findings.

These results have important implications for clinicians working with brain injury patients in clinical settings: Sufficient follow-up after mild TBI is recommended in order to target patients in need of support and to prevent secondary consequences of TBI, such as depression. Furthermore, examination of the underlying causes of poor HRQoL is an essential part of the rehabilitation process after mild TBI as well as after more severe injuries.

The main limitations of the present study are the selectiveness of the sample and the moderate sample size. Since the sample was limited to patients who have received residential rehabilitation, the results concerning HRQoL cannot be generalized to other TBI populations. For the purpose of validating the Finnish QOLIBRI, the sample was considered to be sufficiently heterogeneous, however. The cross-sectional study design also creates limitations for the study. The participants span different generations, and it can therefore be hypothesized that their concepts and expectations of good quality of life may differ from each other on a group level, as well as on individual level. This factor could, in theory, influence the age- and time-related results.

It is concluded that the Finnish version of the QOLIBRI is reliable, and that it can be used both for scientific and clinical purposes. In addition, the investigation of HRQoL in a patient group referred to residential rehabilitation reveals a unique and interesting pattern of HRQoL, which could be explored further by comparison with other patient groups. Our study, somewhat surprisingly, suggests lower life satisfaction after milder injuries in certain populations. Selection of the sample is probably an explanatory factor in our study, but there might be other factors involved (37, 39). Further investigation into this relationship between injury severity and HRQoL is recom-

mended in order to enhance our understanding of the mediating factors. In future, the use of the QOLIBRI could also be studied in longitudinal settings to examine the potential usefulness of the instrument in setting and measuring attainment of goals in rehabilitation. The QOLIBRI has been in regular clinical use in the Käpylä Rehabilitation Centre since the translation of the questionnaire, and experiences of its use in rehabilitation setting have been positive. As pointed out earlier, HRQoL is not strictly determined by injury severity or the functional status of the patients. Therefore it is important to identify the goals that matter to the patient. The QOLIBRI adds important information to the standard clinical procedure, as it brings out the subjective experience and values of the patient in a structured, comprehensive and practical manner.

REFERENCES

1. Dijkers M. Quality of life after traumatic brain injury: a review of research approaches and findings. *Arch Phys Med Rehabil* 2004; 85: S21–S35.
2. von Steinbüchel N, Richter S, Morawetz C, Riemsma R. (2005b). Assessment of subjective health and health-related quality of life in persons with acquired or degenerative brain injury. *Curr Opin Neurol* 2005; 18: 681–691.
3. Corrigan JD, Bogner JA, Mysiw WJ, Clinchot D, Fugate L. Life satisfaction after traumatic brain injury. *J Head Trauma Rehabil* 2001; 16: 543–555.
4. Hibbard MR, Ashman TA, Spielman A, Chun D, Charatz HJ, Melvin S. Relationship between depression and psychosocial functioning after traumatic brain injury. *Arch Phys Med Rehabil* 2004; 85: S43–S53.
5. Kalpakjian CZ, Lam CS, Toussaint LL, Hansen Merbitz NK. Describing quality of life and psychosocial outcomes after traumatic brain injury. *Am J Phys Med Rehabil* 2004, 83: 255–265.
6. Underhill AT, Lobello SG, Stroud TP, Terry KS, Devivo MJ, Fine PR. Depression and life satisfaction in patients with traumatic brain injury: a longitudinal study. *Brain Inj* 2003, 17: 973–982.
7. Koskinen S. Quality of life 10 years after a very severe traumatic brain injury (TBI): the perspective of the injured and the closest relative. *Brain Inj* 1998, 12: 631–648.
8. Ergh TC, Hanks RA, Rapport LJ, Coleman RD. Social support moderates caregiver life satisfaction following traumatic brain injury. *J Clin Exp Neuropsychol* 2003; 25: 1090–1101.
9. Kozlowski O, Pollez B, Thevenon A, Dhellemmes P, Rousseaux M. Outcome and quality of life after three years in a cohort of patients with severe traumatic brain injury. *Ann Readapt Med Phys* 2002; 45: 466–473.
10. Baumann CR, Werth E, Stocker R, Ludwig S, Bassetti CL. Sleep-wake disturbances 6 months after traumatic brain injury: a prospective study. *Brain* 2007; 130: 1873–1883.
11. Emanuelson I, Andersson Holmkvist E, Björklund R, Stålhammar D. Quality of life and post-concussion symptoms in adults after mild traumatic brain injury: a population-based study in western Sweden. *Acta Neurol Scand* 2003; 108: 332–338.
12. Branca B, Lake AE. Psychological and neuropsychological integration in multidisciplinary pain management after TBI. *J Head Trauma Rehabil* 2004; 19: 40–57.
13. Dahlberg C, Hawley L, Morey C, Newman J, Cusick CP, Harrison-Felix C. Social communication skills in persons with post-acute traumatic brain injury: three perspectives. *Brain Inj* 2006; 20: 425–435.
14. Pierce CA, Hanks RA. Life satisfaction after traumatic brain injury and the World Health Organization model of disability. *Am J Phys Med Rehabil* 2006; 85: 889–898.

15. Bullinger M. Assessing health related quality of life in medicine. An overview over concepts, methods and applications in international research. *Rest Neurol Neurosci* 2002; 20: 93–101.
16. Corrigan JD, Bogner J. Latent factors in measures of rehabilitation outcomes after traumatic brain injury. *J Head Trauma Rehabil* 2004; 19: 445–458.
17. Neugebauer E, Bouillon B, Bullinger M, Wood-Dauphinee S. Quality of life after multiple trauma-summary and recommendations of the consensus conference. *Rest Neuro Neurosci* 2002; 20: 161–167.
18. von Steinbüchel N, Petersen C, Bullinger M, and the QOLIBRI group. Assessment of health-related quality of life in persons after traumatic brain injury – development of the Qolibri, a specific measure. *Acta Neurochir Suppl* 2005; 93: 43–49.
19. von Steinbüchel N, Wilson L, Gibbons H, Hawthorne G, Hofer S, Schmidt S, et al. Quality of Life after Brain Injury (QOLIBRI) – Scale validity and correlates of quality of life. *J Neurotrauma* 2009; 27: 1157–1165.
20. von Steinbüchel N, Wilson L, Gibbons H, Hawthorne G, Höfer S, Schmidt S, et al. Quality of Life after Brain Injury (QOLIBRI) – Scale development and metric properties. *J Neurotrauma* 2010; 27: 1157–1165.
21. Truelle JL, Koskinen S, Hawthorne G, Sarajuuri J, Formisano R, Von Wildt K, et al. Quality of life after traumatic brain injury: the clinical use of the QOLIBRI, a novel disease-specific instrument. *Brain Inj* 2010; 24: 1272–1291.
22. Wilson JT, Pettigrew LE, Teasdale GM. Structured interviews for the Glasgow Outcome Scale and the extended Glasgow Outcome Scale: guidelines for their use. *J Neurotrauma* 1998; 15: 573–585.
23. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983; 67: 361–370.
24. Ware JE, Sherbourne CD. The MOS 36-item Short-Form Health Survey (SF-36). 1. Conceptual framework and item selection. *Med Care* 1992; 30: 473–483.
25. Anagnostopoulos F, Niakas D, Tountas Y. Comparison between exploratory factor-analytic and SEM-based approaches to constructing SF-36 summary scores. *Qual Life Res* 2009; 18: 53–63.
26. Conover WJ, Iman RL. Rank transformation as a bridge between parametric and nonparametric analysis. *Am Stat* 1981; 35: 124–133.
27. WHOQOL group. (1998). The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties. *Soc Sci Med* 46: 1569–1585.
28. Power M, Quinn K, Schmidt S. Development of the WHOQOL-Old module. *Qual Life Res* 2005; 14: 2197–2214.
29. Kim Y-J. A systematic review of factors contributing to outcomes in patients with traumatic brain injury. *J Clin Nurs* 2011; 20: 1518–1532.
30. Hukkelhoven C, Steyerberg E, Rampen A, Farase E, Habbema J, Marshall L, et al. *J Neurosurg* 2003; 99: 666–673.
31. Himanen L, Portin R, Isoniemi H, Helenius H, Kurki T, Tenovuo O. Longitudinal cognitive changes in traumatic brain injury. *Neurology* 2006; 66: 187–192.
32. Jacobsson LJ, Westerberg M, Malec JF, Lexell J. Sense of coherence and disability and their relationship with life satisfaction 6–15 years after traumatic brain injury in Northern Sweden. *Neuropsychol Rehabil* 2011; 21: 383–400.
33. Cicerone KD, Azulay J. Perceived self-efficacy and life satisfaction after traumatic brain injury. *J Head Trauma Rehabil* 2007; 22: 257–266.
34. Mailhan L, Azouvi P, Dazard A. Life satisfaction and disability after severe traumatic brain injury. *Brain Inj* 2005; 19: 227–238.
35. Colantonio A, Dawson D, McLellan B. Head injury in young adults: long-term outcome. *Arch Phys Med Rehabil* 1998; 79: 550–558.
36. Findler M, Cantor J, Haddad L, Gordon W, Ashman T. The reliability and validity of the SF 36 health survey questionnaire for use with individuals with traumatic brain injury. *Brain Inj* 2001; 15: 715–723.
37. Jones JM, Haslam SA, Jetten J, Williams WH, Morris R, Saroyan S. That which doesn't kill us can make us stronger (and more satisfied with life): the contribution of personal and social changes to well-being after acquired brain injury. *Psychol Health* 2011; 26: 353–369.
38. Shukla D, Devi B. Mild traumatic brain injuries in adults. *J Neurosci Rural Pract* 2010; 1: 82–88.
39. Sasse N, Gibbons H, Wilson L, Martinez-Olivera R, Schmidt H, Hasselhorn M, et al. Self-awareness and health-related quality of life after traumatic brain injury. *J Head Trauma Rehabil* 2012 Aug 29 [Epub ahead of print].
40. Prigatano P. Disturbances of self-awareness and rehabilitation of patients with traumatic brain injury: a 20-year perspective. *J Head Trauma Rehabil* 2005; 20: 19–29.