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**ORIGINAL ARTICLE** 

## Health-Related Quality of Life 3 Years After Moderate to Severe Traumatic Brain Injury: A Prospective Cohort Study



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#### Abstract

**Objectives:** To evaluate the time course of health-related quality of life (HRQoL) after moderate to severe traumatic brain injury (TBI) and to identify its predictors.

Design: Prospective cohort study with follow-up measurements at 3, 6, 12, 18, 24, and 36 months after TBI.

Setting: Patients with moderate to severe TBI discharged from 3 level-1 trauma centers.

**Participants:** Patients (N=97, 72% men) with a mean age  $\pm$  SD of 32.8 $\pm$ 13.0 years (range, 18–65y), hospitalized with moderate (23%) or severe (77%) TBI.

Interventions: Not applicable.

Main Outcome Measures: HRQoL was measured with the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36), functional outcomes with the Glasgow Outcome Scale (GOS), Barthel Index, FIM, and Functional Assessment Measure, and mood with the Wimbledon Self-Report Scale.

**Results:** The SF-36 domains showed significant improvement over time for Physical Functioning (P<.001), Role Physical (P<.001), Bodily Pain (P<.001), Social Functioning (P<.001), and Role Emotional (P=.024), but not for General Health (P=.263), Vitality (P=.530), and Mental Health (P=.138). Over time there was significant improvement in the Physical Component Summary (PCS) score, whereas the Mental Component Summary (MCS) score remained stable. At 3-year follow-up, HRQoL of patients with TBI was the same as that in the Dutch normative population. Time after TBI, hospital length of stay (LOS), FIM, and GOS were independent predictors of the PCS, whereas LOS and mood were predictors of the MCS.

**Conclusions:** After TBI, the physical component of HRQoL showed significant improvement over time, whereas the mental component remained stable. Problems of disease awareness seem to play a role in self-reported mental HRQoL. After TBI, mood status is a better predictor of the mental component of HRQoL than functional outcome, implying that mood should be closely monitored during and after rehabilitation. Archives of Physical Medicine and Rehabilitation 2014;95:1268-76

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Long-term outcome after traumatic brain injury (TBI) is commonly described in terms of activities and participation according to the *International Classification of Functioning*, *Disability and Health* of the World Health Organization.<sup>1</sup> In addition, subjective well-being or health-related quality of life (HRQoL) is an important outcome, providing information on impairments, disabilities, and the need for rehabilitation interventions.<sup>2,3</sup> HRQoL questionnaires measure the impact of a disease or disability, or its treatment, on physical, emotional, and social health, including participation in the community and level of everyday functioning.<sup>4</sup> Because the consequences of TBI may vary between individuals (depending on, eg, TBI severity and/or personal circumstances), insight into the impact of TBI on quality of life, as experienced by the patient, is required.

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The Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36), frequently used to assess HRQoL, is validated for the assessment of patients with TBI.<sup>5-8</sup> Evaluating HRQoL at multiple points over time provides insight into how and when HRQoL may change after sustaining a TBI in relation to physical and mental recovery.

The SF-36 scores of persons after mild, moderate, and severe TBI have been reported to be lower compared with those of control subjects.<sup>7,9,10</sup> On the different subdomains of the SF-36, poor scores are often related to lower intelligence, more post-concussion symptoms, more posttraumatic fatigue, female sex, Medicaid coverage, not having health insurance, inadequate or moderate social support, comorbidities, cognitive complaints, and limitations in activities of daily living.<sup>10-13</sup> In a selected sample of 37 patients with mild TBI, SF-36 scores improved to normative values at 3 months postinjury and did not change thereafter; this suggests that most of the self-reported problems are present in moderate to severe TBI.<sup>11</sup>

Recovery after TBI is a long and complex process in which physical and psychosocial well-being may change over time. Studies on HRQoL after TBI often have shortcomings because of methodological issues such as a retrospective or cross-sectional design, small numbers of patients, or a focus only on patients with mild TBI.<sup>9,11</sup>

Therefore, the current study has a prospective design, in which patients with moderate or severe TBI are followed up from hospital admission until 3 years postinjury. The multiple measurements that are obtained make it possible to determine which variables change over time, and at which moment in time. The extensive measurements, recorded 6 times during a 3-year period (with 3 measurements in the first year), provide extensive insight into recovery patterns after TBI.

This study aims to evaluate the course of HRQoL in homedwelling patients up to 3 years after moderate or severe TBI (as measured with the SF-36), and to identify which determinants are associated with the physical and mental components of HRQoL in the long-term. We hypothesized that HRQoL will improve over time (with most improvement during the first year postinjury) and that the physical and mental components will likely have different determinants.

### Methods

#### Procedure

Details of the study design are published elsewhere.<sup>14-16</sup> In short, consecutive patients with moderate or severe TBI were enrolled between January 1999 and April 2004 at 3 acute care hospitals (all

List of abbreviations:	
BI	Barthel Index
FAM	Functional Assessment Measure
GCS	Glasgow Coma Scale
GOS	Glasgow Outcome Scale
HRQoL	health-related quality of life
LOS	length of stay
MCS	Mental Component Summary
PCS	Physical Component Summary
SF-36	Medical Outcomes Study 36-Item Short-Form Health
	Survey
TBI	traumatic brain injury
WSRS	Wimbledon Self-Report Scale

supraregional level-1 trauma centers): the Erasmus MC, University Medical Center Rotterdam (January 1999 to April 2004); the Medical Center Haaglanden, The Hague (January 2003 to February 2004); and the University Medical Center Utrecht, Utrecht (April 2003 to February 2004). Patients were prospectively followed up for 3 years.

Acute treatment of the patients was in accordance with the guidelines of the European Brain Injury Consortium.<sup>17</sup> If possible, informed consent was obtained from the patient; otherwise, informed consent was obtained from a family member, and patients were asked to give consent later. The study was approved by the Medical Ethics Committee of the Erasmus MC, University Medical Center Rotterdam.

After baseline measurements were completed on hospital admission, patients were followed up prospectively at 3, 6, 12, 18, 24, and 36 months postinjury. After hospital discharge, potential destinations for patients are the home setting (with/without outpatient rehabilitation), inpatient rehabilitation centers, or nursing homes.<sup>18</sup>

Measurement of HRQoL and mood started from the time at which the patient was discharged home only. These self-report questionnaires were not administered during admission to the hospital or to the rehabilitation center or nursing home.

#### Participants

For the present study, inclusion criteria were admission to a hospital for moderate (Glasgow Coma Scale [GCS] score, 9-12) or severe (GCS score, 3-8) TBI caused by a nonpenetrating trauma. Exclusion criteria were inadequate knowledge of the Dutch language or important pretraumatic neurologic, oncologic, or systemic impairments (eg, spinal cord injury, psychiatric disorder, or cancer) that may interfere with TBI-related assessment of disability.

#### **Outcome measure**

The Dutch version of the SF-36 was used to assess HRQoL in the home setting only.<sup>5,6,19</sup> This is a valid and reliable instrument for use in various conditions, including TBI.<sup>6-8</sup> The SF-36 consists of 36 items measuring 8 domains: Physical Functioning; Role Physical (the extent to which physical health interferes with daily activities); Bodily Pain; General Health; Vitality; Social Functioning; Role Emotional (the extent to which emotional health interferes with daily activities); and Mental Health. All domains are transformed into a scale from 0 to 100, with 100 indicating the best possible condition. The 8 domain scores can be summarized into a Physical Component Summary (PCS) score (to which Physical Functioning, Role Physical, Bodily Pain, and General Health contribute most) and a Mental Component Summary (MCS) score (to which Mental Health, Social Functioning, Role Emotional, and Vitality contribute most). The PCS and MCS are scored using norm-based methods (T scores); for example, in the general United States population, the PCS and MCS have a mean  $\pm$  SD of 50 $\pm$ 10.<sup>20</sup> For the present study, age-adjusted norm values from the Dutch normative population were used.<sup>6</sup>

In this study, the internal consistency of the PCS and MCS subscales was adequate ( $\alpha = .72$  and  $\alpha = .76$ , respectively). Correlation between the summary scales and the associated subscales was highly significant (PCS: r > .55 and MCS: r > .56; P < .001), whereas correlation between the PCS and MCS was not (r = -.13; P > .300), indicating that the construction of the summary scores was valid.

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