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## Health-related quality of life after mild, moderate and severe traumatic brain injury: Patterns and predictors of suboptimal functioning during the first year after injury



A.C. Scholten <sup>a,\*</sup>, J.A. Haagsma <sup>a</sup>, T.M.J.C. Andriessen <sup>b</sup>, P.E. Vos <sup>c</sup>, E.W. Steyerberg <sup>a</sup>, E.F. van Beeck <sup>a</sup>, S. Polinder <sup>a</sup>

- <sup>a</sup> Department of Public Health, Erasmus MC, PO Box 2040, 3000 CA Rotterdam, The Netherlands
- <sup>b</sup> Department of Neurology, Radboud University Medical Center, PO Box 9101, 6500 HB Nijmegen, The Netherlands
- <sup>c</sup> Department of Neurology, Slingeland Hospital, PO Box 169, 7000 AD Doetinchem, The Netherlands

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#### ABSTRACT

Background: The Glasgow Outcome Scale Extended (GOSE) is the established functional outcome scale to assess disability following traumatic brain injury (TBI), however does not capture the patient's subjective perspective. Health-related quality of life (HRQL) does capture the individual's perception of disability after TBI, and has therefore been recognized as an important outcome in TBI. In contrast to GOSE, HRQL enables comparison of health outcome across various disease states and with healthy individuals. We aimed to assess functional outcome, HRQL, recovery, and predictors of 6 and 12-month outcome in a comprehensive sample of patients with mild, moderate or severe TBI, and to examine the relationship between functional impairment (GOSE) and HRQL.

Methods: A prospective cohort study was conducted among a sample of 2066 adult TBI patients who attended the emergency department (ED). GOSE was determined through questionnaires or structured interviews. Questionnaires 6 and 12 months after ED treatment included socio-demographic information and HRQL measured with Short-Form Health Survey (SF-36; reflecting physical, mental and social functioning) and Perceived Quality of Life Scale (PQoL; measuring degree of satisfaction with functioning).

Results: 996 TBI survivors with mild, moderate or severe TBI completed the 6-month questionnaire. Functional outcome and HRQL after moderate or severe TBI was significantly lower than after mild TBI. Patients with moderate TBI showed greatest improvement. After one year, the mild TBI group reached outcomes comparable to population norms. TBI of all severities highly affected SF-36 domains physical and social functioning, and physical and emotional role functioning. GOSE scores were highly related to all SF-36 domains and PQoL scores. Female gender, older age, co-morbidity and high ISS were strongest independent predictors of decreased HRQL at 6 and 12 months after TBI.

Conclusions: HRQL and recovery patterns differ for mild, moderate and severe TBI. This study indicates that GOSE, although clinically relevant, fails to capture the subjective perspective of TBI patients, which endorses the use of HRQL as valuable addition to established instruments in assessing disability following TBI. Influence of TBI severity on recovery, together with female gender, older age, co-morbidity and high ISS should be considered in long-term follow-up and intervention programs.

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#### Background

Traumatic brain injury (TBI) is a leading cause of death and long-term disability, particularly in young adults. TBI can cause

assorted impairments and disabilities in functional, physical, emotional, cognitive, and social domains which drastically reduce health-related quality of life (HRQL) [1,2]. Because of major improvements in trauma care, the number of survivors of severe TBI has rapidly grown [3]. However, the disability due to TBI has not appreciably reduced [4]. This has resulted in a shift in attention from mortality towards disability of TBI patients.

<sup>\*</sup> Corresponding author. Tel.: +31 10 7038465. E-mail address: a.scholten@erasmusmc.nl (A.C. Scholten).

Disability following TBI is often assessed by functional measurement scales that have been designed for TBI specifically, e.g. the Glasgow Outcome Scale (GOS) and the GOS Extended (GOSE) [4,5]. The GOS is a descriptive outcome scale with 5 categories. Five categories are believed to be too few to represent the wide range of mental and physical disability a patient can suffer following TBI [6,7]. Therefore, the GOS was extended to 8 categories, by dividing 3 categories into a lower and upper one. The GOSE is more sensitive to change than the GOS [6,8], is quick to administer, can be applied to all cases, and has clinically relevant categories. These practical advantages have led to its widespread adoption in early management studies and clinical trials. However, one criticism of scales such as the GOSE is that they fail to capture the subjective perspective (e.g. HRQL) of TBI patients [8].

HRQL reflects an individual's perception of how an illness and its treatment affect physical, mental and social aspects of his/her life [9]. HRQL has been recognized as an important outcome in TBI, because it provides well-standardized information on recovery patterns and frequency, nature, and predictors of disabilities [10]. In contrast to the GOSE, HRQL measures enable comparison of health outcome after TBI with other diseases and the general population, and their outcome in terms of an health status on a scale from 0 (death) to 1 (perfect health) scale can be used in economic evaluations. Research has shown that even years after injury, many TBI patients still report significantly lower HRQL than the general population [1,2,11–14]. Most studies however, focus on recovery after mild [15–17] or moderate and severe [1,12,13,18,19] TBI. HRQL and recovery pattern differences between mild, moderate and severe TBI are not often

Large variation exists in the use of HRQL instruments to quantify the impact of TBI on population health over time. The most widely used instrument to estimate HRQL after TBI is the 36-Item Short-Form (SF-36) Health Survey [20]; a multidimensional questionnaire, reflecting features of health including physical, mental, and social functioning. Another HRQL instrument that has previously been used in TBI [21,22], is the Perceived Quality of Life Scale (PQoL); a measure of the degree to which the individual is satisfied with his/her functioning, or global life satisfaction [23]. Findings from earlier studies suggest similar SF-36 and PQoL patterns after TBI [7,21,24].

Due to the heterogeneity of TBI patients and their wide array of short- and long-term recovery patterns, accurate measurement of HRQL and the impact of all severities of TBI over time is needed. Furthermore, more insight is needed in the assessment of HRQL following TBI as a potential addition to established instruments, such as the GOSE. Therefore, the current study focused on HRQL after mild, moderate and severe TBI, and on the relationship between functional outcome measured with GOSE and HRQL measured with the SF-36 (including all domains) and PQoL.

The objectives of the present prospective cohort study were to (1) assess the functional outcome (GOSE), HRQL (SF-36 and PQoL), and recovery patterns at 6 and 12 months after mild, moderate and severe TBI, (2) assess the relationship and discrepancies between GOSE and HRQL for all TBI severity levels, and (3) test sociodemographic and injury-related characteristics as predictors for suboptimal functioning after TBI.

#### Methods

Study design

Data for the present study were obtained from the Radboud University Brain Injury Cohort Study (RUBICS) [25–27]. RUBICS is a

prospective observational cohort study on the association between demographic and clinical variables, posttraumatic complaints, and functional outcome of patients with brain injury. This study encompassed multiple outcome measures (GOSE, SF-36 and PQoL) of patients 6 and 12 months after mild, moderate and severe TBI.

Between 1998 and 2010, patients admitted to the emergency department (ED) of the Radboud University Nijmegen Medical Centre (RUNMC), a level I trauma centre, with a diagnosis of mild. moderate or severe TBI were included in the RUBICS database. TBI was defined as an acute insult to the brain caused by an external physical force [28]. Mild and moderate TBI were defined by an ED Glasgow Coma Scale (GCS) score of, respectively, 13-15 [29] and 9-12 [30] after initial resuscitation at the ED or an admission GCS of, respectively, 13-15 and 9-12 followed by sedation and intubation during resuscitation for a non-neurological cause. Severe TBI was characterized by an ED GCS  $\leq$  8 [31] after resuscitation. Clinical data registered by a neurologist and/or neurosurgeon in the ED were collected by a research nurse and entered into the RUBICS database. The RUBICS database comprised demographic data, trauma mechanism, hospitalization, clinical injury variables, and comorbidities. Co-morbidity was defined as the presence of any co-existing medical diseases or disease processes additional to the injury that the injury patients sustained. The following diseases were assessed as co-morbid disease: asthma, chronic bronchitis, chronic non-specific lung disease (not questioned), heart disease, diabetes, back hernia or chronic backache, osteoarthritis, rheumatoid arthritis, and cancer. Further, Abbreviated Injury Scale of the Head (AISH) revised 1990 (AIS-90) [32], Injury Severity Score (ISS), and GOSE were recorded.

#### Study participants

In the current study, all patients, aged 16 years and older, with mild, moderate and severe TBI, admitted to the ED of RUNMC, between June 2003 and June 2010, who completed the 6 month questionnaire, were selected from the RUBICS database. Exclusion criteria were no informed consent, alcohol or drug abuse or dementia, unknown address, and inability to speak or write Dutch. Furthermore, patients who died within 6 months were excluded. Written informed consent was obtained from all participating patients.

#### Functional outcome measure

The GOSE scores functional outcome with eight questions covering consciousness, independence at home, major social roles (work, social and leisure activities, family and friendships), and return to normal life [33]. It results in an 8-point scale classifying functional outcome from 1 (dead) to 8 (complete recovery). GOSE scores were determined using a structured interview during regular visits to the outpatient clinic or during consultation by telephone [34]. Patients not visiting the outpatient clinic were sent a GOSE questionnaire by regular mail, and when not returned a reminder was sent [35]. Finally, we attempted to reach all nonresponding patients by telephone to acquire an outcome score. Assessment often took place at 6 (70%) and 12 (66%) months postinjury. Outcomes obtained within a 2 months range were also accepted if no outcome at exactly 6 or 12 months was available. Patients with a GOSE score of 1 (dead) were excluded from this study.

#### Health-related quality of life measures

HRQL was determined using the SF-36 (Version 1) and PQoL. Patients were asked to fill in a questionnaire, which included the HRQL measurements at 6 and 12 months post-injury.

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