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ORIGINAL ARTICLE

Introduction of the Uppsala Traumatic Brain Injury register for regular surveillance of patient characteristics and neurointensive care management including secondary insult quantification and clinical outcome

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Abstract

Background. To improve neurointensive care (NIC) and outcome for traumatic brain injury (TBI) patients it is crucial to define and monitor indexes of the quality of patient care. With this purpose we established the web-based Uppsala TBI register in 2008. In this study we will describe and analyze the data collected during the first three years of this project.

Methods. Data from the medical charts were organized in three columns containing: 1) Admission data; 2) Data from the NIC period including neurosurgery, type of monitoring, treatment, complications, neurological condition at discharge, and the amount of secondary insults; 3) Outcome six months after injury. Indexes of the quality of care implemented include: 1) Index of improvement; 2) Index of change; 3) The percentages of 'Talk and die' and 'Talk and deteriorate' patients.

Results. Altogether 314 patients were included 2008–2010: 66 women and 248 men aged 0–86 years. Automatic reports showed that the proportion of patients improving during NIC varied between 80% and 60%. The percentage of deteriorated patients was less than 10%. The percentage of Talk and die/Talk and deteriorate cases was <1%. The mean Glasgow Coma Score (Motor) improved from 5.04 to 5.68 during the NIC unit stay. The occurrences of secondary insults were less than 5% of good monitoring time for intracranial pressure (ICP) >25 mmHg, cerebral perfusion pressure (CPP) <50 mmHg, and systolic blood pressure <100 mmHg. Favorable outcome was achieved by 64% of adults.

Conclusion. The Uppsala TBI register enables the routine monitoring of NIC quality indexes.

Key words: Database, neurointensive care, outcome, quality register, secondary insults, traumatic brain injury

Introduction

Quality of treatment and care of patients with traumatic brain injury (TBI) is traditionally measured in clinical outcome and related to patient characteristics. There are many other factors that affect clinical outcome, e.g. the amount of secondary insults (high intracranial pressure (ICP), hypotension, fever, etc.), types of treatment, and the occurrence of complications during neurointensive care (NIC). These factors, which are related to NIC, have so far not been followed regularly for quality assurance of the management of TBI. During the last decades of the twentieth century, the development of NIC contributed to substantially

improved results (1). To improve further the care and outcome for these patients it is crucial to monitor quality parameters routinely in the NIC unit. Such parameters include monitoring time spent over/under predefined secondary insult levels (e.g. proportion of time with ICP >25 mmHg) and many other measures. This was the purpose for us establishing the Uppsala TBI register, an internet (world wide web)-based quality register for traumatic brain-injured patients treated at the NIC unit in Uppsala, Sweden. The quality register was established in 2008 in collaboration with Uppsala Clinical Research Center (UCR, www.ucr.uu.se, Uppsala University). The objectives behind the Uppsala TBI register were to be able

Table I. Outline of the Uppsala TBI register.^a

| First column: Admission to NIC unit | Second column: NIC period | Third column: Six-month follow-up |
|--|---|---|
| Date of accident | Deceased or not | Evaluation of outcome using GOSE for adults and GOS for children ≤15 years. |
| Name, age, and address | Number of days spent at the NIC unit | Registration of VP shunt operation after discharge |
| Medical history | RLS and GCS assessment at discharge from the NIC unit | |
| Cause of accident | Treatments | |
| Accident circumstances | Artificial ventilation | |
| Events pre NIC period | Neuromonitoring | |
| RLS and GCS (Supplementary Table 4) | Secondary insult occurrence | |
| Dominant finding on first CT scan | Complications | |
| Other injuries | | |

^aFor details and definitions see Supplementary Material.

CT = computerized tomography; GCS = Glasgow Coma Scale (11); GOS = Glasgow Outcome Scale (8); GOSE = Glasgow Outcome Scale extended (8); NIC = neurointensive care; RLS = Reaction Level Scale (10); VP = ventriculoperitoneal.

regularly to: 1) Obtain information about demographic data, clinical outcome, and how treatments and care affected outcome; 2) Identify patients who did not have the expected result or the right treatment and why that happened; 3) Provide data and select patients for research studies. The specific purpose of this paper is to present the design of the quality register including definitions and to demonstrate the functionality by reporting the first results from the register.

Material and methods

Standardized management protocol system and treatment goals

Routines and treatment goals at the NIC unit in Uppsala are described in a standardized management protocol system which is based on good laboratory practice (GLP) principles (2). In the system it is, for example, declared that patients with TBI who are not responding to commands should be intubated and ICP should be monitored. These rules represent two management principles relevant for quality assurance of the NIC.

The treatment and care of these patients are focused on avoiding secondary insults. There are, for example, treatment goals of keeping ICP <20 mmHg and cerebral perfusion pressure (CPP) >60 mmHg written in the standardized management protocol system (1). These rules represent other important management goals important to follow in a quality assurance program. The blood pressure is measured at heart level, and ICP is measured 2 cm below the head's highest point. The head was elevated 30°.

The Uppsala TBI register

The Department of Neurosurgery in Uppsala receives patients from a region with a population of 1.9 million. Most patients are secondary admissions from local hospitals in the region. All patients with TBI admitted to the NIC unit at Uppsala University Hospital are entered in the register. The register was developed in collaboration with UCR. UCR provides comprehensive solutions for web-based quality registers including e.g. design and maintenance of the database, electronic reports, and statistical analysis. The web-based register allows easy 'push-button' statistics of predefined parameters (standardized summary reports) with data up to the previous day included as well as spreadsheet downloading options of the entire register for detailed analysis of specific questions.

Data elements

Data are extracted from the medical charts by a small group of persons. Predefined criteria are set up for the data set (see Supplementary Tables 1–3, only available in the online version of the journal; please find this material with the following direct link to the article: <http://www.informahealthcare.com/doi/abs/10.3109/03009734.2013.806616>). There are three columns for each patient where data are inserted (Table I). The *first column* includes admission data (Table I; Supplementary Table 1). The *second column* includes data from the NIC period concerning surgery, types of monitoring, if and how long the patient was intubated, complications, and neurological condition at discharge. In this column it is also possible to

Table II. Overview of automatic daily standardized summary reports. Figures denote series of patients reported (1 = All patients last 12 months; 2 = All patients since 2008; 3 = Patients by year; 4 = Last 20 patients).

| |
|--|
| Age (1+2) |
| Sex (1+2) |
| Referring hospitals (1+3) |
| Cause of accident (1+3) |
| RLS and GCS-M assessment on admission to the NIC unit (1+3) |
| Monitoring (1+3) |
| Index of improvement (1+2+3+4) ^a |
| Index of change (improved, unchanged, and deteriorated) (1+2+3+4) ^a |
| Talk and deteriorate (1+2+3+4) ^a |
| Talk and die (1+2+3+4) ^a |
| Clinical outcome for all patients ≥16 years (GOSE) (1+2+3) |
| Clinical outcome for all patients ≥16 years (GOSE) by age (1+2) |
| Clinical outcome for all patients ≥16 years (GOSE) by neurological status on admission (1+2) |
| Clinical outcome for children ≤15 years (GOS) (1+2+3) |

^a For definitions see text.

GCS-M = Glasgow Coma Scale–Motor (11); GOS = Glasgow Outcome Scale (9); GOSE = Glasgow Outcome Scale extended (8); NIC = neurointensive care; RLS = Reaction Level Scale (10).

register the amount of secondary insults as assessed from the monitoring data (see below) (Table I; Supplementary Table 2). The *third column* is used for six-month outcome follow-up (Table I; Supplementary Table 3).

Secondary insult quantification

The secondary insults are organized in different categories: ICP, CPP, and blood pressure (BP). The amount of secondary insults is presented as the proportion (%) of good monitoring time (GMT) and hours spent at predefined insult levels: ICP >25 and >35 mmHg; CPP <60, <50, <40 mmHg, and >70, >80 mmHg; systolic blood pressure (SBP) <100, <90 mmHg, and >160, >180 mmHg; and mean arterial pressure (MAP) <80, <70 mmHg, and >110, >120 mmHg. The threshold levels for secondary insults were chosen according to existing guidelines and based on the occurrence of secondary insults in a detailed secondary insult quantification study performed earlier at our NIC unit (3-5). GMT is the time left when all gaps in monitoring data associated to, for example, radiology examinations or surgical procedures are removed together with clear artifacts. The Odin monitoring system developed by Tim Howells and colleagues in Edinburgh and Uppsala was used for artifact screening and for the calculations

of percent of GMT that the patients spent at insult level (6).

Outcome

The clinical outcome was assessed using the extended Glasgow Outcome Scale (GOSE) (7) after 6 months (mean 8.2 months). In practice, specially trained nurses interviewed the patients by phone using the standard questionnaire (8). Children (≤15 years) were followed up by interviewing their parents or guardian after 6 months (mean 7.2 months) using the original Glasgow Outcome Scale (GOS) (8,9).

Quality assurance components

Automatic daily standardized summary reports on demand. The Uppsala TBI register provides standardized summary reports on the web page (Table II). The data are updated every night. The mean values of the Reaction Level Scale (RLS) (see Supplementary Table 4 for criteria, only available in the online version of the journal; please find this material with the following direct link to the article: <http://www.informahealthcare.com/doi/abs/10.3109/03009734.2013.806616>) (10) at admission and discharge are automatically calculated for the last 20 patients, patients treated during the last 12 months, and for all patients treated since 2008. From these values the *Index of improvement* and the *Index of change* are calculated (for these special calculations untreatable patients in RLS 7–8 with bilateral unreactive pupils were excluded; for all other calculations all patients in the register are included). *Index of improvement* is calculated as the difference between mean RLS at arrival and mean RLS at discharge. *Index of change* shows the difference between RLS at arrival and RLS at discharge and divides the patients into three groups: improved, unchanged, and deteriorated. In the *Talk and deteriorate report* and *Talk and die report*, all patients who have talked (RLS 1–2 on admission) and then deteriorated (RLS 3–8 at discharge) or died during NIC were registered.

Detailed analysis of database. It is possible to export all data from all patients into a spreadsheet for detailed analysis and research. Every case consists of 1 row and 114 columns. From this Excel file it is possible to study, for example, the amount of secondary insults for every single patient. All data from the start of the registry 2008 to the end of 2010 is summarized and presented in the Results section of this study. Means are presented ± standard deviations.

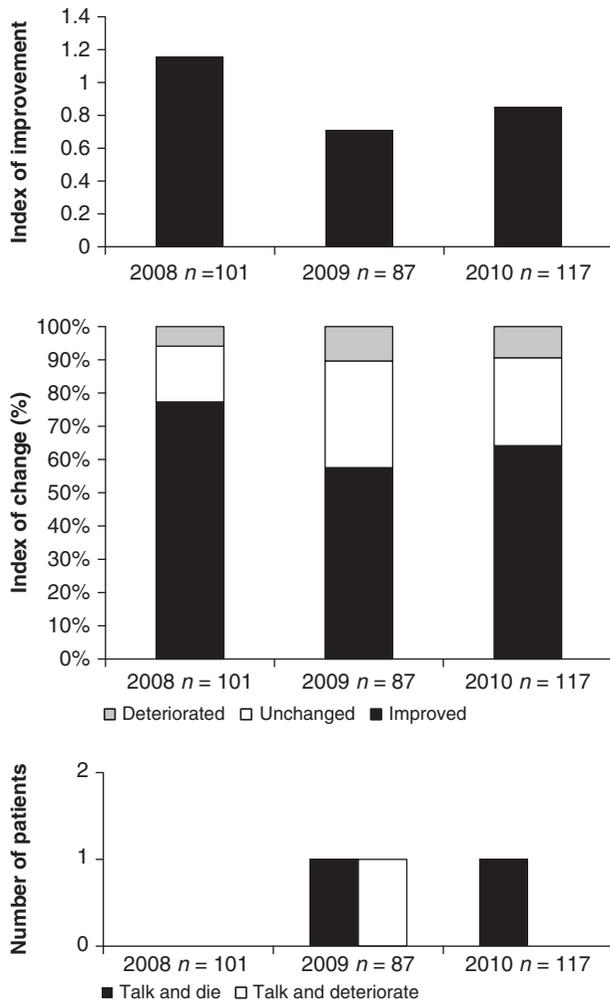


Figure 1. The automatic standardized summary report on demand in treatable patients ($n = 305$) included in the Uppsala TBI register 2008–2010. The upper panel shows 'Index of improvement' calculated by the difference between mean RLS at arrival and mean RLS at discharge. The middle panel shows 'Index of change' calculated by the difference between RLS on arrival and RLS at discharge. The lower panel shows the number of patients talk (RLS 1–2 on admission) and die (dead during NIC), and talk and deteriorate (RLS 3–8 at discharge).

Specific reviews of compliance with standardized management protocols. The occurrence of patients not responding to command who did not receive artificial ventilation and ICP monitoring, respectively, as prescribed in the standardized management protocol system, is investigated. A specific medical chart review is done for these cases to find explanations.

Specific reviews of deteriorating cases. A specific medical chart review was performed in cases with RLS 1–5 at arrival who deteriorated, to find reasons for their deterioration and to identify possible poor management.

Ethics

The study was approved by the local ethics committee.

Results

Between 1 January 2008 and 31 December 2010 the Uppsala TBI register contained 314 patients.

Automatic daily standardized summary reports

Every day, on command, the system displays the mean RLS at admission and discharge for different time periods. The mean RLS at admission were slightly different during 2008–2010 (3.43 in 2008; 2.95 in 2009; and 3.37 in 2010). *Index of improvement* and *Index of change* are presented by year in Figure 1. The patients improved on average during the NIC stay (1.2 RLS levels in 2008; 0.7 RLS levels in 2009; and 0.9 RLS levels in 2010). The proportion of patients improved in RLS scale during NIC varied between 80% in 2008 and 60% in 2009. The proportion of deteriorated patients was stable and less than 10% during the period. Figure 1 shows the occurrence of *Talk and die* and *Talk and deteriorate* by year. In 2008 there were no patients who talked and died and none who talked and deteriorated.

Detailed analysis of database

The 314 patients studied included 66 women and 248 men with an age of 0–86 years (mean 42.9 years, ± 22.2). Out of these 314 cases, 33 were children aged ≤ 15 years (mean 8.9 years, ± 5.4) (Figure 2).

Admission to the NIC unit. The mean GCS-M was 5.04 ± 1.23 (RLS 3.4 ± 1.6) (Table III) (11). The GCS classification was mild (GCS 13–15) (22%), moderate (GCS 9–12) (27%), and severe (GCS 3–8) (51%) (Figure 3). The co-occurrence of some specific diseases that may influence the outcome after TBI is presented in Table IV. The most frequent causes of injury were fall accidents (44%) and vehicle accidents (30%) (Table IV). In 24% of the cases the injury occurred under the influence of alcohol or other drugs (anamnesic or positive serum levels) (Table IV). The patients were transferred with specialized intensive care helicopter in 33% of the cases (Table IV). Acute evacuation of an extracerebral hematoma was done at the referral hospital in 8% of the patients before admission to the NIC unit in Uppsala (Table IV). The primary findings on the initial brain CT scan were contusions (33%) and

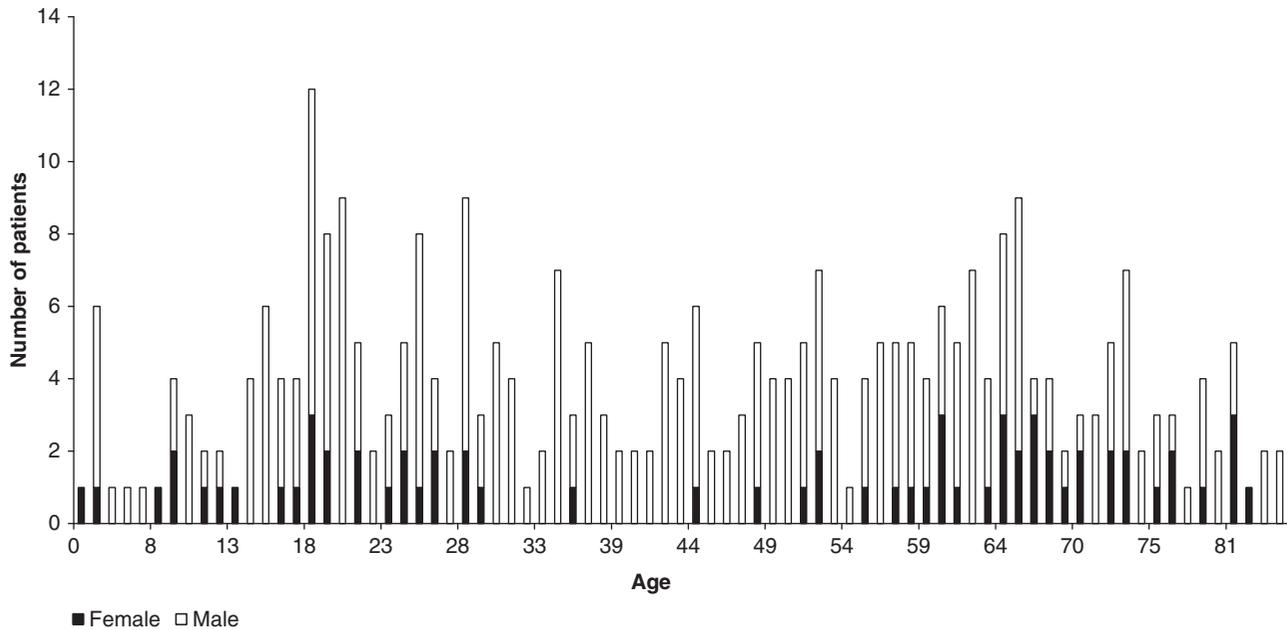


Figure 2. Age and sex in all 314 patients included in the Uppsala TBI register 2008–2010.

acute subdural hemorrhage (23%) (Table IV). The most common injuries beside the brain injury were thoracic injuries (23%) followed by extremity injuries (15%), facial injuries (15%), and spinal column injuries (11%) (Table IV).

Neurointensive care. The patients stayed at the NIC unit for 0–86 days (mean 11 days, ± 10). Craniotomy for evacuation of intracranial hematomas and/or contusions was the most common treatment registered (performed in 30% of all cases), followed by barbiturate coma treatment (8%) and decompressive craniectomy (6%) (Table V). Nine percent of the patients went through multiple neurosurgical operations (insertion of monitoring devices excluded). ICP was monitored in approximately half of the cases, and, of these, 16% had ventricular drainage, 64% had parenchymal probe, and 20% had both (Table V). ICP was monitored between 1 and 50 days (mean 11.1 days, ± 7.3) (Table V). Artificial ventilation was used in 75% of all cases between 0 and 46 days (mean 8.6 days, ± 7.6) (Table V). Other types of neuromonitoring applied was microdialysis (11% of the cases), brain tissue oxygenation (3%), and jugular bulb (2%) (Table V).

Occurrence of secondary insults. Analysis of the occurrence of secondary insults for all patients according to predefined insult thresholds showed that ICP >25 and >35 mmHg, CPP <50 and <40 mmHg, SBP <100 and <90 mmHg, and MAP <70 and >120 mmHg occurred

in less than 5% of GMT (Figure 4). CPP <60 , >70 , and >80 mmHg, SBP >160 and >180 mmHg, and MAP <80 and >110 mmHg were present in a larger proportion of GMT (Figure 4). Eleven cases were excluded from the analysis of secondary insults since no monitoring data were stored for these patients because they had initially been treated in the general intensive care unit.

Neurological status at discharge. At discharge from the NIC unit, the mean GCS-M was 5.68 ± 0.8 (RLS 2.5 ± 2.0) compared to 5.04 ± 1.23 (RLS 3.4 ± 1.6) on admission (Table III). The pupil reaction and size became more normal during the stay at the NIC unit, but the amount of paresis was almost the same at discharge (34%) as at arrival (36%) (Table III).

Complications during the stay at NIC unit. Severe pulmonary problems occurred in 3% of the cases, and 2% of the patients had meningitis with positive bacterial cultures.

Outcome

Forty-one percent of the adult patients (≥ 16 years) had good recovery (GR), 23% moderate disability (MD), 19% severe disability (SD), and two (1%) patients remained in a vegetative state (VS). Five percent died at the NIC unit, and 8% died within six months after discharge (Table VI). Among the children (≤ 15 years), 61% showed GR, 15% MD, 9%

Table III. Neurological status on arrival at the NIC unit and at discharge from the NIC unit in all 314 patients included in the Uppsala TBI register 2008–2010.

| | | Admission <i>n</i> = 314 (%) | Discharge <i>n</i> = 297 (%) |
|-----------------------|-----------------------|------------------------------|------------------------------|
| GCS-M | | | |
| 6 | Obeys commands | 141 (45) | 244 (82) |
| 5 | Localizing pain | 110 (35) | 26 (9) |
| 4 | Withdrawal from pain | 32 (10) | 17 (6) |
| 3 | Abnormal flexion | 7 (2) | 5 (2) |
| 2 | Extending | 15 (5) | 5 (2) |
| 1 | No response | 9 (3) | 0 (0) |
| RLS | | | |
| 1 | Alert response | 34 (11) | 104 (33) |
| 2 | Delayed response | 64 (20) | 118 (38) |
| 3a | Very delayed response | 43 (15) | 31 (10) |
| 3b | Wards off pain | 81 (25) | 7 (2) |
| 4 | Localizes pain | 32 (10) | 10 (3) |
| 5 | Withdrawing movements | 28 (9) | 21 (7) |
| 6 | Stereotype flexion | 8 (2) | 3 (1) |
| 7 | Stereotype extension | 15 (5) | 3 (1) |
| 8 | No response | 9 (3) | 0 (0) |
| | Dead | 0 (0) | 17 (5) |
| Pupil reaction | | Right–Left | Right–Left |
| | Normal | 224 (71)–218 (69) | 272 (92)–266 (90) |
| | Sluggish | 47 (15)–51(16) | 13 (4)–21 (7) |
| | Unreactive | 32 (10)–33(10) | 9 (3)–8 (3) |
| | Unknown | 11 (4)–12 (5) | 20 (1)–19 (1) |
| Pupil size | | Right–Left | Right–Left |
| | Small | 50 (16)–52 (17) | 7 (2)–7 (2) |
| | Normal | 233 (74)–221 (70) | 273 (93)–273 (92) |
| | Dilated | 21 (7)–29 (9) | 13 (4)–13 (4) |
| | Unknown | 10 (3)–12 (4) | 4 (1)–4 (1) |
| Paresis | | | |
| | Yes | 113 (36) | 106 (34) |
| | Arm or leg paresis | 45 (40) | 46 (43) |
| | Hemiparesis | 58 (51) | 50 (47) |
| | Paraparesis | 2 (2) | 7 (7) |
| | Tetraparesis | 8 (7) | 3 (3) |
| | No | 181 (57) | 188 (63) |
| | Unknown | 20 (7) | 3 (1) |

GCS-M = Glasgow Coma Scale–Motor (11); RLS = Reaction Level Scale (10).

SD; no children persisted in VS, and 9% died at the NIC unit (Table VII). Figure 5 shows the clinical outcome for children and adults. Clinical outcome for all adult patients (≥ 16 years) is presented by age in Table VIII and by the severity of the injury in Figure 3.

Specific medical chart review

Compliance with standardized management protocols. The compliance with standardized management protocols was spot-checked by analyzing two management principles selected from the standardized

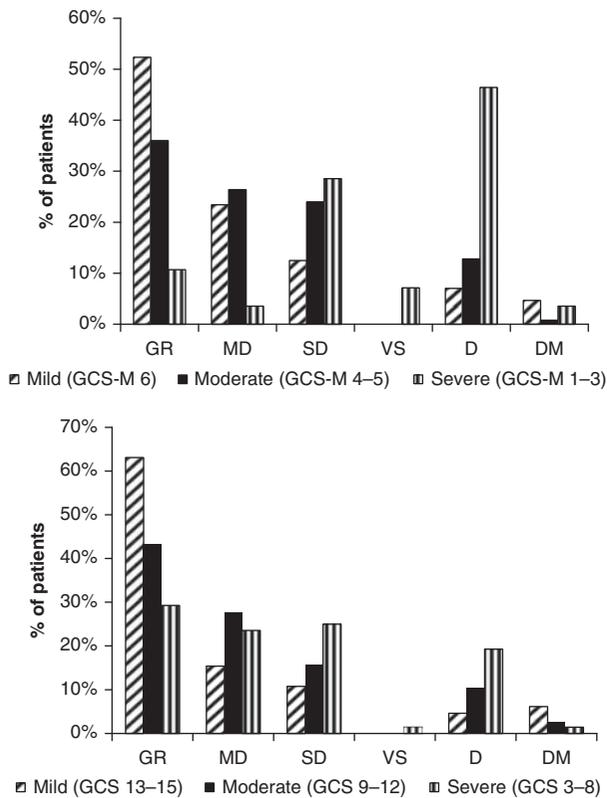


Figure 3. Six-month outcome (GOS) divided by severity of injury at admission to the NIC unit in adult patients ≥ 16 ($n = 181$) years included in the Uppsala TBI register 2008–2010. The severity of injuries was classified as mild, moderate, and severe using the GCS sum score. Unstable reactions were scored as 1 (no reaction) according to common practice. To avoid the problem with unstable reactions and over-classification of severity, a modified classification of the severity of the injury based on the GCS motor score was also used. (GR = good recovery; MD = moderate disability; SD = severe disability; VS = vegetative state; D = dead within six months; DM = data missing).

management protocols, i.e. if patients not responding to commands received ICP monitoring and were artificially ventilated as prescribed. Among 173 cases who did not respond to commands (RLS 3b-8, GCS-M 1-5) on arrival at the NIC unit, ICP was not monitored in 36 (21%) cases. Explanations for not monitoring ICP were found in the medical records and are presented in Table IX. Three cases who did not respond to commands (RLS 3b-8) on arrival at the NIC unit were not intubated and artificially ventilated. According to the medical records, the reason for not intubating those three cases was that all of them made a very quick clinical improvement.

Deterioration in neurological status. Out of all patients who arrived in RLS 1-5 ($n = 282$) at the NIC unit 20 patients deteriorated. Likely patient-related explanations could be found in 19 cases (Table X).

Table IV. Admission data in all 314 patients included in the Uppsala TBI register 2008–2010^a.

| | <i>n</i> (%) | Unknown <i>n</i> (%) |
|--|--------------|----------------------|
| Medical history | | |
| Prior brain diseases | 40 (13) | 17 (6) |
| Diabetes mellitus | 18 (6) | 19 (6) |
| Cardiovascular diseases | 49 (16) | 21 (7) |
| Alcohol addiction | 49 (16) | 31 (10) |
| Anticoagulation treatment | 37 (12) | 20 (7) |
| Cause of accident | | |
| Fall accident | 138 (44) | |
| Vehicle | 94 (30) | |
| Sports | 17 (6) | |
| Assault | 16 (5) | |
| Walker | 14 (4) | |
| Cyclist hit by other vehicle | 12 (4) | |
| Remaining | 23 (7) | |
| Accident circumstances | | |
| Influence of alcohol/drugs | 74 (24) | 62 (20) |
| Work-place accident | 17 (6) | 1 (-0) |
| Events pre NIC | | |
| Severe global ischemia | 8 (3) | 5 (2) |
| Hypothermia | 1 (1) | 3 (1) |
| Urgent surgery at referral hospital | 23 (8) | 0 (0) |
| Transportation | | |
| Helicopter | 105 (33) | 8 (3) |
| Dominant finding on first CT scan | | |
| Acute subdural hematoma | 74 (23) | |
| Contusions | 104 (33) | |
| Epidural hematoma | 23 (7) | |
| Diffuse axonal injury | 32 (10) | |
| Traumatic subarachnoid hemorrhage | 24 (8) | |
| Impression fracture | 9 (3) | |
| Mixed injuries | 33 (11) | |
| Other | 10 (3) | |
| Normal examination | 5 (2) | |
| Other injuries | | |
| Spinal column injury | 34 (11) | |
| Spinal cord injury | 4 (1) | |
| Facial injury | 48 (15) | |
| Thoracic injury | 71 (23) | |
| Abdominal injury | 20 (6) | |
| Pelvic injury | 15 (5) | |
| Extremities | 47 (15) | |
| Large bleeding | 14 (4) | |

^aSee Supplementary material for definitions.

Table V. Treatment and neuromonitoring in all 314 patients included in the Uppsala TBI register 2008–2010.

| | n (%) | Time (days) | | |
|---------------------------|----------|-------------|-----|-----|
| | | Mean (±) | Min | Max |
| <i>Treatments</i> | | | | |
| Craniotomy | 94 (30) | | | |
| Decompressive craniectomy | 19 (6) | | | |
| Barbiturate coma | 24 (8) | 5.9 (3.4) | 1 | 13 |
| Artificial ventilation | 237 (75) | 8.6 (7.6) | 0 | 46 |
| <i>Neuromonitoring</i> | | | | |
| ICP monitoring | 170 (54) | 11.1 (7.3) | 1 | 50 |
| Ventricular drainage | 28 (16) | | | |
| Parenchymal probe | 109 (64) | | | |
| Both | 33 (20) | | | |
| Jugular bulb oxygenation | 6 (2) | | | |
| Microdialysis | 36 (11) | | | |
| Brain tissue oxygenation | 10 (3) | | | |

Out of these 20 patients, two talked (RLS 1–2) and died: in one this was due to cardiac arrest, and the other one died at the NIC unit due to direct consequences of the TBI. Both were older than 70 years and were on anticoagulation treatment. One patient talked (i.e. RLS 1–2 on admission) and deteriorated; this patient was older than 70 years and had

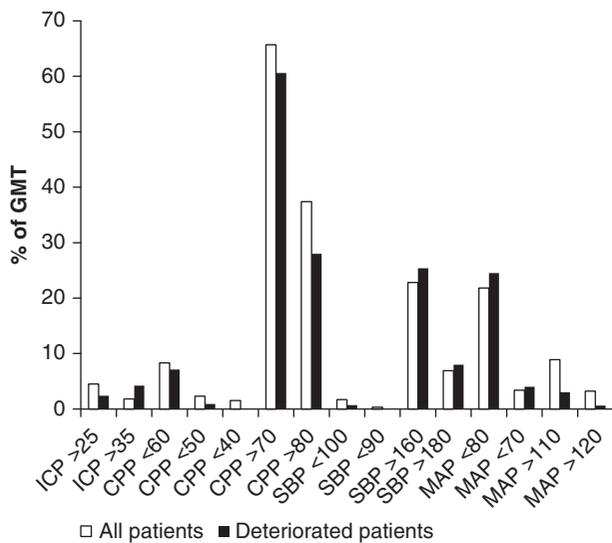


Figure 4. Mean occurrence of secondary insults (% of GMT) according to predefined threshold levels (mmHg) in TBI patients with ICP monitoring ≥ 16 years ($n = 146$) and in deteriorated patients ≥ 16 years ($n = 20$), included in the Uppsala TBI register 2008–2010. (ICP = intracranial pressure; CPP = cerebral perfusion pressure; SBP = systolic blood pressure; MAP = mean arterial pressure).

Table VI. Six-month outcome after traumatic brain injury in all TBI patients ≥ 16 years included in the Uppsala TBI register 2008–2010.

| GOSE | n (%) |
|--|-----------|
| Good recovery—higher | 72 (26) |
| Good recovery—lower | 43 (15) |
| Moderately disabled—higher | 37 (13) |
| Moderately disabled—lower | 27 (10) |
| Severely disabled—higher | 20 (7) |
| Severely disabled—lower | 34 (12) |
| Vegetative state | 2 (1) |
| Dead at the NIC unit | 14 (5) |
| Dead within 1 week after discharge from the NIC unit | 9 (3) |
| Dead 1–24 weeks after discharge from the NIC unit | 15 (5) |
| Missing data | 8 (3) |
| Total | 281 (100) |

anticoagulation treatment. No treatable children deteriorated. The three children who died arrived in RLS 8. Deteriorating patients had a similar amount of secondary insults compared to all patients (Figure 4).

Discussion

The main goal of establishing the Uppsala TBI register was to obtain an instrument for regular quality assurance of the management of TBI with particular focus on NIC. Therefore, a battery of quality assurance components suitable for NIC was introduced to reflect the quality of NIC in different aspects. The introduced quality assurance components and the results in general will be discussed in the following sections.

Automatic daily standardized summary reports on demand

The idea with the standardized summary reports was to be able to get updated reports on demand, with

Table VII. Six-month outcome after traumatic brain injury in all children ≤ 15 years included in the Uppsala TBI register 2008–2010.

| GOS | n (%) |
|----------------------|----------|
| Good recovery | 20 (61) |
| Moderately disabled | 5 (15) |
| Severely disabled | 3 (9) |
| Vegetative state | 0 (0) |
| Dead at the NIC unit | 3 (9) |
| Missing data | 2 (6) |
| Total | 33 (100) |

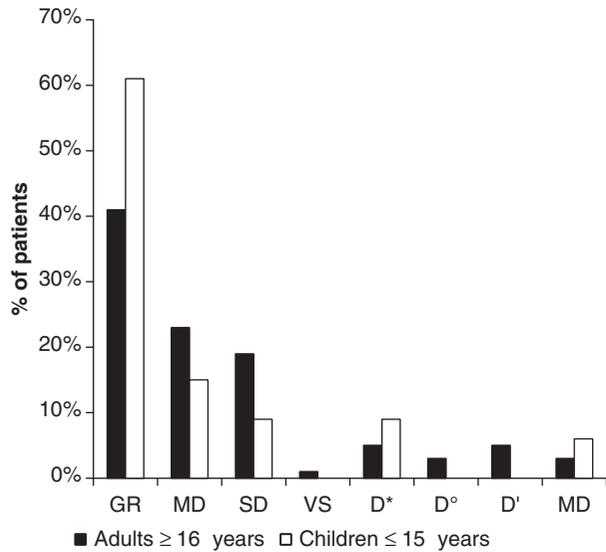


Figure 5. Clinical six-month GOSE and GOS outcome for adults ≥16 years (n = 181) and children ≤15 years (n = 33) in all 314 patients included in the Uppsala TBI register 2008–2010. (GR = good recovery; MD = moderate disability; SD = severe disability; VS = vegetative state; D* = dead at the NIC unit; D° = dead within 1 week after discharge from the NIC unit; D' = dead 1–24 weeks after discharge from the NIC unit; DM = data missing).

predefined selections of patients for overview and comparison (all patients last year, all patients since the start of the register 2008, patients by year, and last 20 patients). The reports would include traditional demographic data, crude outcome data, and outcome in relation to established prognostic admission factors. Furthermore, new quality measures were included in the reports with inspiration from the description of patients with head injuries who talked and died due to secondary brain injury in the 1970s in Glasgow (12), i.e. occurrence of *Talk and die* cases, and occurrence of *Talk and deteriorate* cases.

Concerning using Index of improvement, Index of change, Talk and die, and Talk and deteriorate, the idea was to introduce new quality measures for the intensive care period specifically. If, for example, the number of talk and die cases suddenly increased, this would be a severe warning, indicating an audit of care. In this material, <1% of the TBI patients talked and died, while around 6% have been reported by others (13,14). Talk and deteriorate cases, which means patients who are awake on admission and then deteriorate (15), were also rare and occurred in less than 1% of the patients (Figure 1).

Our impression is that the standardized summary reports on demand provide a valuable tool to monitor demographic changes over time and the quality of NIC in TBI patients. The possibility to get updated reports on demand every day is a great advantage. Inclusion of the different quality measures developed

Table VIII. Age-stratified six-month outcome in all adult TBI patients ≥16 years included in the Uppsala TBI register 2008–2010 (% of patients in each age group).

| Clinical outcome | Age (years) | | |
|--|-----------------------------|----------------------------|--------------------------|
| | 16–39 (n = 110) n (%) | 40–59 (n = 79) n (%) | ≥60 (n = 92) n (%) |
| Good recovery—higher | 39 (35) | 17 (22) | 16 (17) |
| Good recovery—lower | 14 (13) | 12 (15) | 17 (18) |
| Moderate disability—higher | 18 (16) | 12 (15) | 7 (8) |
| Moderate disability—lower | 16 (15) | 6 (8) | 5 (5) |
| Severe disability—higher | 4 (3) | 6 (7) | 10 (11) |
| Severe disability—lower | 8 (7) | 16 (20) | 10 (11) |
| Vegetative state | 2 (2) | 0 (0) | 0 (0) |
| Dead at the NIC unit | 4 (4) | 4 (5) | 6 (7) |
| Dead within 1 week after discharge from the NIC unit | 0 (0) | 0 (0) | 9 (10) |
| Dead 1–24 weeks after discharge from the NIC unit | 1 (1) | 4 (5) | 10 (11) |
| Missing data | 4 (4) | 2 (3) | 2 (2) |

from the talk and die concept adds valuable information to ordinary long-term outcome analysis by reflecting the NIC period specifically. These measures need to be evaluated further.

Review of deteriorating cases

The researchers from Glasgow, who described the talk and die cases, found a number of secondary

Table IX. Medical chart review—explanations why and the occurrence of patients not responding to command who did not receive ICP monitoring according to standardized management protocol among all 314 patients included in the Uppsala TBI register 2008–2010.

| Possible explanation | Number of patients |
|---|--------------------|
| Quick improvement | 16 |
| Coagulopathy and quick improvement | 5 |
| Other severe diseases | 2 |
| Fast deterioration after arrival | 1 |
| Fatal brain herniation during evacuation of acute subdural hematoma | 2 |
| Minor mass effect on CT scan and improvement | 1 |
| Coagulopathy | 3 |
| Poor neurological status and coagulopathy | 1 |
| Poor neurological status | 5 |
| Total | 36 |

Table X. Medical chart review—possible patient-related explanations and occurrence of patients in RLS 1–5 on arrival at the NIC unit who deteriorated among all 314 patients included in the Uppsala TBI register 2008–2010.

| Possible explanations | Number of patients |
|---|--------------------|
| Old patient (>69 years) | 1 |
| Anticoagulantia or coagulopathy | 1 |
| RLS 4–5 on arrival | 4 |
| Two or more of the above-mentioned explanations | 11 |
| Severe complication ^a | 2 |
| No explanations | 1 |
| Total | 20 |

^aBasilaris dissection ($n = 1$) and sinus thrombosis ($n = 1$).

insults which could explain the fatal clinical courses and judged that those insults to some extent could have been avoided (12). In order to understand better why some patients (both initially conscious and unconscious) deteriorated during their stay at the NIC unit and to identify suboptimal care, we did a specific medical chart review in all patients who were RLS 1–5 on admission and then deteriorated or died. In this series of patients, the specific medical chart review revealed that 17 out of 20 deteriorating patients had patient-related factors (i.e. high age, on-going anticoagulation treatment or coagulopathy, severe neurological status on arrival) contributing to the deterioration. Two patients had complications (basilar dissection, $n = 1$; sinus thrombosis, $n = 1$) which were judged not to have been preventable. Only one patient had no obvious reason for deterioration, and he deteriorated from RLS 3b to RLS 4.

This structured way to investigate patients who deteriorate during the stay at NIC unit illustrates a way to survey the occurrence of avoidable factors contributing to poor outcome, e.g. misjudgments, incorrect treatment, and complications.

Reviews of compliance with standardized management protocols

It is well established that application of management protocols improves care (1,16). However, the compliance with management protocols has been found to be as low as around 50% (17,18). At the NIC unit in Uppsala, a standardized management protocol system has been developed and maintained by the nursing staff in collaboration with the doctors for many years (1). By involving doctors and nurses we hoped that the guidelines would be followed in daily care. In this study, we checked for the compliance with two crucial

standardized management principles, i.e. ICP monitoring and artificial ventilation. The compliance with the indication for ICP monitoring was 79% and for artificial ventilation 98%. When the reasons were investigated for not monitoring ICP when indicated according to the management protocol, reasonable explanations were found, e.g. coagulopathy. There were somewhat fewer patients monitored with ICP than treated with artificial ventilation. The reason is that some patients arrived at the NIC unit intubated in order to make the transport secure, and after arrival patients who obeyed commands were extubated and not in need of ICP monitoring. It is important in our opinion that quality assurance programs include evaluation of compliance with applied management protocols and reasons for exclusions.

Detailed analysis of database—occurrence of secondary insults

To our knowledge, quantification of secondary insults during NIC has never been mandatory in any quality assurance program for TBI management, although specific studies of secondary insults have been performed (3,19–21). No ideal quantitative measure of secondary insult burden exists. Mean ICP per day or for the whole NIC period are obviously too crude as summary measures. We believe that proportion of GMT above/below a defined threshold level for certain types of insults provides better information (3,15). Quantification of secondary insults within this quality assurance program revealed that all investigated parameters except four had less than 10% of GMT out of the threshold, i.e. high levels of CPP >70 mmHg and >80 mmHg, SBP >160 mmHg, and MAP <80 mmHg. ICP >25 mmHg occurred in 4.5% of GMT and SBP <100 mmHg in 1.7% of GMT. Thus, the occurrence of secondary insults appears to be low. Quantification of secondary insults during NIC is in our opinion of utmost importance in any quality assurance program concerning TBI management.

Detailed analysis of database—general results

Admission to the NIC unit. Patients of all ages were admitted to the NIC unit, and all ages are represented in the material with two peaks around 20 and 60 years. Several patients obeyed command (44%) and only a few (10%) were GCS-M 1–3 at arrival, i.e. there were only a few severely injured patients. Falls (44%) and vehicle (30%) accidents were the most common causes of TBI, which is rather similar to studies from Finland (22) but different from some other countries (23,24). The elderly patients had more

fall accidents, and they were often afflicted with an acute subdural hematoma. The younger patients had more vehicle accidents. Contusions (33%) and acute subdural hematoma (23%) were the most common findings on the first CT scan. Regular evaluation of the automatic summary reports on demand in combination with the detailed analysis of the database can be used to follow any changes in demographic patterns over time for TBI.

NIC period. It is difficult to compare the length of stay at the NIC unit between different centers due to different structure and organization of health care. Analysis of the TBI cases managed in Uppsala revealed that length of stay varied considerably (0–86 days) but was around 11 days on average. Another study from Austria reported a mean of 10 days at the intensive care unit for TBI patients (25). It was also interesting to see that intracranial hematomas/contusions were evacuated in 30% of all cases and that barbiturate coma treatment and decompressive craniectomy were required in 8% and 6% of the patients, respectively, which underlines the need for highly specialized care of TBI. The number of complications during NIC appeared to be small with pulmonary complications in 3% of patients and meningitis in 2%.

Clinical outcome. The Uppsala TBI register includes all patients managed at the NIC unit without selections, which is preferable when the overall results are reported and for comparisons. It is also important that the clinical outcome is assessed in an established and validated way. The Glasgow Outcome Scale, both the original form and the extended version, is assessed reliably by a structured interview, and the result describes an overall social outcome (9). However, there are many sources of bias which need to be considered when making interviews with TBI patients. Patients in poor pre-traumatic state only need a small deterioration to become dependent. Patients may lack insight and be unconcerned about his/her deficits. Patients may return early to home or work because of a caring family or employer (9). These confounding factors may have influenced the results in this material as well.

Looking at the follow-up results of this patient material, 64% of the adult patients had a favorable outcome (good recovery or moderately disabled). This result can be compared with other studies which reported favorable outcome in 50%–70% of cases (26–30) and the earlier results from Uppsala presented by Elf et al. who reported favorable outcome in 78% of the cases treated 1996–1997 (1). It should

be emphasized that it is difficult to compare overall results between different studies because of differences in e.g. the selection of patients and demographics. The TBI patients treated in Uppsala 1996–1997 were younger but in poorer GCS-M grade at admission compared to the present series, and patients potentially not possible to treat were excluded ($n = 18$) (1). The results from the present study also showed that younger patients and patients with better neurological status at arrival had better outcomes overall which is in accordance with other studies (31,32). The children in our material made good recovery in 61% of the cases, and 9% died at the NIC unit, which is comparable with another Swedish study (33).

Concluding remarks

The specific objectives of establishing the Uppsala TBI register were to be able regularly to: 1) Obtain information about demographic data, clinical outcome, and how the treatments and care affected outcome; 2) Identify patients who did not have the expected result or the right treatment and to determine why that happened; 3) Provide data and select patients for research studies.

The conclusion of this study, presenting the design of the register and the first results, is that the Uppsala TBI register is functional in these objectives. If quality is measured routinely, problem areas can be identified and corrected continuously, which should produce improvements in neurointensive care and outcome for TBI patients.

The Uppsala TBI register is internet-based which makes it possible for other centers to enter their data.

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Supplementary material available online

Supplementary Tables 1-4.