

ORIGINAL ARTICLE

Long-term outcome of medically confirmed and self-reported early traumatic brain injury in two nationwide samples

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Abstract

Primary objectives: To assess long-term effects of early traumatic brain injury (TBI) on mental health, cognition, behaviour and adjustment and to identify prognostic factors.

Methods and procedures: A 1-year nationwide cohort of all 0–19 year old Icelandic children and adolescents diagnosed with TBI in 1992–1993 ($n = 550$) received a questionnaire with clinical outcome scales and questions on TBI and socio-economic status (SES) by mail ~16 years post-injury. A control group ($n = 1232$), newly selected from the National Registry, received the same questionnaire. Non-respondents answered a shorter version by telephone. Overall participation was 67%.

Main outcomes and results: Medically confirmed and self-reported TBI was reflected in worse outcome. Force of impact, number and severity of TBIs predicted poorer results. Parental SES and demographic factors had limited effects. Not reporting early, medically confirmed TBI did not exclude cognitive sequelae. In self-reported disability, absence of evaluation for compensation was not linked to outcome.

Conclusions: Clinical outcome was consistent with late complaints attributed to early TBI. TBI-related variables had greater prognostic value than other factors. Self-reporting of TBI sustained very early in life needs supplementary information from parents and medical records. More consistency in compensation evaluations following paediatric TBI is indicated.

Keywords

Adolescents, children, longitudinal, nationwide, outcome, prognosis, traumatic brain injury, young adults

History

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Introduction

Blunt (closed) traumatic brain injury (TBI) is caused by a forceful impact to the head resulting in rapid acceleration, deceleration and rotation of brain tissue, triggering a cascade of pathophysiological and neurometabolic changes [1]. In 'mild' TBI, these changes may be temporary and recovery apparently complete, while more severe TBI may lead to lasting structural damage and persistent symptoms, affecting cognition, adjustment, behaviour and mental health. Repeated mild TBI or excessive stimulation of an injured brain can be detrimental for the recovery process [1, 2].

It is important to estimate the severity and prognosis of TBI accurately in the acute phase or early in the post-acute phase, as specialized intervention and follow-up may improve outcome [3–6]. In the absence of accurate data on pathophysiological, neurometabolic and structural changes this can be challenging, as length of loss of consciousness (LOC) or post-traumatic amnesia (PTA), cerebral computed

tomography (CT) or conventional magnetic resonance imaging (MRI) findings and other indicators of acute severity may not accurately reflect the extent and nature of TBI [7–9]. This may be especially true for TBI in infants and young children [10–12] and for less severe TBI with traumatic axonal injuries or microenvironment changes in the brain, affecting cognitive factors and adaptive abilities [13, 14]. Studies have suggested that a substantial proportion of children and adolescents who have sustained TBI have an unrecognized or unmet need for healthcare services or rehabilitation, especially those with the less severe TBI and those with cognitive sequelae [15, 16].

A number of studies have indicated that the sequelae of paediatric TBI may be moderated by non-injury factors, such as age at injury and gender, health, parental socio-economic status (SES) and family resources and functioning [17–27]. The relationship, however, may be complex, the prognostic value unclear and findings conflicting, suggesting the need for further research.

Although TBI is generally considered one of the main causes of disability in young age, accurate information is lacking on the prevalence and extent of long-term paediatric TBI-related sequelae. This is in part due to non-reported

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TBI [27, 28], flawed or inaccessible documentation of TBI and its sequelae [27, 29–31] and paucity of high-quality, well-defined, follow-up studies on representative samples [32, 33]. Such information, however, is important from the perspectives of injury prevention, intervention and health care planning.

The Icelandic TBI (ICTBI) research project is prospective and longitudinal, aimed at assessing the nationwide incidence, prevalence and short-term and long-term cognitive, health-related and socioeconomic consequences of early TBI [34–37]. It includes a 12-month nationwide cohort of children and adolescents, 0–19 years old, diagnosed with TBI in Iceland in 1992–1993 ($n = 550$), designated as the ICTBI study group (SG).

A questionnaire follow-up study 16 years post-injury, aimed at assessing long-term effects of paediatric TBI, included the ICTBI SG as well as a control group (CG) newly selected from the Icelandic National Registry ($n = 1232$). A previous paper was based on participants' responses to questions on TBI sustained and on late symptoms attributed to early TBI [37]. The analyses indicated that 'minimal/mild' paediatric TBI may lead to late sequelae, increased severity of TBI is related to more late complaints and greater reported force of impact to the head is reflected in worse outcome, independent of estimated severity of TBI in the acute phase. In the CG, there was a relatively high prevalence of TBI and TBI-related long-term 'moderate' disability with symptoms interfering with activities of daily life. Moreover, the findings raised questions regarding disability and compensation issues, the significance of not reporting/recalling early medically confirmed TBI and the effects of gender, age and other pre-morbid or demographic factors on late sequelae [37].

The present paper is based on the questionnaire data and adds to the previous analyses of complaints of late symptoms attributed to TBI [37] by presenting participants' results on four clinical outcome scales, aimed at assessing mental health, cognition, behaviour and adjustment. The clinical outcome scales provide a more objective measure of current problems than questions of complaints attributed to early TBI. In addition, especially in the case of relatively large samples with predominantly minimal or mild TBI, self-rating scales may be more practical in terms of cost and time than extensive neuropsychological evaluations, ratings by significant others or specialized assessment in real-life situations.

Primary aims of the study

In view of the previous findings of the questionnaire study on the relatively high prevalence of early TBI and 'moderate' TBI-related disability in Iceland [37], the first aim of the present paper was to assess whether the late complaints of symptoms attributed to early TBI were reflected in results on clinical outcome scales.

In the same context, the second aim was to examine the prognostic value of TBI severity (i.e. duration of LOC and PTA) in the acute phase, event-related variables (i.e. force of impact and number of TBIs sustained) and pre-morbid or demographic factors (i.e. age, gender, urban/rural residence and parental SES) for outcome on clinical scales.

A few research projects have studied the long-term consequences of paediatric TBI prospectively [38–45].

The present questionnaire study, based on the ICTBI research project, provided a unique opportunity to do so by adopting two nationwide, representative samples.

Materials and methods

ICTBI study group (SG)

The SG was a nationwide general population sample, comprising all 550 children and adolescents 0–19 years old, consecutively diagnosed with TBI (ICD-9 850–854) in Iceland during the period 15 April 1992–14 April 1993. In order to obtain a nationwide sample patient data were collected from all acute medical services available to patients with TBI in Iceland at that time, hospitals, emergency departments (EDs) and healthcare centres. To achieve enhanced representativeness no exclusion criteria were applied.

In 1992 the total population at risk in the 0–19 year age range was 85 746. The population was evenly distributed with regard to gender and age and 55% lived in the Reykjavik area.

In the SG 57% were males and 74% lived in the Reykjavik area. The highest percentage was in the age group 0–4 years old (41%) and the lowest among the 15–19 year olds (15%).

In the Reykjavik area, the collection of patient data in the acute phase was prospective. The ED serving the Reykjavik area was at Reykjavik City Hospital (RCH). The only neurosurgical department in Iceland was based at RCH. No CT scanners were available outside Reykjavik. Practically all patients in Iceland diagnosed with, or suspected of, moderate or severe TBI (ICD-9 851–854) were brought to RCH. When the diagnosis and degree of severity was uncertain, expert advice was readily available by telephone and transport to RCH encouraged. At the ED of RCH, a neurosurgical consultation was standard procedure regarding referral to CT and hospital admission for patients with TBI. In order to minimize the risk of failing to identify patients with TBI due to lacking or inaccurate recordings, the first author verified and collected patient and injury data from neurosurgeons and other ED and hospital personnel, as well as from written and computerized patient records, on a daily basis during the 1-year period. Of the 550 patients 409 (74%) were treated at RCH. Of the 409 patients, 62 were admitted to RCH.

At the end of the 1-year period, the first author collected computerized patient TBI data from all rural hospitals, EDs and healthcare centres. Patients who were diagnosed with TBI and received medical services in rural areas totalled 141 (26%). According to national medical guidelines, patients with suspected moderate/severe TBI were to be transported to RCH. Consequently, it was assumed that all of the 141 rural patients had sustained minimal/mild TBI. All had received ICD-9 diagnosis 850 (concussion) and 86 (61%) had been admitted to hospital. The computerized data on patients receiving medical care in rural areas were not as detailed as data on patients treated in the Reykjavik area, e.g. lacking information on causes and circumstances of TBI.

Control group (CG)

The CG ($n = 1232$) was selected in 2008 and, thus, participants' reports were not affected by previous follow-ups or other links to the SG. The CG was selected from the

Table I. Contents of the questionnaire answered by mail (unabridged version) and by telephone (abbreviated version).

Section	Mail (unabridged version) question numbers	Telephone (abbreviated version) question numbers
Questions on traumatic brain injuries*	1–16	1–16
Questions on demographic and socio-economic variables*	17–30	17, 18, 24, 25, 29, 30
Memory Complaint Questionnaire (MCQ)	1–13	2, 7, 9
General Health Questionnaire (GHQ-12)	1–12	1, 5, 9, 10
Frontal Systems Behavior Scale (FrSBe)	1–46	4, 7, 10, 15, 19, 29
European Brain Injury Questionnaire (EBIQ)	1–63	1, 4, 15, 18, 22, 32, 44, 45

*See Appendix.

December 1993 Icelandic National Registry in order to be as comparable to the SG as possible, while also being representative of the Icelandic population. A stratified random sampling method was applied. There was an equal number of individuals in each sub-group of the CG, i.e. the CG divided by age, gender and urban/rural residence, $n=77$. The controls were 15–34 years old at the time of selection, i.e. in the same age range as the SG. All had at least one parent of Icelandic origin and were residents of Iceland in 2008.

CG, CG without TBI, CG with TBI and SG

The main reason for including a CG was to be able to compare the SG to a nationwide general population sample. The relatively high percentage of controls reporting to have sustained TBI (49.5%) was unexpected and led to two groups of similar size: the CG without self-reported TBI and a second clinical group, i.e. the CG with self-reported TBI [37]. No medically confirmed data were available for the two groups and there were no exclusion criteria. Both groups were included in the present analyses for comparison and validation purposes and for the statistical advantage of a larger number of participants.

As reported in a previous paper [37], the CG with TBI was in many respects remarkably similar to the SG, in spite of not having sustained medically confirmed TBI 16 years earlier and thus not having the same distribution as regards age at injury. The CG with TBI and the SG compared well regarding percentage of participants reporting more than one TBI, moderate/severe TBI and moderate TBI-related disability. 'Group' (CG with TBI and SG) was not a statistically significant variable, neither as a main effect nor as a two-way interaction, in the binary logistic regression analysis used to predict complaints of late TBI-related consequences [37].

Instruments and outcome measures

Participants answering by mail responded to a comprehensive questionnaire. Included were four clinical self-rating scales, as well as questions on SES of parents and self (education, occupation and living arrangements), demographics (year of birth, gender and residence) and TBI (see Appendix). The TBI questions provided information on the number of TBIs sustained, TBI severity (scored according to the Head Injury Severity Scale (HISS) [46, 47] criteria), TBI outcome (scored with reference to the King's Outcome Scale for Childhood Head Injury (KOSCHI) [48], the Glasgow Outcome Scale (GOS) [49] and the Extended Glasgow Outcome Scale (GOS-E) [49, 50] criteria) and force of impact to the head

Table II. Participation, by group and mode of response.

Response	Individuals contacted		
	SG	CG	SG and CG combined
By mail	117 (22%)	385 (31%)	502 (28%)
By telephone	214 (40%)	474 (39%)	688 (39%)
Non-respondents	204 (38%)	373 (30%)	577 (33%)
Total	535* (100%)	1232 (100%)	1767 (100%)

*Fifteen of the total SG ($n=550$) were not listed in the National Registry, leaving 535 to be contacted.

(TBI question 12). The four clinical outcome scales were the Memory Complaint Questionnaire (MCQ) [51], the General Health Questionnaire (GHQ-12) [52], the Frontal Systems Behavior Scale (FrSBe) [53] and the European Brain Injury Questionnaire (EBIQ) [54]. The scales assess aspects of cognition, mental and physical health, adjustment and behaviour. A shorter version of the questionnaire was adopted for those who participated by telephone. The shorter version included the TBI questions, questions on participants' education, occupation and residence and selected items from the four clinical outcome scales. The selection of items was based on results of factor analyses of the clinical scales [55–57], clinical judgement and practical issues regarding the length of the telephone survey. Table I shows the contents of the unabridged version and the abbreviated version of the questionnaire.

With the exception of the effect of parental SES on late outcome, the main findings of the present analyses were based on the items common to the two versions of the questionnaire.

Procedure

The mail questionnaire was sent to the SG and the CG in December 2008. Non-respondents were requested to answer the shorter version of the questionnaire by telephone. In the SG and CG combined, 28% of participants answered by mail and 39% answered by telephone, with an overall participation of 67% (Table II).

The participation rate was comparable for the SG (62%) and the CG (70%), males (65%) and females (71%), the Reykjavik area (67%) and rural areas (69%) and different age groups (63–75%).

Of the total number of 1767 individuals contacted in the SG and the CG combined, 577 (33%) did not participate in the study. Of the 577 non-respondents, 393 (68%) could not be found or reached despite the information available in the

National Registry and a search in the telephone directory, 92 (16%) declined participation, 75 (13%) resided abroad, 10 (2%) were unable to respond and seven (1%) were deceased.

In the CG answering by mail and the CG answering by telephone the ratios of participants reporting to have sustained TBI were nearly identical (55.6% and 51.7%, respectively). This was also the case for those who reported TBI-related symptoms of moderate disability (7.2% vs. 6.8%).

In implementing the questionnaire study, a four step model, a modified version of the Tailored Design Method [58], was applied. The questionnaire mailing, including a cover letter, the questionnaire, a return envelope and a small gift, as a token of gratitude, followed a pre-notice letter. A few weeks later, non-respondents received a reminder cover letter and a replacement questionnaire. Finally, a few weeks after the third contact, non-respondents were telephoned and asked to respond to the shorter version of the questionnaire.

All participants responded to the same questions. Participants were not informed whether they belonged to the SG or to the CG. All questions were kept neutral regarding the TBI-status of respondents. However, a number of participants in the SG may have recalled previous participation in the research project, as 62 patients had taken part in a neuropsychological follow-up study 6 months and 6 years post-injury and 409 had been included in a mail questionnaire study 4 years post-injury.

Definitions and classifications

A participant was recorded as having sustained TBI if he/she so indicated in his/her answers to TBI questions 1–16 of the questionnaire. An exception to this criterion was made in the case of the ~20% of participants of the SG who did not report ever having sustained TBI [37]. Those participants were recorded in the data file as having sustained the single medically confirmed TBI 16 years earlier. In the present analyses, participants pertaining to the CG who indicated in their answers to TBI questions 8–16 that they had sustained traumatic impact to the head with noteworthy consequences were defined as having sustained TBI, even when they did not suggest short-term symptoms of concussion, LOC or PTA in their responses to TBI questions 1–7. Age at injury was computed from year of birth and the self-reported year of injury. However, when participants in the SG and the CG who reported having sustained TBI did not provide a year of injury, multiple imputation [59] was used to estimate age at injury (see following section). In all other respects, e.g. regarding number of TBIs sustained, results were based on participants' reports in order to enhance the comparability of the data. Allowing for a 1–2 year inaccuracy of recall, 3% of SG respondents reported having sustained TBI with the most consequences prior to the year 1991 and 22% after the year 1994 [37]. Ninety-five per cent of participants in the SG reported having sustained the TBI with most consequences prior to 20 years of age, as compared to 84% for respondents in the CG with TBI [37]. Participants in the SG reporting one TBI but not in the year of the medically confirmed instance were recorded as having sustained only one TBI. Consequently, the recorded year of injury was the self-reported one (TBI question 8) used for the calculation of age at injury.

Force of traumatic impact to the head was based on answers to TBI question 12, i.e. 'never sustained a traumatic impact to the head that has had any noteworthy consequences', 'mild' traumatic impact to the head, 'moderate', 'strong' or 'very strong'. For enhanced clarity, the question included examples of traumatic impact to the head.

Acute severity of TBI was estimated based on answers to TBI questions 6 and 7 with reference to the HISS criteria and the Scandinavian Guidelines for the Initial Management of Minimal, Mild and Moderate Head Injuries [47], adopted by the Icelandic Directorate of Health. Moderate/severe TBI was indicated by LOC for more than 5 minutes following TBI and/or PTA (i.e. 'unable to recall') 1 hour or more following TBI.

Reported outcome of TBI was based on answers to TBI questions 13 and 14, with reference to the KOSCHI, GOS and GOS-E criteria. 'Good recovery (b)' meant no TBI-related consequences. 'Good recovery (a)' represented minor consequences that did not interfere with the participant's functioning (e.g. minor headaches, mild vertigo, scars and bumps on head). 'Moderate disability (b)' referred to symptoms that interfered with daily functioning (e.g. persistent or chronic headache or vertigo, problem with memory and concentration, change in temperament and personality or depression and anxiety). 'Moderate disability (a)' referred to combinations of the above symptoms. There were no cases of 'severe disability', which was not unexpected as it is relatively rare [60].

Both the HISS criteria and the KOSCHI/GOS/GOS-E criteria were well suited for the present purposes, allowing differentiation of reports of acute severity of TBI and complaints of late TBI-related symptoms that were predominantly in the mild-to-moderate range.

All SG participants who did not indicate having sustained TBI reported no TBI-related sequelae and were recorded as having sustained 'minimal/mild' TBI, with 'good recovery (b)'.

For analysis of symptoms in the EBIQ, the answer 'A lot' was defined as indicating a symptom, while the answers 'Not at all' and 'A little' were not.

Statistics

Analysis of variance and the Tukey post-hoc comparison test were used to compare the CG without TBI to the SG and the CG with TBI on each of the four abbreviated clinical outcome scales.

In the combined groups of SG and CG with TBI, linear regression analysis was used to develop a model for each of the four clinical outcome scales. Each model contained six main effects: group (SG and CG with TBI), force of impact (TBI question 12), number of TBIs sustained (i.e. once or more than once), TBI severity (HISS), gender and age at injury. Group (a design variable) was not statistically significant but was included in the models because of its relevance. The urban/rural variable was removed from the final models, as it did not have any substantial effect and was not statistically significant. As force of impact was an ordinal variable with a predominantly linear effect, it was added to the models as a continuous variable with the values 0, 1, 2, 3 and 4.

As the age-at-injury variable had sizeable instances of missing values, especially related to younger respondents and milder TBI, multiple imputation was performed to reduce bias

and increase power by the inclusion of participants that would otherwise have been lost from the analysis [59]. Care was taken to include all independent and dependent variables in the imputation model, as well as the relevant interactions. The use of multiple imputation avoids the MCAR (missing completely at random) assumption of older more naïve methods, such as listwise deletion, substituting it with the less restrictive MAR (missing at random) assumption [59].

Model selection was based on the Akaike Information Criterion (AIC) and statistical comparisons of models.

With more than one dependent variable (four in the present analysis), probability of type-I error will increase and result in spurious significance for minor effects in the sample. To counteract this, the Bonferroni correction method [61] was applied.

The linear regression analysis was based on items from the four scales, MCQ, GHQ, FrSBe and EBIQ, common to both modes of data collection, i.e. mail and telephone. The correlations between the summed scores of those items for each scale and the summed scores of all remaining items of the same scale responded to by those participating by mail ranged from $r = 0.75$ – 0.86 , validating this approach.

In the group with TBI, logistic regression analysis was used to assess the probability of having one or more symptoms on the EBIQ, indicating clinical importance. In the analysis, there were two main effects: force of impact and number of TBIs sustained.

R: A Language and Environment for Statistical Computing, Release 2.11.1 [62] and SPSS for Windows, Release 15.0.0 [63] were used for the statistical analyses.

Ethics

The research was granted ethical clearance by the Data Protection Authority (Ref. 2008090617), the National Bioethics Committee (Ref. VSNb2008090010/03-1) and the Medical Director of Landspítali University Hospital (Ref. 16).

Results

Results on the clinical outcome scales: SG vs. CG with TBI vs. CG without TBI

Analysis of variance was used to compare the two clinical groups and the control group without TBI. On all four clinical outcome scales the Tukey post-hoc comparison test indicated that the CG without TBI ($n = 400$) did significantly better than the SG ($n = 331$) (p values <0.05) and the CG with TBI ($n = 459$) (p values <0.01). The difference between the SG and the CG with TBI did not reach statistical significance, with the exception of EBIQ, where the CG with TBI had a slightly *worse* outcome than the SG.

Prognostic factors

The prognostic value of TBI-related and demographic variables for late results on the clinical outcome scales was studied in the SG and in the CG with TBI combined ($n = 790$) using linear regression analysis. The CG without TBI was excluded, as TBI was the object of study.

Force of impact was a significant main effect for EBIQ ($t(725) = 3.3$; $p = 0.004$) and GHQ ($t(739) = 3.2$; $p = 0.004$).

Force of impact was also significant for MCQ as a two-way interaction with severity ($t(769) = 3.2$; $p = 0.006$). The effect of severity was more prominent in the case of strong and very strong impact to the head than in mild or moderate impact.

Number of TBIs sustained was a significant main effect for FrSBe ($t(692) = 3.0$; $p = 0.01$) and as a two-way interaction with severity for EBIQ ($t(763) = 2.5$; $p = 0.048$). The effect of severity of TBI was more prominent in the case of more than one TBI sustained than in one TBI sustained. This tendency was evident in the effect plots of all the clinical scales and reached statistical significance in EBIQ.

Age at injury was only a significant main effect for GHQ ($t(243) = 2.6$; $p = 0.04$), possibly reflecting higher prevalence of mental health problems with increasing age in the general population.

Gender was a significant main effect for MCQ ($t(770) = 3.2$; $p = 0.006$), EBIQ ($t(768) = 4.9$; $p \leq 0.001$) and GHQ ($t(770) = 4.4$; $p \leq 0.001$). However, viewing the gender effect plots, females showed only a slightly worse outcome than the males on the three outcome scales, indicating an immaterial or nominal effect.

In summary, force of impact and number of TBIs sustained had a marked prognostic value for late clinical outcome. TBI severity had limited effect, except as a two-way interaction, when force of impact was strong or very strong or number of TBIs sustained was more than one. The effects of age at injury and gender appeared limited or nominal.

Participants answering by mail: Prognostic value of parental SES factors

Based on responses to the unabridged version of the questionnaire answered by mail, participants reporting to have sustained TBI did not have parents of lower SES, as indicated by parents' education or occupation, compared to those not reporting TBI. Furthermore, controlling for TBI-related variables, no evidence was present for effect of those SES background factors on late outcome of the four clinical scales. The highest effect ($F = 1.75$; $p = 0.08$) was found for the marginal results of paternal occupation on MCQ, essentially due to the effect of the occupational category 'office worker, clerk' on late outcome.

SG: Reporting vs. not reporting paediatric TBI

Approximately one fifth of the SG did not report having sustained TBI [37]. Not reporting/recalling TBI was most common in the youngest age group. A *t*-test was performed in the SG, with reporting vs. not reporting TBI as an independent variable. Not reporting to have sustained TBI was related to better results on the clinical outcome scales GHQ-12 ($t(323) = -3.5$; $p < 0.001$) and EBIQ ($t(323) = -2.5$; $p = 0.01$), but not on MCQ ($t(325) = -1.3$; $p = 0.21$) and FrSBe ($t(320) = -0.2$; $p = 0.83$). The findings indicate that not reporting/recalling early, medically confirmed TBI does not exclude TBI-related sequelae.

Moderate TBI-related disability: Evaluated vs. not evaluated for compensation

A majority (75%) of those reporting moderate disability did not indicate having been awarded or evaluated for

compensation (TBI question 16) [37]. Compensation or evaluation for compensation was more associated with age 15 years or older at the time of injury than with younger age groups. A *t*-test was carried out in the group with self-reported disability, with evaluated vs. not evaluated as an independent variable. The results suggested that not having been evaluated for compensation because of TBI-related sequelae was not related to better or worse results on any of the four clinical outcome scales (lowest *p* value = 0.21). The findings may indicate inconsistencies in the praxis of evaluation for compensation following paediatric TBI.

Clinical importance

The eight-item version of the EBIQ that delineated well the sequelae of early TBI was used to assess the clinical importance of the results. Logistic regression analysis indicated that, in the case of TBI without any noteworthy consequences, the probability of having one or more symptoms was close to 20%, which was comparable to 15% in the case of no TBI. In the majority of instances, there was only one symptom. With increased force of impact (TBI question 12), the probability gradually increased to more than 40% and a substantial proportion of participants reported up to six symptoms. Having sustained more than one TBI added slightly to the probability. Thus, with increased force of impact the number of symptoms grew rapidly, suggesting clinically relevant sequelae for a substantial proportion of those suffering a strong or very strong impact to the head.

Discussion

Early medically confirmed and self-reported TBI was reflected in worse results on each of the four clinical outcome scales assessing cognitive factors, mental health, behaviour and adjustment. This was the case in each of the two clinical groups and in the clinical groups combined. Data indicated that individuals with TBI were more likely to meet clinically relevant criteria than those without TBI. In the case of EBIQ, increased force of impact to the head (question 12) was associated with more symptoms. The findings were consistent with the previous report based on data from the present questionnaire study, on complaints of late symptoms attributed to paediatric TBI [37].

In the two clinical groups combined, the variables found to have the greatest prognostic value for results on clinical outcome scales were force of impact and number of TBIs sustained. In two instances, effects were moderated by TBI severity: for MCQ, the effect of force of impact was greater with moderate/severe TBI (i.e. LOC > 5 minutes or PTA \geq 1 hour) than minimal/mild TBI; for EBIQ, the same was the case for number of TBIs sustained.

Demographic or pre-morbid non-injury factors, such as age at injury, gender, urban/rural residence and SES of parents seemed to have limited, nominal or non-significant prognostic value for results on the clinical outcome scales. In view of previous findings [17–26] those results may reflect complex relationships between factors, while they do not diminish the significance of those factors in intervention and rehabilitation efforts following paediatric TBI.

In the SG, not reporting to have sustained TBI, most pronounced in the youngest age group 0–4 years old [37], was related to better outcome on GHQ and EBIQ, but not on MCQ and FrSBe. Considering the content of items of each abbreviated scale, not recalling/reporting early, medically confirmed TBI may be associated with better emotional well-being, without being reflected in fewer cognitive symptoms.

In the group, reporting TBI-related moderate disability, not being evaluated for or not having received compensation was not reflected in results on the clinical outcome scales. The probability of not being evaluated for self-reported moderate disability was highest for those younger than 15 years old at the time of injury [37]. The findings call for an evidence-based, co-ordinated longitudinal approach to the assessment of moderate disability and compensation following TBI sustained in infancy, childhood and early adolescence.

The two clinical groups reported more problems related to cognition, mental health, behaviour and adjustment than the CG without TBI. However, the present data did not provide conclusive evidence regarding whether or to what extent non-TBI-related, post-injury factors contributed to this difference.

As in the previous analyses of the questionnaire data [37], force of impact had a greater prognostic value for late outcome than estimates of severity of TBI in the acute phase, possibly indicating ease of recall regarding the former over the latter. On the other hand, the effect of gender was not as obvious as in the earlier report. The previous finding that females may be more vulnerable or sensitive to the long-term effects of mild TBI than males [37] was only nominally reflected in worse results on the clinical outcome scales. The findings may indicate some discrepancy between the way in which individuals perceive traumatic events and their consequences, on the one hand, and how they respond to clinical outcome scales, on the other hand.

In summary, the present findings compare well with previous conclusions of the ICTBI questionnaire study regarding the long-term consequences of paediatric TBI, factors with prognostic value and the scope of TBI as a health concern [37]. The paper highlights the effect of force of impact to the head, the use of representative samples, self-reporting and clinical outcome scales in TBI research and the ambiguities and arbitrariness related to early TBI.

Limitations

For increased participation, a paper and pencil questionnaire was used, followed by a telephone survey with an overall 67% participation. While the two groups, i.e. participants answering by mail vs. telephone, were inherently different, the mode of answering may have had an effect over and above that. However, the proportion of controls reporting to have sustained TBI was nearly identical in the two groups, as were reported symptoms of moderate disability.

The main findings of the present analyses were based on a limited number of items of the clinical outcome scales, which may have affected their validity. However, items were selected with reference to factor analyses of scales and in the group participating by mail the correlation for each scale between the summed scores of the selected items and the summed scores of all remaining items was very high, validating this approach.

Care was taken to avoid clinical or unfamiliar terms, such as 'traumatic brain injury (TBI)' and 'post-traumatic amnesia (PTA)', in the phrasing of the TBI questions of the questionnaire and to provide examples of symptoms and contexts. However, the meaning of concepts such as 'concussion' or 'reduced consciousness' may have been unclear to some participants, affecting responses. In the case of 'concussion', its graphic equivalent in Icelandic 'heilahristingur' ('shaking of the brain') may have helped participants to associate the concept with traumatic impact to the head and the symptoms of TBI.

Participants were asked to recall information regarding events taking place up to 35 years earlier. In some cases, participants were very young at the time of injury and will have had to rely on information from parents. These factors may have affected the reliability and accuracy of responses to questions and led to an under-estimation of TBI and its severity. A long recollection period is, however, not unprecedented in self-report studies [64, 65]. Reports have indicated that the details of traumatic injuries and medical emergencies experienced after the first 2–3 years of life may be relatively well preserved for long-term recall, possibly related to the stressful and intense emotional reactions involved [66–68].

The findings of the present analyses were based on participants' self-reports, which may have been affected by exaggeration, under-estimation, lack of insight or poor recall. Adopting clinical self-rating scales provides a more objective measure than questions on complaints of late symptoms attributed to early TBI. However, a more stringent or objective approach may be preferable, including thorough neuropsychological evaluations, reports by significant others and specialized assessment in real life situations. Conversely, self-rating may be more relevant in the clinical perspective several years post-injury in relatively large groups with predominantly mild TBI, where most participants are adolescents and young adults not receiving specialized intervention for TBI-related sequelae. In the ICTBI research project, the 62 patients admitted to RCH, including all those with medically confirmed moderate and severe TBI, were evaluated using neuropsychological tests and checklists 6 months, 6 years and 17 years post-injury.

It would have been preferable to validate the present findings by comparing late outcome to information from medical records on acute severity of TBI, causes and circumstances. This was not possible due to a lack of data and the length of time since injury.

Participation rate was 62% for the SG and 70% for the CG. However, participants and non-participants in the SG were comparable as regards age, gender, urban–rural residence and medically estimated severity of injury in the acute phase. In the CG, participants and non-participants had similar demographics.

Conclusions and future directions

Early medically confirmed and self-reported TBI had long-term effects on mental health, cognition, behaviour and adaptation, as assessed by each of the four clinical self-rating scales. The present findings were consistent with previous

analysis of the questionnaire data on late symptoms attributed to early TBI [37]. Greater force of impact and sustaining more than one TBI were related to worse results on clinical scales. Worst outcome was connected with high force of impact or more than one TBI, associated with moderate/severe TBI (HISS). Data indicated that results on clinical outcome scales were more likely to be clinically important among those with medically confirmed or self-reported TBI than among uninjured controls. In the case of EBIQ, increased force of impact was associated with a growing number of clinically relevant symptoms. Urban/rural residence, parental SES, gender and age at injury had non-significant, nominal or limited effects on present mental health, cognition, behaviour or adaptation. TBI-related variables had more prognostic value for long-term clinical outcome than demographic factors. Early, medically confirmed TBI was associated with long-term cognitive sequelae, independent of whether or not the injury was reported or recalled 16 years later. In the case of self-reported complaints indicating moderate disability, absence of evaluation for compensation was not reflected in better or worse outcome.

TBI in the youngest age group, 0–4 years old, merits further study. In the SG, the highest number of patients was in this age group and this age group had as many patients with 'moderate/severe' TBI, medically confirmed in the acute stage, as the older age groups [35]. However, results of the present analyses suggested that there was an increased probability that those TBIs were hidden, misdiagnosed and under-estimated with regard to severity, not reported or recalled and not evaluated for compensation. All the above factors may lead to less than optimal intervention and support.

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Appendix

An English translation of the original Icelandic version of the questionnaire, clinical outcome scales not included. Questions marked with an asterisk (*) in front of their number were not included in the abbreviated version of the questionnaire answered by telephone.

Questions on traumatic impact to the head (TIH) (TBI questions)

- (1) Have you had mild symptoms of concussion, such as nausea, dizziness or somnolence, following TIH?
 - No
 - Yes, once
 - Yes, more than once
- (2) Have you lost consciousness or had reduced consciousness for any period following TIH?
 - No
 - Yes, once
 - Yes, more than once
- (3) Have you had signs of concussion or reduced consciousness following TIH, *without being transported to an emergency department (ED) or hospital?*
 - No
 - Yes, once
 - Yes, more than once
- (4) Have you been *transported to an ED* with signs of concussion or reduced consciousness following TIH?
 - No
 - Yes, once
 - Yes, more than once
- (5) Have you been *admitted to hospital* with signs of concussion or reduced consciousness following TIH?
 - No
 - Yes, once
 - Yes, more than once

(6) Have you lost consciousness for more than 5 minutes following TIH?

- No
- Yes

(7) Have you been unable to recall what happened following TIH?

- No
- Yes, I have been unable to recall what happened up to 1 hour following TIH
- Yes, I have been unable to recall what happened 1–24 hours following TIH
- Yes, I have been unable to recall what happened more than 24 hours following TIH

(8) What year did you sustain the TIH that had the most consequences? Write the year if you select the latter option.

- I have never sustained a TIH that has had any noteworthy consequences
- The TIH that had most sequeale, I received in the year: _____

(9) What was the cause of the TIH that had the most consequences?

- I have never sustained a TIH that has had any noteworthy consequences
- I fell from something, tripped on level ground or received an accidental blow
- I fell from a bicycle or horseback
- I got hit by or fell from a car, heavy machinery or another motor vehicle
- I was in a car, heavy machinery or another motor vehicle that had a collision or tipped over
- I was hit intentionally on the head by someone
- Other cause

(10) Where were you when you sustained the TIH that had the most consequences?

- I have never sustained a TIH that has had any noteworthy consequences
- At home
- At school or at a school playground
- At a sports facility or public playground
- At a club, bar or discotheque
- On a street or on a road
- Other place

(11) In what region were you when you sustained the TIH that had the most consequences?

- I have never sustained a TIH that has had any noteworthy consequences
- In the Reykjavik area (from Hafnarfjordur to Kjalarne)
- In a town or village outside the Reykjavik area
- In farmland or other inhabited more rural areas
- In an uninhabited wilderness area
- At sea
- Abroad

(12) How forceful was the impact when you sustained the TIH that had the most consequences?

- I have never sustained a TIH that has had any noteworthy consequences
- Mild impact (e.g. knocked your head against a door frame)
- Moderate impact (e.g. accidentally knocked by a player's elbow in sports)
- Strong impact (e.g. intentionally punched in the head by force)
- Very strong impact (e.g. head being thrown forcefully onto a hard surface in a motor vehicle collision)

(13) Do you feel that you have fully recovered from the TIH you have sustained?

- I have never sustained a TIH that has had any noteworthy consequences
- I was fully recovered within 1 month
- I was fully recovered in 1–6 months
- I was fully recovered in 7–12 months
- I had TIH consequences for more than 1 year, but I am fully recovered now
- No, I still have not recovered fully

(14) What are the consequences of the TIH you have sustained? Please describe in a couple of sentences the consequences or symptoms you still suffer from now. Write the answer if you select the last option.

- I have never sustained a TIH that has had any noteworthy consequences
- I have had TIH consequences for a period of time, but I am fully recovered now
- Consequences now are: _____

(15) Have you sought professional advice from medical doctors or other specialists regarding the consequences of TIH you have sustained?

- I have never sustained a TIH that has had any noteworthy consequences
- I have suffered TIH consequences but professional advice has *not* been sought
- Yes, professional advice has been sought

(16) Have you received compensation from the Social Insurance Administration and/or from insurance companies or been evaluated regarding disability pension or reimbursements because of TIH consequences?

- I have never sustained a TIH that has had any noteworthy consequences
- I have suffered TIH consequences, but I have not received any compensations, or been evaluated regarding disability pension or reimbursements because of this
- Yes, I have received compensation or been evaluated regarding disability pension or reimbursement because of TIH consequences

Questions about you, your family and residence

(17) Are you a male or a female?

- Male
- Female

(18) What year were you born? _____

(19) Which of the following best describes your father's education?*

- Did not complete grade school
- Has completed grade school
- Has completed vocational and/or academic courses for increased occupational entitlements
- Has completed trade school
- Has completed college
- Has completed other specialized vocational and/or academic studies
- Has completed a university degree
- Other

(20) What has been your father's main occupation?*

- Elected public representative, highest office holder or chief administrator
- Specialist (with university degree)
- Specialized employee (not with university degree)
- Office worker, clerk
- Attendant, salesman or shop assistant
- Farmer
- Fisherman, sailor
- Tradesman
- Specialized worker
- Worker
- Takes care of the home
- Has not had a paid job

(21) Which of the following best describes your mother's education?*

- Did not complete grade school
- Has completed grade school
- Has completed vocational and/or academic courses for increased occupational entitlements
- Has completed trade school
- Has completed college
- Has completed other specialized vocational and/or academic studies
- Has completed a university degree
- Other

(22) What has been your mother's main occupation?*

- Elected public representative, highest office holder or chief administrator
- Specialist (with university degree)
- Specialized employee (not with university degree)
- Office worker, clerk
- Attendant, salesman or shop assistant
- Farmer
- Fisherman, sailor
- Tradesman
- Specialized worker
- Worker
- Takes care of the home
- Has not had a paid job

(23) Where did you live for the longest period of time while growing up?*

- In the greater Reykjavik area (from Hafnarfjordur in the south to Mosfellsbaer and Kjarnarnes in the north)
- In a small town or village outside the greater Reykjavik area

- In the countryside, on a farm
- Abroad

(24) What best describes your present living arrangements?

- I live in my parent's/parents' accommodations
- I live in my own accommodation
- I live in accommodation that I rent
- I live in my spouse's accommodation
- I live in my parents-in-law's accommodations
- I live in a sheltered housing arrangement
- Other living arrangements

Questions on your education

(25) What best describes your education?

- Have not completed grade school
- Have completed grade school
- Have completed vocational and/or academic courses for increased occupational entitlements
- Have completed trade school
- Have completed college
- Have completed other specialized vocational and/or academic studies
- Have completed a university degree
- Other

(26) In total, for how many semesters have you pursued formal academic and/or vocational studies following grade school?*

- I have not begun post-grade school studies
- 1–4 semesters (0.5–2 school years)
- 5–8 semesters (2.5–4 school years)
- 9–16 semesters (4.5–8 school years)
- 17 semesters or more (8.5 school years or longer)

(27) What was your average score on the comprehensive examinations that you took at the end of grade school (at age 15 years)?*

- I have not taken any of the comprehensive examinations
- 0–2.9
- 3.0–4.9
- 5.0–6.9
- 7.0–8.9
- 9.0–10.0

(28) Please answer the following statements.*

<input type="radio"/> I received remedial teaching in reading in grade school	<input type="radio"/> No	<input type="radio"/> Yes
<input type="radio"/> I received remedial teaching in mathematics in grade school	<input type="radio"/> No	<input type="radio"/> Yes
<input type="radio"/> I received remedial teaching in spelling in grade school	<input type="radio"/> No	<input type="radio"/> Yes
<input type="radio"/> I received remedial teaching in hand-writing in grade school	<input type="radio"/> No	<input type="radio"/> Yes

Questions about your occupation

(29) Please answer the following questions.

<input type="radio"/> Are you an employee?	<input type="radio"/> No	<input type="radio"/> Yes
<input type="radio"/> Are you an employer?	<input type="radio"/> No	<input type="radio"/> Yes
<input type="radio"/> Are you a student?	<input type="radio"/> No	<input type="radio"/> Yes
<input type="radio"/> Is household work your main job?	<input type="radio"/> No	<input type="radio"/> Yes
<input type="radio"/> Are you on maternity/paternity leave?	<input type="radio"/> No	<input type="radio"/> Yes
<input type="radio"/> Are you ill or temporarily unable to work?	<input type="radio"/> No	<input type="radio"/> Yes
<input type="radio"/> Are you unemployed?	<input type="radio"/> No	<input type="radio"/> Yes
<input type="radio"/> Are you on 50–74% disability pension?	<input type="radio"/> No	<input type="radio"/> Yes
<input type="radio"/> Are you on 75% disability pension?	<input type="radio"/> No	<input type="radio"/> Yes

(30) Which of the following best describes your occupation?

- Elected public representative, highest officeholder or chief administrator
- Specialist (with university degree)
- Specialized employee (not with university degree)
- Office worker, clerk
- Attendant, salesman or shop assistant
- Farmer
- Fisherman, sailor
- Tradesman
- Specialized worker
- Worker
- I take care of the home
- I am a student with no paid job
- I have no paid job