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The scope of early traumatic brain injury as a long-term health concern in two nationwide samples: Prevalence and prognostic factors

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Abstract

Primary objectives: To examine the scope of paediatric traumatic brain injury (TBI) as a health concern and to identify prognostic factors for TBI-related sequelae.

Methods and procedures: The study was prospective and nationwide. A questionnaire was sent to a study group (SG) of all 0–19 years old in Iceland, diagnosed ~16 years earlier with TBI during a 1-year period, 1992–1993 ($n = 550$) and to a control group (CG) ($n = 1232$), selected from the National Register.

Main outcomes and results: In the CG 49.5% reported having sustained TBI and 7.0% reported long-term disability. In the group with TBI, force of impact to the head, more than one incident of TBI and the injury severity by gender interaction predicted late symptoms. TBI severity had substantially less effect than force of impact and was close to non-existent for females.

Conclusions: Based on two independent nationwide samples, the scope of TBI as a health concern in adolescence and young adulthood is greater than previously documented. The findings suggest that TBI event-related factors, especially force of impact, have greater predictive value than clinical symptoms of severity at the acute stage, females being more sensitive to the effects of mild TBI than males.

Keywords: *Adolescents, children, disability, health concern, long-term, nationwide, paediatric, prevalence, prospective, traumatic brain injury, young adults*

Introduction

Traumatic brain injury (TBI) is generally acknowledged as one of the main causes of disability and death among children, adolescents and young adults.

TBI is caused by forceful impact to the head, resulting in rapid acceleration, deceleration and rotation of brain tissue. The forces involved trigger a cascade of pathophysiologic and neurometabolic changes. In many cases the changes may be transient, but sometimes they lead to structural damage to the brain and long-lasting symptoms [1].

In the acute phase following a TBI, little is known about the pathological changes taking place in

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the brain. Emergency personnel have to rely on clinical signs, cerebral Computed Tomography (CT) findings and other indicators of acute severity that may not accurately reflect the extent, nature and prognosis of injury. Medically estimating the acute severity of TBI is especially challenging in infancy and early childhood, when clinical signs are less marked and responses to trauma differ from those of older individuals [2–7].

The mildest form of TBI is concussion, characterized by symptoms such as short-term nausea, somnolence, confusion or disorientation. Lower Glasgow Coma Scale scores, extended loss of consciousness (LOC), longer periods of post-traumatic amnesia (PTA) and neurological abnormalities are clinical indicators of more severe TBI.

TBI occurs frequently at a young age. Accurate information on the incidence and prevalence of TBI and its severity and outcome is important for preventive purposes and for healthcare planning and intervention services. Such information is lacking, in part due to non-reported TBI [8, 9], flawed or inaccessible documentation of TBI [8, 10–12] and paucity of high-quality, well-defined, follow-up studies on representative samples [13, 14].

Bearing these limitations in mind, it has been estimated that the overall annual incidence of medically diagnosed paediatric TBI may be 600–900 per 100 000 [13, 15–18] and the annual incidence of paediatric TBI leading to hospital admission 100–300 per 100 000 [13, 17, 19–23]. Recently, studies have reported a decrease in hospitalizations in the case of mild paediatric TBI [15, 16, 24, 25], emphasizing the importance of identifying TBI severity accurately at emergency departments (EDs).

Less is known about the prevalence of TBI in young age than its incidence. The few studies available, however, suggest that the prevalence of having sustained TBI is higher than might be anticipated in view of the incidence estimates. In the Christchurch, New Zealand, cohort study, 18% of children had sustained medically confirmed TBI prior to 14 years of age and 32% at 25 years of age [18, 26]. Two studies on adolescents, adopting self-report questionnaires, have reported 31–41% prevalence of TBI [27, 28]. Also based on self-report, higher prevalence has been described in samples of young university athletes, 63–70% [29]. The estimated prevalence of TBI leading to hospital admission in the young adult population may be 4–12% [18, 23, 30]. Regarding TBI outcome, it has been estimated that the overall prevalence of living with long-term TBI-related disability is 0.3–2% [10, 14, 23, 30–32].

The more severe paediatric TBI is more likely to lead to poor outcome than minimal or mild TBI [33–37]. Severe TBI often leads to persistent long-term deficits in cognition, social functioning and academic performance [38, 39]. In some cases, a declining trend in function may be observed post-injury in childhood and through adolescence to adulthood, with serious implications for late adjustment, education and occupation [40, 41]. Late outcome of the more severe paediatric TBI may be moderated by age at injury, socio-economic status (SES) and family resources and functioning [38, 42].

As regards minimal or mild paediatric TBI, the prognosis is good. In the majority of cases recovery seems fast with no obvious evidence of persistent deficits [43]. This is especially true in the case of a single, uncomplicated, minimal or mild paediatric TBI, not requiring hospital admission [35, 44–47]. Several recent studies, however, suggest that mild TBI may lead to persistent post-concussive symptoms (PCS) and long-term sequelae related to behaviour, adaptation, emotion and cognition [34, 36, 45, 46, 48–50]. In some cases these long-term symptoms may be aggravated or exaggerated to some extent by non-injury factors, such as adjustment, health, family functioning, social support and compensation issues [47, 51–54]. Conversely, late complaints may reflect an under-estimation and misdiagnosis of paediatric TBI severity in the acute phase.

Infants and young children may be more vulnerable to the long-term effects of severe TBI on cognition, behaviour and adjustment than older children and adolescents [44–46, 55]. In some cases of severe TBI, young children may develop increasing problems with age [41, 56]. In other cases, an initial decline in function may come to a halt, to be followed by developmental gains [57]. As regards minimal or mild TBI, information on prognosis in infancy and early childhood compared to late childhood and adolescence is lacking [58], but school-age children may be more susceptible to the pathological effects of sports-related concussion than older athletes [59].

Little is known about the effects of gender on paediatric TBI outcome. However, recent evidence suggests that girls may be more likely to report PCS following mild TBI than boys [49].

Reports have indicated that fatal paediatric accidents and fatal paediatric brain injuries are more common in rural than urban areas [17, 60–63]. However, findings have been inconclusive regarding urban/rural differences in the incidence of moderate/severe non-fatal TBI and minimal/mild TBI [17, 62].

The present questionnaire study is part of a larger, prospective, longitudinal research project in Iceland, aimed at assessing the nationwide incidence, prevalence and short-term and long-term cognitive,

health-related and socioeconomic consequences of TBI in childhood, adolescence and young adulthood. Previous findings have indicated that the incidence of paediatric TBI in Iceland is similar to other western countries [17, 64].

Aims of the study

As information on the prevalence of paediatric TBI is lacking, the first aim of the present paper was to assess the prevalence and scope of paediatric TBI as a health issue in Iceland. The study provided a unique opportunity to do so in two nationwide, representative samples: a clinical sample diagnosed with TBI ~16 years earlier and a control group (CG) selected with a stratified random sampling method from the Icelandic National Register.

As noted previously, it is difficult to estimate the severity of paediatric TBI in the acute phase without accurate data on the pathophysiologic, neurometabolic and structural changes involved. Inaccurate estimates of severity will affect prognostic value for persistent PCS and TBI-related disability. A second objective was therefore to investigate the predictive validity of TBI severity in the acute phase (duration of LOC and PTA), event-related variables (force of impact and number of TBIs sustained), age, gender and urban/rural residence, for long-term symptoms. Earlier findings of the research project have indicated that force of impact to the head may have significant prognostic value for late TBI-related complaints and disability [34].

Material and methods

Study group

The study group (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 to 14 April 1993. In order to obtain a nationwide sample, patient data were collected from all urban and rural hospitals, EDs and healthcare centres in Iceland, i.e. all acute medical services available to patients with TBI in Iceland at that time. Private clinics and physicians' offices were not contacted as they did not provide acute services for patients with TBI. For 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. Table I shows the total population at risk in December 1992 by gender, age and urban/rural residence.

In the SG 57% were males and 74% lived in the Reykjavik area. The highest percentage was in the youngest age group (41%) and the lowest in the oldest age group (15%). Table II shows the SG by gender, approximate age at the time of follow-up and urban/rural residence at the time of injury. Due to the 1-year range for the time of injury and a several months range for the time of data collection in 2008–2009, follow-up took place 15–17 years post-injury.

In the Reykjavik area, the collection of patient data in the acute phase was fully prospective. The ED serving the Reykjavik area was at Reykjavik City Hospital (RCH) and RCH had the only neurosurgical department in Iceland. 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 by ambulance, helicopter, airplane or by sea. 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 consult was standard procedure regarding referral to CT and hospital admission for patients with TBI. To minimize the risk of missing out patients with TBI due to missing or inaccurate recordings, the first author verified and collected patient and injury data on a daily basis during the 1-year period from neurosurgeons and other ED and hospital personnel, as well as written and computerized patient records. Of the 550 patients, 409 (74%) were treated at RCH. Of the 409 patients, 62 were admitted to RCH.

Table I. Number of Icelandic children and adolescents 0–19 years old in December 1992, by gender, age and urban/rural residence.

	Boys				Girls				Total (%)
Age in years	0–4	5–9	10–14	15–19	0–4	5–9	10–14	15–19	
Reykjavik area*	6639	5559	6022	5775	6377	5545	5799	5611	47 327 (55%)
Rural areas†	5052	4792	5177	4868	4682	4440	4779	4629	38 419 (45%)
Total	11 691	10 351	11 199	10 643	11 059	9985	10 578	10 240	85 746 (100%)

*Reykjavik area refers to the city of Reykjavik and the surrounding towns and suburbs, from Hafnarfjordur in the south to Mosfellsbaer and Kjalarnes in the north.
†Rural areas refer to other parts of Iceland, small towns, villages and farmland.

Table II. Number of Icelandic children and adolescents 0–19 years old, diagnosed with TBI in Iceland from 15 April 1992 to 14 April 1993, by gender, age in 2008* and urban/rural residence at the time of injury.

	Males				Females				Total (%)
Age in years	15–19	20–24	25–29	30–35	15–19	20–24	25–29	30–34	
Reykjavik area†	108	48	52	26	73	38	35	29	409 (74%)
Rural areas‡	22	14	20	22	24	19	13	7	141 (26%)
Total	130	62	72	48	97	57	48	36	550 (100%)

*The number of individuals with TBI in each age group is based on the 0–19 year age distribution at the time of injury. It is a close approximation of the age distribution in 2008.
†Reykjavik area refers to the city of Reykjavik and the surrounding towns and suburbs, from Hafnarfjordur in the south to Mosfellsbaer and Kjalarnes in the north.
‡Rural areas refer to other parts of Iceland, small towns, villages and farmland.

Prior to the launch of the study, the Icelandic Directorate of Health and the Icelandic Ministry of Health approved the protocol. At that time, there was a well-defined, co-ordinated, computerized recording of injured patient data in place for all healthcare institutions in rural Iceland, supervised by the Directorate of Health. By the end of the 1-year period, in mid 1993, the first author collected computerized patient TBI data from all rural hospitals, EDs and healthcare centres. Patients with TBI who were diagnosed and received medical services in rural areas totalled 141 (26%). As, according to national medical guidelines, patients with suspected moderate/severe TBI were to be transported to RCH, it was assumed that all of the 141 rural patients had sustained minimal/mild TBI. All had received ICD-9 diagnosis 850 (concussion). Eighty-six (61%) of the 141 patients had been admitted to hospital.

Data were obtained from the Icelandic Cause of Death Register [65] regarding persons who sustained fatal TBI during the 1-year period. Included were those who died at the scene, during transport, in the ED or after hospital admission. Two children in the age range 0–14 years and two adolescents in the age group 15–19 years had TBI as cause of death.

Control group

The main reason for including a CG was to collect information on the prevalence of TBI and TBI-related disability in young age in Iceland, as well as to compare the outcome of TBI in a general population sample to TBI outcome in a nationwide clinical sample.

The CG ($n = 1232$) was selected in 2008 and thus participants' reports were not affected or 'tainted' by previous follow-ups or other links to the SG. The CG was selected from the December 1993 Icelandic National Register 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 used. The CG was in the same age range as the SG, 15–34 years old. All had at least one parent of Icelandic origin and were residents of Iceland in 2008. There was an equal number of individuals in the sub-groups of the CG, i.e. the CG divided by age, gender and urban/rural residence, $n = 77$ in each sub-group.

Instrument and outcome measures

Participants responded to a comprehensive questionnaire on TBI, SES variables, health, cognition, adaptation and behaviour. In the present study, the focus was on the first 16 questions of the questionnaire (see Appendix). The questions were specifically composed for the study, designed to collect information on the prevalence of TBI, TBI severity, injury-related variables and TBI outcome. Answers to questions 6 and 7 on TBI severity (length of LOC and PTA) were scored according to the Head Injury Severity Scale (HISS) [66, 67] medical criteria. Information on event-related TBI variables was obtained through questions 1–5 (more than one TBI) and question 12 (force of impact). TBI outcome was scored with reference to the King's Outcome Scale for Childhood Head Injury (KOSCHI) [68], Glasgow Outcome Scale (GOS) [69] and the Extended Glasgow Outcome Scale (GOS-E) [69, 70] criteria, based on responses to questions 13 and 14 (recovery and consequences).

Procedure

The study was carried out ~16 years post-injury. All participants responded to the same questionnaire. Participants were not informed whether they belonged to the SG or to the CG. A number of participants in the SG may, however, have recalled previously participating in the research project. Sixty-two of the 550 had taken part in a neuropsychological follow-up study 6 months and 6 years

post-injury and the parents of 409 patients or the patients themselves, if older than 17 years of age, had taken part in a mail questionnaire study 4 years post-injury.

For unknown reasons, 15 SG patients of the 550 could not be located in the Icelandic National Register, leaving 535 to be contacted.

Participants in the SG who did not report having sustained TBI were not excluded from the SG, but were recorded in the data file as having sustained the medically confirmed TBI 16 years earlier. Otherwise, results were based on participants' reports, as well as information on their age, gender and urban/rural residence.

Prior medical data for the CG were not available and there were no exclusion criteria.

In implementing the questionnaire study, a four step model, a modified version of the Tailored Design Method (TDM) [71], was adopted:

- First contact: a brief letter that was sent to respondents a week prior to the questionnaire.
- Second contact: the questionnaire mailing that included a detailed cover letter, the questionnaire with a stamped and addressed return envelope, as well as a small gift (a safety reflector) as a token of gratitude.
- Third contact (a combination of the third and the fourth contact suggested by TDM): a reminder cover letter and a replacement questionnaire were sent to non-respondents a few weeks after the first mailing of the questionnaire.
- The fourth and final contact: non-respondents were telephoned a few weeks after the third contact and requested to respond to selected questions, including all the questions of the present study.

In the SG and CG combined, 29% of participants answered by mail and 39% answered by telephone, with an overall participation of 68%. Mode of responding did not affect outcome in a statistically significant way, neither as main effect nor as two-way interaction (lowest p-value = 0.27).

Participation rate was similar for the SG (62%) and the CG (70%), males (65%) and females (71%), the Reykjavik area (67%) and urban rural areas (69%) and age group (63–75%) distribution.

Of 577 non-participants, 68% could not be found or reached in spite of a thorough search in the National Registry and the telephone directory. When telephone numbers were available, non-respondents were called more than once a week, at different times of the day, for a period of 2 months. Sixteen per cent of non-participants declined to participate, 13% resided abroad, 2% were unable to answer due to their condition and 1% ($n = 7$) were deceased. All the deceased individuals were in the SG, as the CG was newly selected.

Definitions and classifications

A participant was recorded as having sustained TBI if he/she so indicated in his/her answers to the questionnaire or if he/she was a member of the SG. Participants in the SG who reported a TBI in a different year from the medically confirmed one, while not indicating more than one TBI event, were recorded as having sustained one TBI.

Acute severity of TBI was estimated based on answers to questions 6 and 7 with reference to the HISS criteria [67] and the Scandinavian Guidelines for the Initial Management of Minimal, Mild and Moderate Head Injuries [66], adopted by the Icelandic Directorate of Health. Moderate/severe TBI was indicated by LOC for more than 5 minutes following TBI and/or not being able to recall 1 hour or more following TBI.

TBI outcome was based on answers to questions 13 and 14, with reference to the GOS [69], GOS-E [70] and KOSCHI [68] criteria. 'Good recovery (b)' meant no reported TBI consequences. 'Good recovery (a)' represented minor TBI 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 complaints of symptoms that interfered with daily functioning to some extent, e.g. persistent or chronic headache or vertigo or problem with memory and concentration affecting learning or change in temperament and personality or depression and anxiety. 'Moderate disability (a)' referred to a description of more complex combinations of complaints of physical, cognitive, behavioural and mental health problems. Reviewing complaints, there were no cases of 'severe disability', requiring assistance with self-care and activities of daily living. However, in 10 cases (six in the SG and four in the CG) significant other reported that the participant was not fit to answer. In four cases, it was due to mental retardation, but in six cases, the reason was not given. The absence of severe disability was not unexpected as it is relatively rare. Hawley et al. [36] found that severe TBI may lead to severe disability in ~8% of cases.

All participants of the SG who did not indicate having sustained traumatic impact to the head (TIH) leading to TBI, in their answers to questions 1–7, selected the first option (i.e. 'I have never sustained a TIH that has had consequences worth considering') in their responses to questions 13 and 14 of the questionnaire. They were recorded as having sustained 'minimal/mild TBI', with 'good recovery (b)'.

Statistics

The CG participants provided information on the prevalence of TBI and TBI-related sequelae in a nationwide sample.

Binary logistic regression analysis was used to predict complaints of TBI-related consequences in the SG and in the part of the CG that reported having sustained TBI (CG w/TBI) combined. The final model contained the six main effects, group (SG and CG w/TBI), force of impact (question 12), number of TBIs sustained (once or more than once), TBI severity (HISS), gender and age at injury. Group (a design variable) and age at injury were not statistically significant but were included in the model because of their relevance. The urban/rural variable was not related to outcome in a statistically significant way and was removed from the final model. The two main effects, gender and severity, were not interpreted separately because of their two-way interaction. Statistical significance was calculated with chi-squares based on likelihood ratio. Model selection was based on the Akaike Information Criterion (AIC) and statistical comparisons of models. As force of impact was an ordinal variable, it was added to the model as a continuous variable with the values 1, 2, 3 and 4. R: A Language and Environment for Statistical Computing, Release 2.11.1 [72] and SPSS for Windows, Release 15.0.0 [73] were used for statistical analyses.

Ethics

The Data Protection Authority (Ref. 2008090617), the National Bioethics Committee (Ref. VSNb2008090010/03-1) and the Medical Director of Landspitali University Hospital (Ref. 16) approved the study. Permission was obtained from Statistics Iceland regarding use of data from the Icelandic Cause of Death Register.

Results

The prevalence of TBI in the CG

The CG provided information on the prevalence of TBI in a nationwide, representative sample of adolescents and young adults in Iceland. According to participants' ($n = 859$) reports, 49.5% (95% confidence interval [CI] = 46.0–52.5) had sustained concussion or more severe TBI, leading to LOC, and 20.6% had had more than one TBI incident. Possibly indicative of predominantly mild TBI, 27.6% of the 859 participants had sustained TBI without being taken to ED or hospital and 24.2% had been transported to ED. As for the more complicated or severe TBI, 7.6% of the CG had been hospitalized with TBI and 9.1% reported clinical signs (LOC or PTA) in the acute phase indicating moderate/severe TBI.

Regarding long-term sequelae, 7.0% (95% CI = 6.5–7.4) of the CG described TBI-related symptoms suggesting moderate disability (b) or (a), but only 2.4% claimed to have been evaluated for or received compensation because of TBI consequences.

The prevalence of TBI in the CG was higher than expected, based on prior findings, emphasizing the scope of TBI as a health concern.

Reported TBI, SG vs CG w/TBI

The controls who indicated that they had sustained TBI were selected to form a new group (CG w/TBI). This provided the unique opportunity to compare responses from a group of individuals, randomly selected from the general population and reporting to have sustained TBI, to responses from a group with medically confirmed TBI ~16 years earlier.

According to the HISS criteria, 23.9% of the SG participants ($n = 331$) and 18.4% of the CG w/TBI ($n = 425$) reported having sustained moderate/severe TBI. The corresponding percentages for TBI-related moderate disability were 11.8% and 13%. The two groups were also comparable in terms of minimal/mild TBI leading to disability (7.1% vs 9.0%), moderate/severe TBI leading to disability (26.6% vs 30.8), repeated TBI (35.0% vs 41.6) and having been evaluated for or received compensation (3.3% vs 4.5%).

The remarkable similarities between the SG and CG w/TBI supported the validity and reliability of participants' reports of TBIs sustained, TBI severity and TBI consequences.

In the SG and the CG w/TBI combined, reports on having been evaluated for or received compensation were more common among those 15 years or older at the time of injury (9.9%) than in the age range 0–14 years (2.2%), with the lowest ratio in the youngest age group, 0–4 years (1%). Overall, 21.1% ($n = 70$) of participants in the SG did not report having sustained TBI in their answers to questions 1–7 of the questionnaire and consequently denied TIH with consequences worth considering (questions 8–16). All of them had received ICD-9 diagnosis 850 (concussion) in the acute phase and 84% ($n = 58$) had been treated at EDs. The ratio of participants in the SG not reporting their medically confirmed TBI was highest in the youngest age at injury group, 0–4 years old, 35.7%, as compared to 12–16% in older age groups. Based on the present data, it is unclear if the above findings are indicative of minimal and forgettable TBI in the youngest age groups or a lack of awareness and denial regarding the sequelae of TBI in infancy and early childhood.

Allowing for a possible 1–2 year inaccuracy in recall of the medically confirmed TBI, 3% of participants in the SG reported having sustained the TIH with the most consequences prior to the year 1991 and 22% after the year 1994. In the majority of cases, the TIH reported that had the most consequences occurred before 20 years of age, the ratio being 95% for the SG and 84% for the CG.

Prognostic factors

The prognostic value of injury-related and demographic variables for long-term symptoms of TBI was studied in the SG and the CG w/TBI combined. Binary logistic regression analysis was used to predict late outcome of paediatric TBI. The final model adopted for interpretation included the four main effects, group (SG and CG w/TBI), force of impact, number of TBIs sustained and age at TBI, as well as the two-way interaction severity (HISS) by gender.

Late TBI-related consequences were more common among participants describing greater force of impact TBI compared to those reporting less force of impact TBI ($\chi^2(1) = 31.4$; $\Delta AIC = 29.4$; odds ratio [OR] $= 2.1$; 95% CI $= 1.6$–2.7; $p < 0.001$). Considering that force of impact has values from 1–4, potentially the effect is very large, as can be seen in Figure 1.

The two-way interaction severity by gender was statistically significant ($\chi^2(1) = 5.2$; $\Delta AIC = 3.2$; $p < 0.05$). For males, increased severity predicted reports of worse outcome ($\chi^2(1) = 9.0$; OR $= 2.5$; 95% CI $= 1.4$–4.7; $p < 0.01$), but a similar effect could not be established for females ($\chi^2(1) = 0.1$; OR $= 0.9$; 95% CI $= 0.5$–1.8; $p < 0.79$). Despite being numerically greater, the total effect of severity, a dichotomous variable, on late symptoms was substantially less than the effect of force of impact, a four-point variable, and close to non-existent for females.

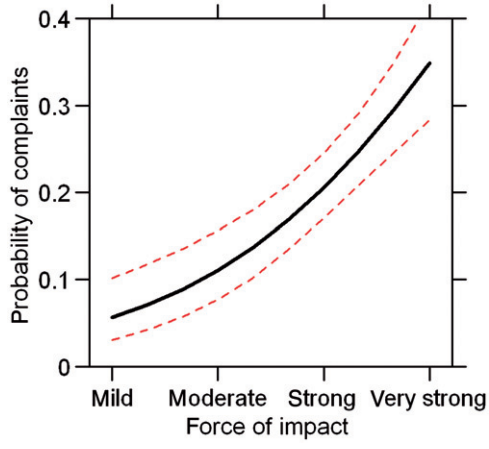

Figure 1 Greater force of impact increases the probability of long-term TBI-related complaints. The unbroken line shows the predicted probability and the dotted lines indicate 95% pointwise confidence envelope.

Having sustained TBI more than once was related to poorer outcome ($\chi^2(1) = 8.3$; $\Delta AIC = 6.3$; OR $= 1.9$; 95% CI $= 1.2$–2.9; $p < 0.01$).

No further two-way interactions were statistically significant, but closest were the interactions gender by force of impact ($\chi^2(1) = 3.2$; $\Delta AIC = -1.2$; $p = 0.07$) and group by age at injury ($\chi^2(1) = 2.0$; $\Delta AIC = 0.02$; $p = 0.16$).

Convincing evidence was not found that age predicted TBI-related sequelae ($\chi^2(1) = 3.5$; $\Delta AIC = 1.5$; OR $= 1.0$; 95% CI $= 1.0$–1.1; $p = 0.06$), suggesting a minimal or non-existing effect for age at injury.

There was a non-significant statistical difference between the SG and the CG w/TBI when predicting TBI sequelae ($\chi^2(1) = 1.4$; $\Delta AIC = -0.6$; $p = 0.24$).

Overall, the binary logistic regression analysis revealed the prognostic value of event-related variables over and above clinical symptoms of severity in the acute phase.

Discussion

The two main findings of the study are that the prevalence and scope of TBI in young age and TBI-related long-term consequences in a general population sample are greater than previously documented and that TBI event-related factors, especially force of impact, have greater predictive value than clinical symptoms of severity at the acute stage.

The prevalence of TBI in the present nationwide random sample is higher than the prevalence based on adolescent self-reports [27, 28] and the prevalence of medically confirmed TBI at age 25 [18], but lower than the self-reported prevalence in higher-risk groups of university athletes [29]. The prevalence of reported TBI-related long-term disability is also distinctly higher than previously suggested [10, 14, 23, 30–32].

As approximately one fifth of participants in the SG did not report having sustained TBI, it may be that the CG under-reported TBI sustained to a similar extent. Not reporting TBI sustained may be indicative of minimal TBI, without long-term consequences and, therefore, forgotten, but the issue merits further study.

Participants with paediatric TBI of varied degrees of severity reported TBI-related consequences 15–17 years post-injury. In the nationwide sample of individuals with confirmed medical TBI diagnosis, 11.8% reported moderate disability (b) or (a).

The findings also suggest that minimal/mild TBI may have long-term consequences. As would be expected, moderate disability was more common among those reporting moderate/severe TBI than those reporting minimal/mild TBI.

The present findings may reflect a general lack of awareness of paediatric TBI consequences, especially so for those of younger age at the time of injury. The majority of those who reported TBI-related moderate disability had not received compensation and compensation was more associated with age 15 years or older at the time of injury than with younger age groups. Lack of awareness regarding paediatric TBI and TBI outcome may be especially pronounced in the youngest age group, 0–4 years old, where close to 36% of SG participants did not report having sustained TBI, as compared to 12–16% in older age groups. In this context, it is of interest to note that the highest number of individuals in the SG were in the youngest age group (see Table II) and the more severe incidents of TBI, medically estimated in the acute phase, were equally distributed across age groups at injury [17].

The variables found to have the highest predictive value for long-term outcome and TBI-related disability in the SG and CG w/TBI combined were force of impact and the number of TBIs sustained. In the present 16 years post-injury self-report study, questions relating to the TBI events had greater predictive value than questions relating to symptoms of acute medical severity, LOC and PTA, based on the HISS criteria. The former information may have been more readily and accurately accessible in the participant's memory, but it may also be assumed that heavy force of impact to the head and repeated TBI are detrimental for brain functioning. The interaction between gender and severity revealed that females were more likely than males to report PCS following minimal/mild TBI, which is in line with earlier findings [49, 53]. Girls may be more vulnerable and/or sensitive to the subtle effects of mild TBI than boys.

There was no conclusive evidence indicating that age at TBI was associated with outcome, but especially in the CG w/TBI there was a tendency for worse outcome to be associated with increasing age at injury. This may be related to closer proximity in time, enhancing recall.

The present findings have relevance and are representative in the international context. This is supported by previous reports [17, 64] that the incidence of paediatric TBI in Iceland is similar to other western countries and by the present 7.6% prevalence of having been hospitalized with TBI, which is comparable to the 4–12% reported elsewhere [18, 23, 30]. The findings have important implications for injury prevention, healthcare planning, cognitive health concerns and compensation issues.

The monetary cost of long-term consequences of TBI in Iceland may be estimated based on the present findings and disability reference tables from the Danish National Board of Industrial Injuries (DNBII) [74]. The present data suggest that in Iceland 7.0% ($n = 6002$) of the total population in the age range 15–34 years ($n = 85\ 746$) may be suffering TBI-related moderate disability. Given the data from the DNBII, a conservative estimate of the average percentage of permanent disability caused by TBI encountered by the 6002 individuals is 8%. This corresponds to 480 individuals with 100% permanent disability or 0.6% of the total population within the age range 15–34 years. Assuming that each fully disabled individual in this age range is unable to earn his/her wages for 40 years, with an annual average income of 3.5 million Icelandic kronur (ISK), the cumulative cost of TBI for each individual is ISK 140 million (US$1.2 million; €0.9 million). For all 480 individuals in the age range the cost is ISK 67 200 million (US$576 million; €432 million). Based on the Icelandic gross domestic product (GDP) for the year 2008 (ISK 1 477 938 million), during the 40-year period the cost accumulates to 4.55% of a 1-year GDP [75].

Limitations

The findings in the present study are based on participants' self-reports, which may be affected by exaggeration or under-estimation. Due to lack of insight into their own problems, patients with TBI may be less reliable informants than professionals or caregivers in the post-acute phase. However, patients may be more reliable informants in the case of long-term sequelae [76].

When asked, some participants in the CG, as was the case in the SG, may not have recalled or been unaware of having sustained a TBI, e.g. due to young age at injury and not having been informed by their parents about the event. This may have led to an under-estimation of TBI and TBI-related consequences.

The recollection period ranged from 15–16 years for the youngest participants to 35 years for the oldest ones. Although not unprecedented in self-report studies of injury prevalence [77, 78], this relatively long recollection period may have affected detailed recall of TBI sustained early in life and led to an under-estimation of the prevalence of TBI. However, research indicates that details of traumatic injuries and medical emergencies, experienced after the first 2–3 years of life, may be well preserved for long-term recall. Late recall may be enhanced by

stressful and intense emotional reactions often caused by paediatric traumatic injuries [79–81].

TBI data collection was to some extent based on indirect phrasing of questions. To avoid clinical or unfamiliar terms, 'traumatic brain injury (TBI)' was replaced by 'traumatic impact to the head (TIH)' and 'post-traumatic amnesia (PTA)' by 'having been unable to recall what happened following TIH'. The questions were designed to collect the relevant information for the classification of data. The similarities between the SG and the CG w/TBI support the validity of participants' reports.

To avoid restricting responses or leading to or encouraging certain kinds of answers, the questionnaire did not specifically link TIH to TBI and the possible consequences of TIH or TBI were not listed. In question 14, participants were asked to describe any symptoms they attributed to the TIH they reported. In some cases participants may have failed to associate TIH with TBI and its long-term symptoms, leading to an under-estimation of TBI-related sequelae. However, the Icelandic word 'hofudhogg', adopted for TIH, is familiar to Icelanders, and may have enhanced association with TBI and its possible consequences.

The HISS [66, 67] definition of TBI severity used in the study differs from the definition proposed by the WHO Task Force [58, 82]. The HISS criteria of severity, adopted in the Scandinavian countries, allowed for differentiation of severity in the milder range and were well suited for the present purposes.

For increased participation, a paper and pencil questionnaire was adopted, followed by a telephone survey. The mode of answering may have affected how respondents answered. However, statistical analyses suggested that the mode of answering had non-significant effects on reports of TBI severity and outcome.

Participation rate was 62% for the SG and 70% for the CG. Participants and non-participants in the SG were, however, comparable regarding 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.

For additional validation of findings, it would have been preferable to compare reports of TBI severity and TBI force of impact to information from medical records on causes and circumstances of TBIs sustained. This was, however, problematic due to a lack of data and the long time since injury.

In the present study, the aim was not to present information on pre-morbid health, SES or post-injury non-TBI-related factors that might have affected reports of TBI severity and outcome. This issue will be addressed in a later paper based on the questionnaire data.

Conclusions and future directions

The scope of TBI in young age and TBI-related long-term consequences is greater than previously documented. In the present self-report study, the TBI event-related variable, force of impact, had prognostic value over and above clinical symptoms of severity (HISS). The finding emphasizes that TBIs involving strong or very strong force of impact should always warrant post-acute follow-up, even in the absence of pronounced symptoms of acute severity (LOC or PTA). According to the present findings, the consequences of early TBI are still evident 15–17 years post-injury. More severe TBI leads to poorer outcome than minimal/mild TBI, but the latter may also have long-term sequelae. The majority of those reporting TBI-related moderate disability may not receive compensation, especially in the age group younger than 15 years of age at the time of TBI. In a self-report study, TBI sustained in the first years of life may not be recalled or reported in adolescence or early adulthood. How this is reflected in long-term health and adjustment is one of the aims of a second paper based on the questionnaire data. In young age, girls may be more vulnerable or sensitive to the long-term effects of mild TBI than boys. The monetary cost of TBI in the 15–34 year age range is substantial, accumulating over the lifespan to 4.55% of a 1-year GDP. The present findings of the scope and prevalence of paediatric TBI have relevance and are representative in the international context.

Further research is needed on TBI in infancy and early childhood and the effects of minimal/mild TBI on girls.

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Appendix

An English translation of the original Icelandic version of the first 16 questions of the questionnaire.

Questions on traumatic impact to the head (TIH)

(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 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?
- ☐ I have never sustained a TIH that has had consequences worth considering
- ☐ The TIH that had the most consequences, 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 consequences worth considering
- ☐ 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 consequences worth considering
- ☐ 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 consequences worth considering
- ☐ In the Reykjavik area (from Hafnarfjordur to Kjalarnes)
- ☐ 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 consequences worth considering
- ☐ 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 consequences worth considering
- ☐ 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 then 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.
- ☐ I have never sustained a TIH that has had consequences worth considering
- ☐ 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 consequences worth considering
- ☐ 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 consequences worth considering
- ☐ I have suffered TIH consequences, but I have not received any compensation or been evaluated regarding disability pension or reinbursements because of this
- ☐ Yes, I have received compensation or been evaluated regarding disability pension or reinbursement because of TIH consequences