Early traumatic brain injury in Iceland

Incidence, prevalence, long-term sequelae and prognostic factors

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Heilaáverkar á íslenskum börnum, unglingum og ungu fólki á fullorðinsaldri

Nýgengi, algengi, langtímaafleiðingar og batahorfur

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ÁGRIP

Markmið: Meginmarkmið Íslenska rannsóknarverkefnisins um heilaáverka á ungu fólki voru: (1) að meta nýgengi og algengi heilaáverka og afleiðinga heilaáverka á ungum aldri í þjóðarúrtökum; (2) að meta forspárgildi þátta sem tengjast heilaáverka og þátta sem ekki eru tengdir heilaáverka fyrir síðbúnar afleiðingar; og (3) að leggja grunninn að og styðja við uppbyggingu skipulagðra fyrirbyggjandi aðgerða og þjónustu fyrir ungt fólk sem tekst á við afleiðingar heilaskaða á Íslandi og fjölskyldur þeirra.

Efniviður og aðferðir: Þátttakendur í þeim hlutum rannsóknarverkefnisins sem lýst er hér voru: (1) öll börn og unglingar á aldrinum 0-14 ára, sem greind voru með heilaáverka (ICD-9 850-854 (WHO, 1977)) og lögð inn á sjúkrahús í Reykjavík á fimm ára tímabili 1987-1991 (n = 359) (rannsóknarhópur 1 (RH1)); (2) öll börn og unglingar á aldrinum 0-19 ára á Íslandi, sem greind voru með heilaáverka á eins árs tímabili frá 15. apríl 1992 til 14. apríl 1993 (n = 550) (RH2); og (3) samanburðarhópur (n = 1,232) (SH) valinn úr Þjóðskrá árið 2008 með lagskiptri tilviljunaraðferð. Gögnum um sjúklingana sem lagðir voru inn á sjúkrahús í Reykjavík á árunum 1987-1991 var safnað afturvirkt á tímabilinu 1992-1993, samhliða því sem hleypt var af stokkunum framsýnni rannsókn á heilaáverkum barna og unglinga á Íslandi.

Fjöldi sjúklinga í RH1 og RH2 var skráður og hópunum var skipt í undirhópa eftir alvarleika heilaáverka, aldri við áverka, kyni og búsetu. Árlegt nýgengi var reiknað fyrir fimm ára tímabilið 1987-1991 og fyrir 12 mánaða tímabilið 1992-1993.

Afleiðingar heilaáverka í þeim hluta RH2 sem hlaut meðferð í Reykjavík á árinu 1992-1993 (n = 408) voru metnar með stuttum spurningalista fjórum árum síðar. Í meirihluta tilfella svöruðu foreldrar vegna ungs aldurs þátttakenda. Þátttökuhlutfall var 59.6%.

Síðbúnar afleiðingar heilaáverka í RH2 voru metnar á ný á árunum 2008 og 2009 með ítarlegum spurningalista. SH, sem fékk sendan sama spurningalistann, gaf m.a. upplýsingar um algengi heilaáverka og afleiðinga þeirra í þjóðarúrtaki völdu með lagskiptri tilviljunaraðferð úr Þjóðskrá. Þátttakendur fengu ekki upplýsingar um

hvorum hópnum þeir tilheyrðu (RH2 eða SH) og spurningar listans gáfu ekki til kynna hvort þátttakendur hefðu hlotið heilaáverka eða ekki. Í meirihluta tilfella svöruðu þátttakendur sjálfir, enda voru um 16 ár liðin frá áverka og SH var á sama aldursbili og RH2.

Allir þátttakendur fengu spurningalistann sendan í bréfpósti. Í spurningalistanum voru spurningar um heilaáverka og afleiðingar þeirra, félagsstöðu og aðrar lýðfræðilegar breytur, svo og fjórir klínískir matskvarðar til að meta afleiðingar heilaáverka: (1) Memory Complaint Questionnaire (MCQ); (2) General Health Questionnaire (GHQ); (3) Frontal Systems Behavior Scale (FrSBe); og (4) European Brain Injury Questionnaire (EBIQ). Hringt var í þá sem ekki svöruðu með pósti og þeir beðnir að svara styttri útgáfu spurningalistans í símtali. Heildarþátttökuhlutfall var tæplega 70%.

Sjálfsmat þátttakenda hvað snerti alvarleika heilaáverka í bráðafasa var skorað með hliðsjón af viðmiðum Head Injury Severity Scale (HISS). Svör um síðbúnar afleiðinar heilaáverka voru skoruð með hliðsjón af viðmiðum King’s Outcome Scale for Childhood Head Injury (KOSCHI), Glasgow Outcome Scale (GOS) og Extended Glasgow Outcome Scale (GOS-E).

Þátttakendur í SH sem gáfu til kynna að hafa hlotið heilaáverka mynduðu sérstakan (klínískan) samanburðarhóp (SH með heilaáverka). Tölfræðilegar greiningaraðferðir voru notaðar til að bera saman hópa og meta forspárgildi eða áhrif þátta, sem tengdir voru heilaáverka eða voru ótengdir heilaáverka, hvað snerti síðbúnar afleiðingar.

Niðurstöður: Niðurstöður rannsóknanna tveggja fyrir tímabilin 1987-1991 og 1992-1993 um árlegt nýgengi heilaáverka (ICD-9 850-854) sem leiddu til innlagnar á sjúkrahús, nýgengi miðlungs/alvarlegra heilaáverka (ICD-9 851-854) og nýgengi banvænna heilaáverka bar vel saman við nýgengi sem kynnt hafði verið í fyrri rannsóknum hér á landi og í öðrum vestrænum löndum. Nýgengi mjög vægra (minimal) heilaáverka sem metnir voru á bráðadeildum og leiddu ekki til innlagnar var áberandi lægra í dreifbýli (1.93 á 1,000) en á Reykjavíkursvæðinu (6.87 á 1,000) á árinu 1992-1993. Þessi munur var sérstaklega áberandi í yngsta aldurshópnum. Nýgengi mjög vægra heilaáverka (meðhöndlaðir á bráðadeildum) var hæst í yngsta aldurshópnum, sem hlaut þjónustu á Reykjavíkursvæðinu. Búseta eða aldur hafði ekki tölfræðilega marktæk áhrif á nýgengi vægra heilaáverka sem leiddu til innlagnar eða miðlungs eða alvarlegra heilaáverka. Nýgengi heilaáverka var hærra meðal stráka en stelpna.

Fall var algengasta orsök heilaáverka í yngri aldurshópunum, en heilaáverkar af völdum óviljahöggs, íþróttaþátttöku og umferðar urðu algengari með aldri.

Fjórum árum eftir áverka lýstu 39 (16.0%) af 243 þátttakendum í RH2 (sá hluti RH2 sem hlaut meðferð í Reykjavík) því að þeir væru enn með sjúkdómseinkenni, sem þeir töldu vera afleiðing fyrri heilaáverka, og 16 (6.6%) lýstu einkennum sem fylltu viðmið um hömlun (disability) samkvæmt GOS. Þyngd höfuðhöggs, sem áætluð var út frá staðfestum orsökum og hvar heilaáverki átti sér stað, reyndist hafa forspárgildi fyrir kvartanir um síðbúnar afleiðingar óháð læknisfræðilega staðfestum alvarleika heilaáverka í bráðafasa.

Sextán árum eftir heilaáverka lýstu 39 (11.8%) af 331 þátttakanda í RH2 einkennum af völdum heilaáverka sem fylltu viðmið um miðlungs hömlun. Samkvæmt sjálfsmati leiddi mjög vægur eða vægur heilaáverki (n = 252) til hömlunar í 7.1% (n = 18) tilfella og miðlungs eða alvarlegur heilaáverki (n = 79) í 26.6% tilfella (n = 21). Á seinni hluta áttunda áratugarins og snemma á þeim níunda hlutu að meðaltali 1-2 börn endurhæfingu á ári hverju vegna afleiðinga heilaskaða. Endurhæfingin var aðallega í formi skammtíma sjúkraþjálfunar. Ofangreindar niðurstöður benda til þess að endurhæfing hafi ekki mætt þörfum hópsins, hvorki hvað snerti fjölda né innihald.

Læknisfræðilega staðfestir heilaáverkar og heilaáverkar sem lýst var með sjálfsmati endurspegluðust í verri útkomu á klínísku matskvörðunum fjórum, þegar klínísku hóparnir tveir RH2 og SH með heilaáverka voru bornir saman við SH sem ekki lýsti heilaáverka.

Þyngd höfuðhöggs hafði forspárgildi hvað snerti síðbúin einkenni og útkomu umfram alvarleika höfuðhöggs (HISS). Það að hafa hlotið heilaáverka oftar en einu sinni hafði einnig áhrif á einkenni og útkomu á klínískum matskvörðum. Áhrif aldurs þegar áverki átti sér stað, kyns, búsetusvæðis (Reykjavíkursvæðið eða dreifbýli) og félagsstöðu foreldra virtust takmörkuð sextán árum eftir áverka.

Algengi heilaáverka mældist 49.5% í SH, sem var tilviljunarúrtak úr Þjóðskrá. Í SH lýstu 7.0% þátttakenda síðbúnum einkennum af völdum heilaáverka, sem fylltu viðmið um miðlungs hömlun.

Um þrír fjórðu hlutar þátttakanda í sameinuðum hópi RH2 og SH, sem lýstu miðlungs hömlun, höfðu ekki verið metnir til bóta. Í þessum hópi þátttakenda með miðlungs hömlun var það að vera ekki metinn til bóta ekki tengt betri útkomu á klínísku matskvörðunum fjórum. Að vera metinn til bóta var hins vegar tengt aldri. Meðal þeirra sem voru eldri en 14 ára, þegar heilaáverki átti sér stað, höfðu 9,9% þátttakenda verið metin til bóta, miðað við 2.2% í sameinuðum aldurshópum barna yngri en 15 ára.

Um það bil einn fimmti hluti þátttakenda í RH2 kvaðst aldrei hafa hlotið heilaáverka 16 árum síðar. Þetta var algengara í yngsta aldurshópnum (35.7%) en í þeim eldri (12-16%). Það að gefa ekki til kynna að hafa hlotið læknisfræðilega staðfestan heilaáverka á ungum aldri var tengt betri útkomu á EBIQ og GHQ, en ekki á MCQ og FrSBe.

Könnun á heilaáverkum barna og unglinga í tölvuvæddu sjúklingabókhaldi Landspítala bendir til þess að árlegur fjöldi alvarlegri heilaáverka (ICD-9 851-854/ICD-10 S06.1-S06.9 (WHO, 1992)) hafi haldist tiltölulega stöðugur á tímabilinu frá 1990 til 2006. Þessar niðurtöður gefa til kynna að það sé enn þörf á fyrirbyggjandi aðgerðum og sérhæfðri íhlutun.

Umræða og ályktanir: Fjöldi þátttakenda sem lýsir síðbúnum afleiðingum heilaáverka á ungum aldri og tiltölulega lítil breyting á fjölda barna og unglinga sem hljóta alvarlegri heilaáverka í Reykjavík á undanförnum árum, gefa til kynna áframhaldandi þörf fyrir fyrirbyggjandi aðgerðir og fjölbreytta sérhæfða íhlutun á Íslandi.

Það er líklegra að lýsing á síðbúnum afleiðingum fylgi miðlungs og alvarlegum heilaáverkum en mjög vægum eða vægum heilaáverkum. Þó verður að hafa í huga að þar sem mjög vægir og vægir heilaáverkar eru tiltölulega algengir þá er fjöldi þeirra einstaklinga sem lýsa afleiðingum af völdum slíkra áverka umtalsverður.

Þyngd höfuðhöggs og endurtekinn heilaáverki hafa forspárgildi gagnvart síðbúnum einkennum og útkomu á klínískum kvörðum óháð læknisfræðilega staðfestum alvarleika og sjálfsmati á alvarleika heilaáverka í bráðafasa. Því er líklegt að þessar breytur muni styrkja og auka gildi viðmiða og kvarða sem meta eiga alvarleika og horfur heilaáverka í bráðafasa.

Tiltölulega lágt nýgengi mjög vægra heilaáverka í yngsta aldurshópnum í dreifbýli er umhugsunarefni fyrir heilsugæslu, þar sem það getur bent til vangreindra heilaáverka eða að skráningu heilaáverka sé áfátt. Tiltölulega hátt nýgengi mjög vægra heilaáverka af völdum falls í yngsta aldurshópnum á Reykjavíkursvæðinu gefur til kynna þörf fyrir fyrirbyggjandi aðgerðir.

Algengi heilaáverka á ungum aldri og algengi hömlunar af völdum heilaáverka metið með spurningalista og sjálfsmati var hærra en áður hefur verið lýst í almennum þýðum á alþjóðavettvangi. Hins vegar bendir nýgengi heilaáverka á ungum aldri á Íslandi til þess að algengi heilaáverka sem lýst er hér kunni að vera sambærilegt við það sem gerist í raun erlendis.

Niðurstöður benda til ósamræmis í bótamati eftir heilaáverka, sem er augljósast í yngstu aldurshópunum.

Læknisfræðilega staðfestur heilaáverki mjög ungra barna, sem ekki er getið í svörum við spurningum mörgum árum síðar, kann að hafa síðbúnar afleiðingar hvað snertir hugræna (cognitive) þætti, jafnvel þótt viðkomandi geri sér ekki grein fyrir því.

Niðurstöður um síðbúnar afleiðingar benda til þess að á ungum aldri þurfi að gæta sérstaklega að afleiðingum miðlungs eða alvarlegra heilaáverka, heilaáverka af völdum þungs eða mjög þungs höfuðhöggs og endurtekinna heilaáverka. Í þessum tilfellum er sérhæfð íhlutun og eftirfylgd mikilvæg. Þegar um er að ræða mjög væga eða væga heilaáverka er mikilvægt að fræða sjúkling og foreldra um mögulegar afleiðingar og hvert eigi að leita aðstoðar ef þörf krefur.

Niðurstöður rannsóknarverkefnisins benda til þess að heilaáverkar á ungum aldri sem leiða til miðlungs hömlunar sé áhyggjuefni fyrir hugræna heilsu og hafi áhrif á líf margra einstaklinga og fjölskyldna þeirra.

Lykilorð: Batahorfur, börn, faraldsfræði, heilaáverkar, unglingar, ungt fólk, þjóðarúrtak

ABSTRACT

Main objectives: The main objectives of the Icelandic research project on early traumatic brain injury (TBI), the ICTBI research project, were: (1) to estimate the nationwide incidence and prevalence of early TBI and TBI-related long-term consequences; (2) to assess the prognostic value of injury-related and non-injury-related factors for late outcome; and (3) to serve as a foundation for the development of goal-oriented prevention and intervention in Iceland.

Material and methods: Participants in the present series were: (1) all children and adolescents 0-14 years old diagnosed with TBI (ICD-9 850-854 (WHO, 1977) and admitted to hospital in Reykjavík during the five year period 1987-1991 (n = 359); (2) all children and adolescents 0-19 years old diagnosed with TBI in Iceland from 15 April 1992 to 14 April 1993 (n = 550; the ICTBI study group (SG)); and (3) a control group (CG) (n = 1,232) selected from the Icelandic National Registry in 2008 using a stratified random sampling method. Data on the children and adolescents with TBI admitted to hospital in Reykjavík in 1987-1991 were collected retrospectively in 1992-1993, parallel to the launching of the prospective ICTBI research project.

In study groups (1) and (2), numbers were recorded according to TBI severity, age at injury, gender and residence, and annual incidence rates calculated for the five-year period 1987-1991 and for the one-year period 1992-1993.

In the ICTBI SG sub-sample of patients treated in the Reykjavík area in 1992-1993 (n = 408), outcome was assessed four years post-injury by means of a short questionnaire. In the majority of cases, parents answered the questionnaire due to the young age of the participants. The participation rate was 59.6%.

Approximately 16 years post-injury, in 2008-2009, the late consequences of early TBI in the nationwide ICTBI SG were assessed by means of a comprehensive questionnaire. The newly selected CG, receiving the same questionnaire, provided information on the prevalence of TBI and TBI-related sequelae in a nationwide general population sample. Participants were not informed as to

which group (ICTBI SG or CG) they belonged and the questionnaire was neutral as regards the TBI-status of respondents. Sixteen years post-injury, findings were mostly based on self-report.

All participants received the questionnaire by mail. The questionnaire included questions on TBI and TBI-related consequences, socio-economic status (SES) and other demographic variables, as well as four clinical outcome scales: (1) Memory Complaint Questionnaire (MCQ); (2) General Health Questionnaire (GHQ); (3) Frontal Systems Behavior Scale (FrSBe); and (4) European Brain Injury Questionnaire (EBIQ). Non-respondents were requested to answer an abbreviated version of the questionnaire by telephone. Overall participation was close to 70%.

Self-reports of acute TBI severity were scored with reference to the Head Injury Severity Scale (HISS) criteria. Reports of late symptoms attributed to TBI were scored with reference to the King's Outcome Scale for Childhood Head Injury (KOSCHI), the Glasgow Outcome Scale (GOS), and the Extended Glasgow Outcome Scale (GOS-E) criteria.

The respondents in the CG who reported having sustained TBI formed a separate (clinical) CG (CG with TBI). Statistical analyses were used to compare groups and assess the prognostic value of injury-related and non-injury-related factors for late outcome.

Results: In the two incidence studies, 1987-1991 and 1992-1993, the annual incidence of pediatric TBI (ICD-9 850-854) leading to hospitalization, the incidence of moderate/severe non-fatal TBI (ICD-9 851-854), and the incidence of fatal TBI compared well with previous incidence rates reported in Iceland and in other western countries. In 1992-1993, the incidence of minimal TBI treated at emergency departments (EDs) was markedly lower in rural areas (1.93 per 1,000) than in the Reykjavík area (6.87 per 1,000). This difference was most pronounced in the youngest age group, 0-4 years old. The incidence of minimal TBI (i.e. TBI treated at EDs) was highest in the youngest age group treated in the Reykjavík area. The incidence of hospitalized mild, moderate, and severe TBI was comparable across age and residence (urban/rural) groups. The incidence of TBI was higher among boys than among girls. Fall was the most common cause of TBI in the younger age groups, but unintentional blows and sport- and traffic-related TBIs became more common with age.

Four years post-injury 39 (16.0%) of the 243 participants reported symptoms that they attributed to the previous TBI, and 16 (6.6%) described symptoms indicating disability according to the GOS criteria. Estimated force of impact to the head, based on causes and location of TBI derived from patient records, had prognostic value for late complaints independent of the medically confirmed acute severity of the TBIs sustained.

Sixteen years post-injury 39 (11.8%) of the 331 participants in the ICTBI SG reported TBI-related symptoms indicating moderate disability. Self-reported minimal/mild TBI (n = 252) led to disability in 7.1% (n = 18) of cases and moderate/severe TBI (n = 79) in 26.6% (n = 21) of cases. In the late 1980s and the early 1990s, 1-2 children with TBI received rehabilitation each year, mostly in the form of short-term physiotherapy. This suggests that the rehabilitation effort was far from meeting the need.

In the SG and the CG with TBI, early medically confirmed and self-reported TBI was reflected in worse results on each of the four clinical outcome scales, assessing aspects of cognition, mental health, adjustment and behavior, as compared to the CG without TBI.

Force of impact to the head had prognostic value over and above estimated acute TBI-severity (HISS). Having sustained more than one TBI also predicted worse late outcome. Sixteen years post-injury age at injury, gender, urban/rural residence, and parental SES had a limited, nominal, or non-existent effect.

In the nationwide CG, the prevalence of self-reported early TBI was 49.5%. As regards late sequelae, 7.0% of the total CG reported TBI-related symptoms indicating moderate disability.

In the SG and CG combined, 75% of the participants who reported moderate disability had not been evaluated for or awarded compensation. In the moderately disabled group, not being evaluated for or awarded compensation was not associated with better results on the four clinical outcome scales. In the group with moderate disability, evaluation for compensation was related to age. In the age range older than 14 years at injury, 9.9% reported to have been evaluated for compensation while the corresponding ratio for the younger age groups combined was 2.2%.

Close to one fifth of participants in the SG did not report ever having sustained TBI. This was more prevalent in the youngest age group at injury (35.7%) than in older age groups (12-16%). Not reporting, as compared to reporting, very early medically confirmed TBI was associated with better outcome on EBIQ and GHQ, but not on MCQ and FrSBe.

Based on computerized patient records at Landspítali University Hospital the annual number of children and adolescents with the more severe TBI (ICD-9 851-854/ICD-10 S06.1-S06.9 (WHO, 1992)) was relatively stable from 1990 to 2006, suggesting a continuous need for prevention and intervention.

Main conclusions: The number of participants reporting late consequences of early TBI and the relatively stable annual number of children and adolescents with the more severe TBI in Reykjavík in recent years suggest the need for injury prevention and a broad-based intervention in Iceland.

Moderate/severe TBI is more likely to lead to reports of late sequelae than minimal/mild TBI. However, due to the relatively high incidence of minimal/mild TBI, such injuries contribute substantially to the total number of TBI with late consequences.

Force of impact to the head and repeated TBI were shown to have predictive value for late symptoms and outcome, independent of medically confirmed or self-reported acute TBI-severity (HISS). The findings suggest that these criteria or indicators may add to the prognostic value of scales aimed at assessing the severity of pediatric TBI in the acute phase.

The low incidence of minimal TBI in the youngest age group in rural areas is a public health concern, as it may suggest under-diagnosis or under-recording. The relatively high incidence of minimal TBI caused by fall in the youngest age group in the Reykjavík area indicates a need for TBI prevention measures.

As assessed by a questionnaire, the prevalence of self-reported early TBI and TBI-related disability was higher than previously reported internationally in general population studies. However, the incidence rates of pediatric TBI in Iceland suggest that the present findings on the prevalence of TBI are representative in the international context.

The findings indicate an inconsistency in evaluation for compens-ation, most obviously in the youngest age groups. Very early medi-

cally confirmed TBI not reported by parent or self may have unrecognized late cognitive sequelae.

The present reports on late sequelae suggest that in young age, a moderate/severe TBI or a TBI caused by strong or very strong impact to the head or a repeated TBI requires specialized intervention and follow-up. In the case of ‘minimal’ or ‘mild’ TBI, young patients and parents should be informed of possible consequences and how to seek assistance if the need arises.

The results of the present series of the ICTBI research project suggest that the scope of early TBI leading to moderate disability is a significant cognitive health concern affecting many individuals and their families.

Key words: epidemiology, nationwide, pediatric, prognosis, traumatic brain injury

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LIST OF ABBREVIATIONS

AIC	Akaike Information Criterion
CG	Control group
CT	Computed Tomography
EBIQ	European Brain Injury Questionnaire
FrSBe	Frontal Systems Behavior Scale
ED	Emergency department
GCS	Glasgow Coma Scale
GHQ-12	General Health Questionnaire, 12 items
GOS	Glasgow Outcome Scale
GOS-E	Glasgow Outcome Scale extended version
HISS	Head Injury Severity Scale
ICD-9	International Classification of Diseases, 9^{th} edition
ICD-10	International Classification of Diseases, 10^{th} edition
ICTBI	The Icelandic research project on early traumatic brain injury
ICTBI SG	The original SG of the ICTBI research project
KOSCHI	King's Outcome Scale for Childhood Head Injury
LOC	Loss of consciousness
MCQ	Memory Complaints Questionnaire
MRI	Magnetic Resonance Imaging

PTA	Post-Traumatic Amnesia
RCH	Reykjavík City Hospital
Rural Iceland	Iceland except the Reykjavík area (urban Iceland)
SES	Socio-economic status
SG	Study group
SIA	The Icelandic Social Insurance Administration
SNC	Scandinavian Guidelines for the Initial Management of Minimal, Mild,and Moderate Head Injuries
TBI	Traumatic brain injury
THI	Traumatic head injury
TIH	Traumatic impact to the head
US	The United States of America
Urban Iceland	The Reykjavík area from Hafnarfjörður to Mosfellsbær and Kjalarnes

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LIST OF ORIGINAL PAPERS

This thesis is based on the following original publications, which are referred to in the text by their Roman numerals (I-V):

I. Arnarson, E.O., & Halldorsson, J.G. (1995). Head trauma among children in Reykjavik. *Acta Pædiatrica*, *84*, 96-99.

II. Halldorsson, J.G., Flekkoy, K.M., Gudmundsson, K.R., Arnkelsson, G.B., & Arnarson, E.O. (2007). Urban-rural differences in pediatric traumatic head injuries: a prospective nationwide study. *Neuropsychiatric Disease and Treatment*, *3*, 935-941.

III. Halldorsson, J.G., Flekkoy, K.M., Arnkelsson, G.B., Tomasson, K., Gudmundsson, K.R., & Arnarson, E.O. (2008). The prognostic value of injury severity, location of event, and age at injury in pediatric traumatic head injuries. *Neuropsychiatric Disease and Treatment*, *4*, 405-412.

IV. Halldorsson, J.G., Flekkoy, K.M., Arnkelsson, G.B., Tomasson, K., Magnadottir, H.B., & Arnarson, E.O. (2012). The scope of traumatic brain injury as a long-term health concern in two nationwide samples: Prevalence and prognostic factors. *Brain Injury*, *26*, 1-13.

V. Halldorsson, J.G., Arnkelsson, G.B., Tomasson, K., Flekkoy, K.M., Magnadottir, H.B., & Arnarson, E.O. (2013). Long-term outcome of medically confirmed and self-reported early traumatic brain injury in two nationwide samples. Accepted for publication in *Brain Injury*

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DECLARATION OF CONTRIBUTION

Paper I

JGH and his supervisor designed the study. JGH collected and analyzed the data and wrote the first draft of the manuscript. JGH was responsible for its revising in cooperation with his co-author.

Papers II-V

JGH planned and designed the studies and collected the data supervised by his supervisor and his doctoral committee. JGH was responsible for analyzing the data. JGH wrote the first drafts of the manuscripts and was responsible for its revising in cooperation with his co-authors.

1 INTRODUCTION

1.1 Background

There have been conflicting reports on the sequelae of pediatric ‘traumatic head injury’ (henceforth ‘traumatic brain injury’ (TBI)). In the early 20th century and up to the 1980s, several articles and textbooks on clinical psychology and psychiatry presented a favorable prognosis for pediatric TBI, except in the most severe cases (Beekman, 1928; Blau, 1936; Burkinshaw, 1960; Fabian, 1956; Flach & Malmros, 1972; Hjern & Nylander, 1964; Page, 1947; Pascucci, 1988; Vick, 1976). Children were supposed to recover faster and more fully from mild, moderate and severe TBI than adults (Beekman, 1928; Flach & Malmros, 1972; Heiskanen & Kaste, 1974; Pascucci, 1988), presumably due to anatomical differences (Fabian, 1956) and the assumed enhanced capacity of the young brain for adjustment and re-organization or compensation of function compared to the adult brain (Dennis, 2000; Harris, 1957). It was suggested that late complaints might often be influenced by non-injury, pre-morbid personality, adjustment or familial factors (Fabian, 1956) or litigation issues rather than being a direct consequence of brain injury (Blau, 1936; English, 1904). Reviewing the literature, there appears to have been a limited emphasis on long-term rehabilitation following pediatric TBI. Authors suggested that with proper rest, short-term physical training and encouragement recovery would take place in due course and often relatively soon (Beekman, 1928; Relander et al., 1972). More attention was paid to observable physical consequences than to the less evident mental or cognitive symptoms (English, 1904). Conservative treatment was recommended and medical personnel were advised to adopt an optimistic view and not to foster unwarranted concerns or distress in patients and their families (Beekman, 1928; DeVivo & Dodge, 1971; Relander et al., 1972).

However, there are reports from the early years of the 20th century, apparently representing a minority view at the time, on the seriousness of pediatric TBI for a child’s maturing brain. It was suggested that pathological changes in the brain caused by pediatric TBI disrupted developmental processes and could have significant long-term consequences. It was postulated that these pathological changes were no less extensive in the brains of children than in the brains of adults, and that permanent impairments were even more likely in the young brain than in the mature one due to its delicate structure and the complexities related to the development of intellectual functions (Blau, 1936; English, 1904).

From the late 1970s, with greater interest and with more rigorous research methods and psychometrics, growing evidence was observed supporting the claim that children did not show better recovery from the more severe TBI than adolescents or adults (Blau, 1936; Bruce et al., 1979; Costeff et al., 1990; Ewing-Cobbs et al., 1987; H. S. Levin et al., 1982). Reports indicated that children sustaining the more severe TBI often had long-term sequelae, and that even mild pediatric TBI sometimes had persistent symptoms (Boll & Barth, 1983; Johnson, 1992; Montgomery et al., 1991; Scharli & Weber, 1981). In the case of late symptoms, rehabilitation and specialized services based on the outcome of repeated neuro-psychiatric and neuropsychological evaluations were recommended (Caplan, 1982; Dalby & Obrzut, 1991; Fuld & Fisher, 1977; Obrzut & Hynd, 1987; Parmelee & O'Shanick, 1987; Selz & Reitan, 1979; Shaffer et al., 1980).

In the 1980s and the early 1990s the emerging literature suggested that pediatric TBI was a significant health concern and greater than previously acknowledged, affecting cognitive and physical factors, behavior and adjustment (Telzrow, 1987). Prospective, longitudinal, neuropsychological studies on representative samples were encouraged to collect accurate information on the incidence, prevalence and short-term and long-term consequences of early TBI (Jaffe et al., 1992; Klonoff et al., 1993; Klonoff & Robinson, 1967).

At this time, Iceland was no exception when it came to views on pediatric TBI. Apart from the most severe cases, there was limited knowledge regarding the consequences of pediatric TBI in Iceland or the need for a broad-based long-term rehabilitation. However, from the 1970s there was a strong interest among professionals and specialists in the field in following the emerging trends in research towards a greater understanding of pediatric TBI as a health concern and of the need for organized prevention, intervention, and rehabilitation in Iceland.

Kristinn R. Guðmundsson, neurosurgeon at Reykjavík City Hospital (RCH), collected and published information on children and adolescents diagnosed with TBI and admitted to RCH in the 1970s (1973-1980) (Gudmundsson, 1986).

The present author, in cooperation with Sævar Halldórsson, pediatrician at Landakot Hospital in Reykjavík, collected data on a small group of children with severe TBI that participated in a normative study of the Luria-Nebraska Neuropsychological Test Battery for Children in Iceland in 1982-1983 (Halldorsson, 1984).

In the late 1980s Eiríkur Örn Arnarson, the supervisor of the present research project, gathered centrally recorded retrospective data on children, adolescents and adults diagnosed with TBI in Iceland (Arnarson, 1989), as a participant in a Scandinavian collaboration of specialists on cognitive impairment and rehabilitation, organized by Kjell M. Flekkøy, Director of the Department of Neuropsychology and Rehabilitation at Ullevål University Hospital.

In co-operation with Eiríkur Örn Arnarson and Kristinn R. Guðmundsson, the present author published an article on the incidence of pediatric TBI based on retrospective patient data in Reykjavík from 1987-1991 (Halldorsson et al., 1993). The analyses served as a baseline for the Icelandic TBI (ICTBI) research project launched in 1992 by the present author, in co-operation with Kjell M. Flekkøy, Eiríkur Örn Arnarson and Kristinn R. Guðmundsson.

The ICTBI research project was planned as a prospective, multifaceted, longitudinal, neuropsychological study, aiming at collecting data on several aspects of pediatric TBI, including incidence, prevalence, neuropsychological outcome, short and long-term consequences and prognostic factors. The ICTBI research project was a pioneering effort in a country where limited research had been carried out in the field and basic information was lacking for organized goal-oriented prevention and intervention.

One of the factors that encouraged the initiation of the ICTBI research project in 1992 was an observed discrepancy: while the emerging literature presented the significance of pediatric TBI for public health, on average only 1-2 children received rehabilitation each year in the Reykjavík area in a population of approximately 42,000 children, and that the rehabilitation was mostly limited to short-term physical therapy. Organized cognitive rehabilitation was practically non-existent and the concept virtually unknown. While there was hope that the low number of children receiving rehabilitation reflected successful injury-prevention efforts of the 1980s, the emerging literature and the present author's clinical experience in the field of child neuropsychology suggested a more intricate and a less favorable explanation. The aim of the ICTBI research project was to assess the scope of early TBI as a health concern in Iceland, to explore the need for preventive efforts and dissemination of knowledge, to analyze the need for specialized intervention and follow-up, and to serve as a foundation for the development of services for children and adolescents suffering early and late sequelae of TBI.

1.2 Pediatric TBI

TBI is generally considered one of the main causes of morbidity and death in children, adolescents and young adults, more so among males than females (Emanuelson & v Wendt, 1997; Jennett, 1998; Kraus et al., 1986; Kraus & McArthur, 1996; Rivara, 1994; Zappala et al., 2012). In the majority of cases (88-95%), TBI is blunt (closed) but in other cases it may be penetrating (open), e.g. caused by a sharp object, breaching the cranium and the dura mater and injuring the underlying brain parenchyma and blood vessels. Compared to blunt TBI, penetrating TBI is considerably more likely to be fatal (Santiago et al., 2012).

Blunt TBI is caused by a forceful impact to the head leading to rapid acceleration, deceleration, and rotation of brain tissue. Laboratory studies in recent years have indicated that the forces involved elicit a cascade of pathohysiologic and neurometabolic changes in the brain. In the majority of cases, these changes seem to be temporary and recovery complete, but sometimes they may lead to axonal damage, structural irreversible changes to the brain parenchyma and to associated long-term symptoms, affecting physical and mental health, cognition, behavior, and adjustment (Bigler, 2008; Bigler & Maxwell, 2012; Giza & Hovda, 2001; Lux, 2007).

Excessive physical or mental strain or a second 'mild' pediatric TBI sustained during the recovery process may delay recovery and increase the risk of permanent damage and chronic symptoms (Bigler, 2008; Giza & Hovda, 2001). More severe TBI requires longer periods of rest from excessive strain and high TBI-risk activities (McCrea et al., 2009). Even when the brain has apparently reached previous levels of performance the energy needed to achieve and sustain such levels may be elevated, leading to reduction in cognitive capacity (McCrea et al., 2009). Repeated 'mild' pediatric TBIs, even though not close in time, may increase the risk of long-term sequelae (Lux, 2007; Prins & Giza, 2012).

Secondary brain damage following TBI may be caused by acute hemorrhage in the brain and cerebral meninges and cerebral edema leading to blood-brain barrier dysfunction, elevated intracranial pressure, ischemia and excessive axonal strain (Bowles et al., 2012; Greve & Zink, 2009).

Findings suggest that the developing brains of infants and young children are more sensitive to the adverse effects of severe TBI than the brains of older children and adolescents (Anderson et al., 2000; McKinlay et al., 2002; McKinlay et al., 2009a; McKinlay et al., 2009b) and that the consequences of the 'more severe' pediatric TBI may not be fully manifested until adulthood (Brooke, 1988; Eslinger et al., 1992; Jonsson et al., 2009; Levine et al., 2005). Evidence is lacking as to whether this age difference between infants and young children vs older children and adolescents holds for minimal or mild TBI (Carroll et al., 2004). However, reports indicate that the brains of children and adolescents are more sensitive to the adverse effects of 'mild' TBI or concussion than the adult brain (Giza & Hovda, 2001; Giza et al., 2009; Kirkwood et al., 2006; Prins & Giza, 2012).

Evidence has been presented which supports the hypothesis that early TBI, such as concussive and even frequent sub-concussive impacts, may increase the risk of changes in the brain that affect the cognitive reserve of individuals and accelerate age-related decline in cognitive functions later in life (Bigler & Maxwell, 2012; Broglio et al., 2012).

1.3 Forces involved in TBI

Even a mild force of impact to the head leads to movement of the brain. A magnetic resonance imaging (MRI) study has shown that the brain deforms slightly when the head falls 2 cm to a platform. The forces involved were equal to jumping vertically a few cm on a level ground, or 10-15% of heading a soccer ball, and far less than the forces required to cause concussion (Bayly et al., 2005; Bigler, 2008).

Reports suggest that the extent of axonal damage is an important contributing factor to the severity and outcome of TBI (Bigler, 2010; D. I. Graham & Lantos, 2002; Sharp & Ham, 2011). The movement and deformation of the brain causes strain on axons, blood vessels and the surrounding tissues. With increased force of impact to the head and the strain involved the risk of diffuse axonal injuries and the superimposing cerebral contusions and lacerations increases (Lux, 2007). Evidence suggests that the straining, shearing and deformation forces that are sufficient to cause axonal injuries also rupture blood vessels, leading to cerebral contusions (Bigler, 2010). Studies indicate that the signs of traumatic cerebral hemorrhages and contusions identified by cerebral computed tomography (CT) or MRI are markers of and associated with axonal injuries (Bigler, 2010). In theory, and with some support from recent research, the forces involved in the rapid acceleration-deceleration movement of the brain in motor vehicle crash whiplash injuries without any impact to the head may have the potential to cause damage to the brain parenchyma and the central nervous system (Freeman et al., 2010; Lux, 2007).

Pathological changes can occur in the brain following repeated impacts to the head within a short time interval, even if the blows do not have the force to lead to obvious symptoms of concussion, such as dizziness, disorientation, altered level of consciousness, confusion, nausea or somnolence. Amateur boxers who did not receive a knock-out punch or observed symptoms of concussion during a boxing contest nevertheless had increased levels of indicators of neuronal and astroglial injuries in their cerebrospinal fluid (CSF) compared to controls. The levels of those indicators were positively related to the number of hits to the head sustained during their contest (Bigler, 2008; Zetterberg et al., 2006).

The most severe blunt TBIs are seen when the force of impact to the head is strong, e.g. when the head hits a hard surface in a high-velocity motor vehicle collision (Lux, 2007). High-velocity TBIs have become more common in the past two centuries, among other things because of the advent of machines, advanced weaponry, motor vehicles and relatively tall buildings and structures. In evolutionary terms, the mammalian brain may be more adapted to withstand mild concussion than the more severe TBI associated with the technological advances of modern times (Bigler, 2008).

Certain parts of the brain seem to be especially vulnerable to the forces of TBI, such as the upper brainstem, fornix, corpus callosum, hippocampus, caudate nucleus, amygdala, hypothalamic-pituitary axis, anterior commissure, basal forebrain, orbitofrontal cortex and the medial temporal lobe (Bigler, 2008; Lux, 2007; Zappala et al., 2012). Symptoms attributed to TBI and related to consciousness, sleep, memory and learning, working memory, concentration and stamina, processing speed, initiative, impulsivity, emotion and adaptation, may reflect impaired functions of those parts of the brain, white matter axonal bundles, tracts and pathways (Lux, 2007; Zappala et al., 2012).

1.4 Estimating acute severity and prognosis of pediatric TBI

It is important to estimate accurately the severity of pediatric TBI in the acute phase, as appropriate early intervention may aid the recovery processes and improve the outcome (Chevignard et al., 2010; Galbiati et al., 2009; Kirkwood et al., 2008; Ponsford et al., 2001). Several criteria have been used to classify the severity of TBI. One of them is the Head Injury Severity Scale (HISS (see Appendix 2)) adopted by the Icelandic Directorate of Health.

The chronic, debilitating and sometimes devastating sequelae of severe pediatric TBI are well documented. In the acute phase, the more severe or complicated TBI may be inferred by clinical indicators, such as Glasgow Coma Scale (GCS (see Appendix 2)) scores (G. Teasdale & Jennett, 1974), length of loss of consciousness (LOC) or post-traumatic amnesia (PTA), focal neurologic signs or positive cerebral CT or conventional MRI findings. ICD diagnoses (WHO, 1992), classification of TBI severity, and decisions regarding acute medical or neurosurgical intervention and the need for hospitalization or intensive care, as well as follow-up may be based on those findings.

A majority of pediatric TBIs is ‘minimal’ or ‘mild’ and the recovery relatively quick and apparently complete. However, reports suggest that in some cases there can be long-term sequelae, indicating underestimation of acute TBI severity. As ‘minimal’ or ‘mild’ TBIs are relatively common, the number of children and adolescents complaining of late symptoms following such injuries may be substantial (Ayr et al., 2009).

Estimating accurately the severity of pediatric TBI at emergency departments (EDs) can be challenging due to lack of information on the pathophysiologic and neurometabolic changes taking place in the brain, incomplete or inadequate clinical data and different and less prominent symptoms or responses to TBI in infancy, toddlerhood and childhood compared to adolescence and adulthood (Bernardi et al., 1993; Greenes & Schutzman, 1998; Quayle et al., 1997; Savitsky & Votey, 2000; Schutzman et al., 2001).

Emergency personnel have to rely on clinical signs and symptoms, GCS scores, length of LOC or PTA, neurological evaluation, and, in selected cases, conventional cerebral CT and MRI findings. Those indicators of acute severity may not reflect accurately the extent, nature, and short and long-term prognosis of TBI, especially in the case of ‘mild’ TBI (Bailey et al., 2011; Beauchamp et al., 2011; Dietrich et al., 1993; Kan et al., 2012; Powell et al., 2008; Sharp & Ham, 2011; Zappala et al., 2012).

Head CT serves well in the acute phase following TBI, e.g. in identifying skull fractures and serious or life threatening medical complications, such as intra-cranial cerebral hemorrhage requiring immediate surgical intervention. In the more severe cases CT may also show signs of cerebral contusions and lacerations (Beauchamp et al., 2011; Bigler, 2010; Zappala et al., 2012).

However, cerebral CT has limited sensitivity to the pathological changes in the brain following TBI responsible for clinical consequences related to cognition, behavior and adaptation (Beauchamp et al., 2011). Cerebral CT has been found to underestimate diffuse axonal injuries and correlate poorly with late cognitive symptoms and functional outcome (Ashwal et al., 2006; Beauchamp et al., 2011; Bigler, 2001; Chan et al., 2003; Chastain et al., 2009; Dietrich et al., 1993; Huisman et al., 2004; Lee et al., 2008; Quayle et al., 1997; Sigmund et al., 2007). Negative cerebral CT findings do not exclude parenchymal injuries or petechial hemorrhages (Bigler, 2010).

In the past decade, awareness of the degree of radiation exposure and sedation involved, has called for a more conservative use of CT, especially in the case of infants and children. The use of cerebral CT and other imaging techniques may also be affected by cost and cost-effectiveness (Beauchamp et al., 2011).

MRI is more sensitive to TBI-related changes, such as cerebral contusion and hemorrhage than CT. However, like CT, conventional MRI findings have been found to underestimate diffuse axonal injury and correlate poorly with late cognitive symptoms and functional outcome (Chan et al., 2003; Huisman et al., 2004; Lee et al., 2008; Sharp & Ham, 2011).

Newer, more sophisticated imaging techniques, such as susceptibility weighted imaging (SWI), diffusion weighted imaging (DWI) and diffusion tensor imaging (DTI), are more sensitive to white-matter damage or traumatic axonal injury (Beauchamp et al., 2011; Huisman et al., 2004; Lee et al., 2008; Sharp & Ham, 2011; Zappala et al., 2012). However, these imaging techniques may not be available in acute clinical settings.

More accurate biomarkers for the early assessment of TBI severity and outcome are needed.

The shortcomings of early assessment of TBI severity and prognosis are reflected in findings indicating that medical follow-up is in general limited and inadequate, especially in the case of apparently 'milder' pediatric TBI and cognitive sequelae (Greenspan & MacKenzie, 2000; Powell et al., 2008; Slomine et al., 2006). A report from the US Committee on Trauma Research published in 1985 estimated that only one person in 20 with TBI received appropriate rehabilitation services (CTR, 1985; Greenspan & MacKenzie, 2000).

The most debilitating consequences of pediatric TBI are related to cognition, social adaptation and emotion (Zappala et al., 2012). Studies have indicated the importance of intervention, support, therapy and rehabilitation addressing those factors. Untreated, these problems may lead to delayed recovery and poorer outcome. Underestimating TBI severity and possible consequences may thwart efforts to seek pecuniary damages for TBI-related disability (Powell et al., 2008).

1.5 Factors that predict late outcome of pediatric TBI

Several factors may have prognostic value for late outcome of early TBI: (1) injury related variables, such as GCS score, PTA, LOC, hospitalization, neurological or neuroradiological findings, and TBI severity categorized according to varied criteria; (2) demographic variables, such as age at injury, gender, urban/rural residence, and socio-economic status (SES); (3) pre-morbid factors, e.g. related to cognition, behavior and adjustment; and (4) non-TBI-related post-morbid variables, such as mental and physical health and compensation issues. Further research is needed regarding the prognostic value and interrelationship of these TBI-related variables and moderating factors, especially in the case of young children and 'mild' TBI.

1.5.1 Severity of TBI

TBI severity is linked to outcome. There is, however, no universally accepted definition of 'minimal', 'mild', 'moderate' or 'severe' TBI based on medical findings in the acute phase. The Nordic Countries have adopted the HISS (Stein & Spettell, 1995) and the Scandinavian Guidelines for the Initial Management of Minimal, Mild, and Moderate Head Injury (SNC (see Appendix 2)) (Ingebrigtsen et al., 2000). The HISS, based on GCS scores, length of LOC or amnesia and neurological evaluation outcome, allows for a more detailed differentiation of TBI in the milder range than some other definitions, such as the classification proposed by the WHO Task Force (Borg et al., 2004; Carroll et al., 2004) (see Appendix 2). As indicated earlier, force of impact to the head and a history of previous TBI should be included when estimating the severity of early TBI.

1.5.2 Age at injury

The assumption that young children recover better from TBI than older individuals because of functional plasticity has not been substantiated. Pediatric traumatic brain damage disrupts normal maturation and development, and neuronal plasticity may not always lead to an optimal outcome (Chapman & McKinnon, 2000; Giza & Prins, 2006). Studies have indicated that young children may be more vulnerable to the consequences of severe TBI for cognition, behavior, and adjustment than older children and adolescents (Anderson et al., 2000; McKinlay et al., 2002; McKinlay et al., 2009a; McKinlay et al., 2009b). In some instances children may experience increasing problems with age, but in other cases the declining trend may level off and give way to developmental gains (Anderson et al., 2009; Jonsson et al., 2004; Levine et al., 2005). Information on the prognosis of mild TBI in infants and very young children is lacking (Carroll et al., 2004). A review of concussion in sports has indicated that children may be more vulnerable to the pathological effects of sports-related concussion and repeated TBI than older athletes (Kirkwood et al., 2006).

1.5.3 Gender

Boys are at greater risk of sustaining TBI than girls (Kraus et al., 1986; Langlois et al., 2006; Rivara, 1994). However, the findings are inconclusive regarding if there is a gender-related effect on recovery following TBI. A study published in 1998 reported that in an in-patient rehabilitation program for children, adolescents and adults with severe brain injury, female patients had a better outcome at discharge than male patients (Groswasser et al., 1998). More recent findings have suggested that when controlled for injury severity, girls may be more likely to report post-concussion symptoms following TBI than boys (Taylor et al., 2010), but that there may be no gender effect on the course of recovery and outcome (Renner et al., 2012).

1.5.4 Urban/rural residence

Reports suggest that young people in rural areas may be at a greater risk of sustaining non-fatal and fatal injuries compared to their peers in urban areas (Eberhardt & Pamuk, 2004; Reid et al., 2001; Stefansdottir & Mogensen, 1997; Stefansdottir et al., 1992; Triebel et al., 1998; Vane & Shackford, 1995; Zietlow & Swanson, 1999), possibly due to cultural, socio-economic, and environmental factors and delayed emergency services. The same may be true for the more severe and fatal TBI (Gabella et al., 1997; Reid et al., 2001). It is unclear, however, whether the same applies to minimal, mild or moderate pediatric TBI.

1.5.5 Pre-morbid health and adjustment, cognitive reserve, parental SES, and family variables

Studies have indicated that children with pre-morbid neuropsychiatric and behavioral problems may be at greater risk of post-concussion symptoms and psychiatric disorders following TBI than well adjusted children with good cognitive functioning (Bigler, 2008; Brown et al., 1981; Gerring et al., 2002; Karzmark et al., 1995; Kirkwood et al., 2008; Ponsford, 2005; Schachar et al., 2004; Slomine et al., 2006). Socio-economic factors may also have a moderating influence, as studies have suggested that children and adolescents from families with greater emotional and financial resources recover better and show better outcome following TBI (Taylor et al., 2002; Yeates et al., 1997). There is, however, also a recent study indicating the opposite (Yeates et al., 2012), suggesting a complex interaction.

1.5.6 Post-morbid non-TBI-related factors

Depressive symptoms following TBI have been found to delay the recovery process and lead to poorer outcome, suggesting the need for appropriate intervention (Draper et al., 2007; Mooney et al., 2005). Ongoing evaluation for compensation has been found to delay recovery (Bigler, 2008; Mooney et al., 2005), and possibly affect results of studies on mild TBI or concussion.

1.6 Methods to assess long-term pediatric TBI-related symptoms and consequences

A combination of quantitative and qualitative neuropsychological evaluation may be used to map neuropsychological strengths and weaknesses following ‘moderate’ or ‘severe’ pediatric TBI, e.g. for the purposes of intervention and rehabilitation (Caplan, 1982; Dalby & Obrzut, 1991; Fuld & Fisher, 1977; Lezak, 1995; Obrzut & Hynd, 1987; Parmelee & O'Shanick, 1987; Selz & Reitan, 1979; Shaffer et al., 1980). To increase the ecological validity of results, neuropsychological tests may be supplemented by specialized assessment in real-life situations or by clinical scales filled out by caregivers or significant others (Chaytor & Schmitter-Edgecombe, 2003; Chaytor et al., 2006; Gioia & Isquith, 2004). However, several years post-injury in large groups with predominantly ‘minimal’ or ‘mild’ TBI where most participants are either adolescents or young adults not receiving specialized intervention for TBI-related sequelae, self-report questionnaires and clinical outcome scales may be a practical approach.

1.7 Incidence of pediatric TBI

At a given point in time, each geographical area may have its special TBI-incidence characteristics related to environmental and cultural factors.

Accurate information on the nationwide incidence and prevalence of pediatric TBI and its severity and outcome is important for preventive purposes and for health care planning and intervention services. Such information is lacking, however, in part due to TBI not brought to medical attention (Setnik & Bazarian, 2007; Sosin et al., 1996), unavailable or inaccurate medical records (Moss & Wade, 1996; Powell et al., 2008; Sosin et al., 1996; Summers et al., 2009), and paucity of high-quality, well-defined, follow-up studies on representative samples (Cassidy et al., 2004; Tagliaferri et al., 2006).

It may be assumed that many children and adolescents who sustain TBI, especially mild TBI, are not brought to medical attention. Little is known about the scope of non-reported pediatric TBI, and this scope may vary, e.g. according to age, gender, SES, geographical region, and access to health care services. An interview-based survey in the US in 1991 found that 25% of a mixed sample of children, adolescents, and young adults with TBI had not sought medical care for their injury (Sosin et al., 1996). A more recent web-based survey indicated that 42% of adolescent and adult respondents who reported having sustained TBI had not subsequently sought medical attention (Setnik & Bazarian, 2007). Failing to seek medical care was associated with older age, mild TBI, and sustaining TBI in the home.

Even when children and adolescents who sustain TBI are brought to medical attention, diagnosis may not be recorded in medical files or databases that researchers rely on when estimating the incidence of TBI. In the US information on the estimated 14% of patients with TBI that are treated at private clinics or physicians' offices may never reach such databases (Sosin et al., 1996; Summers et al., 2009). In addition, studies in the US have found that in 56% of mild TBI cases the TBI diagnosis may not be documented in ED records (Powell et al., 2008), and that the same may be true for 51% of patients with TBI admitted to trauma wards. The latter may be related to the presence of other injuries or to the TBI being considered minor or of little significance (Moss & Wade, 1996).

Bearing these limitations in mind, reports from western countries in the 1980s estimated the annual incidence of pediatric head and spinal trauma treated at EDs at 980-1,170 per 100,000 population (Davidson & Maguin, 1984; Nathorst Westfelt, 1982), the incidence of TBI admitted to hospital at 171-262 per 100,000 (Horowitz et al., 1983; Kraus et al., 1986; SINTEF, 1989; Slutenvårdsregisteret, 1988), the incidence of the more severe TBI at 26-30 per 100,000 (A. W. Engberg & Biering-Sorensen, 1990; Horowitz et al., 1983; Kraus et al., 1986), and death due to brain injury at 3-10 per 100,000 (Horowitz et al., 1983; Kraus et al., 1986).

More recently it has been estimated that the overall annual incidence of medically diagnosed pediatric TBI may be 600-900 per 100,000 (Cassidy et al., 2004; Langlois et al., 2005; McKinlay et al., 2008; Rutland-Brown et al., 2006), and the annual incidence of pediatric TBI leading to hospital admission 100-300 per 100,000 (Bruns & Hauser, 2003; Cassidy et al., 2004; A. Engberg & Teasdale, 1998; Hawley et al., 2003; Kraus et al., 1986; Winqvist et al., 2007). In the US, studies have reported a decrease in hospitalizations in the case of pediatric TBI, or to as little as 70 per 100,000 (Bowman et al., 2008; Langlois et al., 2005; Rutland-Brown et al., 2006; Schneier et al., 2006). The reduction has mainly occurred in the frequency of hospitalization in cases of mild TBI, while the annual incidence of hospitalized non-fatal moderate-severe pediatric TBI has remained relatively stable from 1991 to 2005 (28-36 per 100,000) (Bowman et al., 2008). The incidence of TBI-related fatalities following hospitalization has been estimated at 3 per 100,000 (Bowman et al., 2008). In the past decade in the US, an increase has been reported in the incidence of pediatric and adult 'minimal' and 'mild' non-hospitalized TBI treated at EDs (Powell et al., 2008). In part, this may reflect the lower incidence of hospitalizations of 'mild' TBI.

During the period from 1974 to 1991, the annual incidence of pediatric traumatic injuries in Iceland was higher than the incidence rates reported in the Scandinavian countries (Stefansdottir et al., 1992). Children and adolescents in rural Iceland were at greater risk of fatal injuries than their peers in the Reykjavík area (Stefansdottir et al., 1992). These findings gave rise to questions regarding the incidence of pediatric TBI in Iceland compared to the neighboring countries and in rural areas compared to urban areas.

1.8 Prevalence of pediatric TBI and TBI-related disability

Less is known about the prevalence of TBI in young age than its incidence. 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 (McKinlay et al., 2008; McKinlay et al., 2010). Two studies on adolescents, using self-report questionnaires, have reported 31% and 41% prevalence of TBI respectively (Body & Leathem, 1996; Segalowitz & Brown, 1991). Also based on self-report, higher prevalence has been described in samples of young university athletes, 63% for soccer players and 70% for American football players (Delaney et al., 2002). As regards the more severe TBI, the estimated prevalence of TBI leading to hospital admission in the young adult population has been estimated 4-12% (Corrigan et al., 2010; McKinlay et al., 2008; Winqvist et al., 2007). Regarding TBI outcome, it has been estimated that the overall prevalence of living with long-term TBI-related disability is 0.3-

2% (Corrigan et al., 2010; Langlois et al., 2006; Summers et al., 2009; Tagliaferri et al., 2006; Winqvist et al., 2007; Zaloshnja et al., 2008).

1.9 The structure and points of emphasis of the present series of the ICTBI research project

The ICTBI research project was designed to meet the need for a nationwide, longitudinal, neuropsychological study on the scope of pediatric TBI as a health concern, its severity, incidence, prevalence, sequelae and prognostic factors. Prior research on pediatric TBI in Iceland was limited, and research projects of similar design were few in the international context.

The present series of the ICTBI research project includes five papers. **Paper I** is based on a retrospective incidence study of the 359 children diagnosed with TBI and admitted to RCH during the five-year period 1987-1991. **Paper II** is based on a prospective nationwide incidence study of all children and adolescents diagnosed with TBI in Iceland from 15 April 1992 to 14 April 1993 (n = 550) (the ICTBI study group (SG)). **Paper III** is based on a prospective study of a subsample of the ICTBI SG on the sequelae of TBI four years post-injury. **Papers IV** and **V** are based on a study of the ICTBI SG approximately 16 years post-injury on the late sequelae of early TBI and predictive factors. Included is a control group (CG), selected in 2008 from the Icelandic National Registry (n = 1,232). The layout, or structure, of the present series of studies of the ICTBI research project is shown in Figure 1.

The research project originated at a time when there was an increasing emphasis in the emerging literature on the potential seriousness of pediatric TBI and the need for longitudinal research efforts on representative samples to collect accurate information on its incidence, prevalence and short-term and long-term consequences to guide prevention and intervention.

In Iceland, there was a need for information on the incidence of minimal, mild, moderate and severe pediatric TBI in early and late childhood and adolescence and in urban and rural areas. Little was known about the long-term sequelae of pediatric TBI, or which variables best predicted late outcome. The need for rehabilitation was unclear and the information required to establish priorities in goal-oriented pediatric TBI prevention was insufficient.

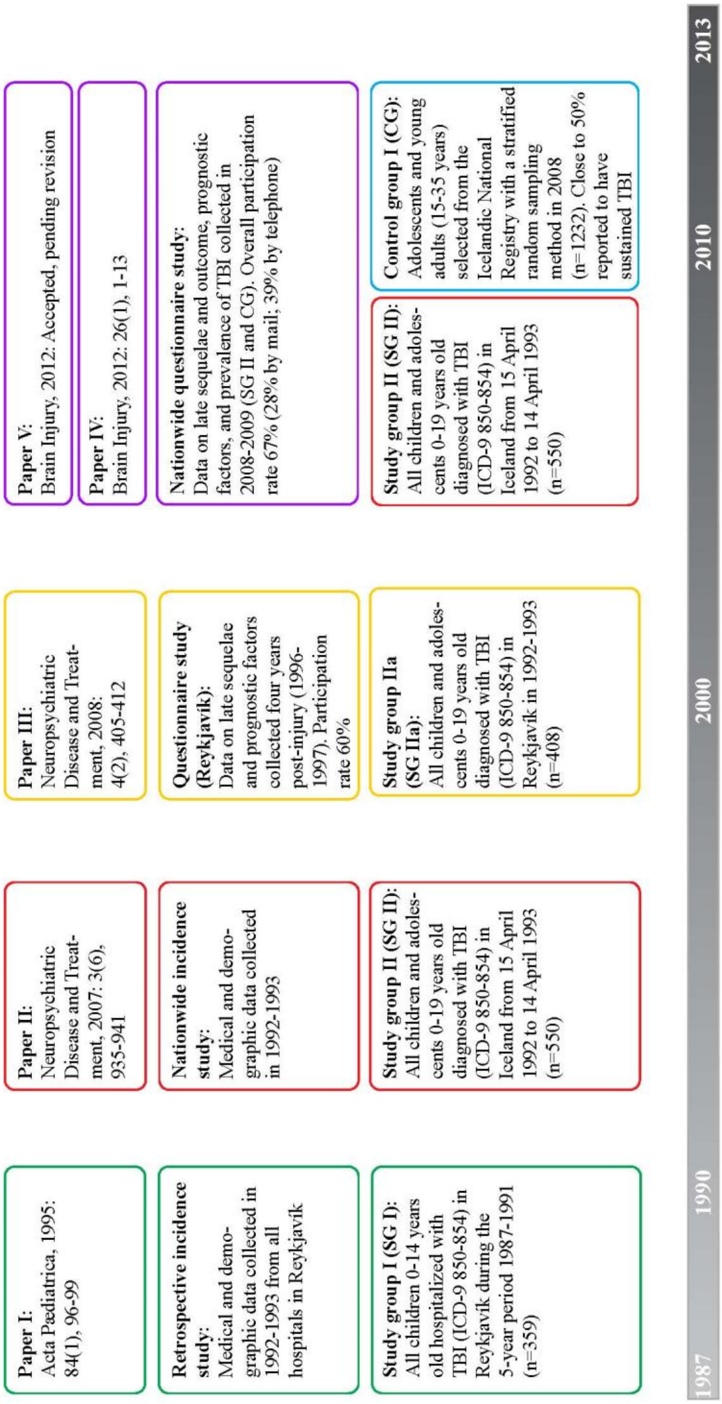

Figure 1**. The main structure of the ICTBI research project.**

In the past two decades from the launching of the ICTBI research project, there has been growing interest in pediatric TBI-research. However, as indicated in the review above, there are still several controversies and uncertainties in the field and a lack of more accurate information, e.g. related to the incidence of pediatric TBI, the prevalence of early TBI and TBI-related disability, the sequelae of 'mild' TBI in very young and young age, and TBI-related, neuropsychiatric and demographic factors predicting long-term consequences.

The number of 'minimal' or 'mild' pediatric TBI treated at EDs, the pathophysiologic and neurometabolic changes in the developing brain caused by impact to the head, the problems related to assessing accurately the severity of pediatric TBI in the acute phase, and the general lack of awareness, intervention, rehabilitation and follow-up, suggest the wide scope of early TBI as a health concern and the need for further research.

The primary objectives of the present thesis were: (1) to estimate the incidence and prevalence of pediatric TBI and TBI-related consequences in urban and rural areas and nationwide in Iceland (**Papers I**-**IV**); (2) to study the long-term consequences of early TBI in two independent nationwide samples (**Papers III**-**V**); and (3) to assess the prognostic value of injury-related and non-injury-related factors for late outcome (**Papers III**-**V**).

1.10 Incidence of TBI in children in Reykjavík 1987-1991 (Paper I)

At the time of data collection in 1992-1993, the aim of this retrospective study was to collect data on the annual incidence, severity and causes of hospitalized pediatric TBI in Reykjavík during the five-year period 1987-1991, and to compare the results to earlier (and later) findings in Iceland and other countries. In spite of the increased emphasis on injury prevention in the 1980s, the annual incidence of pediatric injuries in Iceland was relatively high compared to the Scandinavian countries. There were uncertainties regarding the reasons for the low number of children receiving rehabilitation, i.e. whether it was related to few moderate/severe TBIs or an underestimation of the need for intervention. The data collected on TBI-severity, causes, and age and gender distribution were important for the planning of goal-oriented preventive efforts.

1.10.1 Research questions of Paper I

1. What is the average annual incidence of pediatric TBI in Reykjavík by TBI severity?

2. Are there age and gender differences in the incidence of pediatric TBI?

3. How does the incidence compare to earlier incidence rates reported in Iceland and abroad?

4. What are the causes of pediatric TBI?

5. Does the rehabilitation effort match the need?

1.11 Urban-rural differences in pediatric TBI (Paper II)

At the launch of the ICTBI research project in 1992, there were few, if any, reports available on nationwide incidence rates of pediatric TBI. Findings suggested that the incidence of non-fatal and fatal injuries were more common in rural areas than in urban areas. Whether the same was true in the case of early TBI was not as clear. As in **Paper I**, the information collected was important for intervention and prevention purposes. The results of **Paper I** provided support for the representativeness of the one-year incidence rates reported in **Paper II**.

1.11.1 Research questions of Paper II

1. What is the one-year nationwide incidence of pediatric TBI by TBI-severity?

2. Are there age and gender differences in the incidence of pediatric TBI?

3. Are there urban-rural differences in the incidence of pediatric TBI?

4. How does the incidence compare to earlier incidence rates reported in Iceland and abroad?

5. Does the rehabilitation effort match the need?

1.12 Prognostic value of TBI-related and demographic variables (Paper III)

As indicated earlier, few children and adolescents received rehabilitation each year in Iceland, and the rehabilitation effort was mainly limited to short-term physiotherapy, suggesting quick recovery. Thus, it was of interest to collect information on the number of individuals four years post-injury still reporting symptoms attributed to the early TBI. Information on late sequelae and prognostic TBI-related and demographic factors was important for the planning of early intervention for young patients with TBI. More detailed TBI-data (e.g. related to causes, location, and severity of TBI) were available on the group of patients treated in the Reykjavík area, as compared to the patients treated in rural areas. This was one of the reasons for limiting the study to the former group. The findings as regards late sequelae were mainly based on parental report, as most participants were children and young adolescents.

1.12.1 Research questions of Paper III

1. How many participants report symptoms attributed to TBI sustained four years earlier?

2. Which TBI-related and demographic variables predict late complaints?

1.13 Prevalence of early TBI and its sequelae and prognostic factors (Paper IV)

Early TBI can have life-long consequences, suggesting the importance of longitudinal studies and long-term follow-ups. Such studies may provide information on the scope of late sequelae, prognostic factors and the need for intervention and rehabilitation at different stages during the recovery process. The present follow-up was mainly based on self-reporting, as most participants were now older adolescents or young adults. The newly selected CG provided a unique opportunity to collect information on the prevalence of TBI and TBI-related sequelae in a nationwide general population sample.

1.13.1 Research questions of Paper IV

1. How many participants report TBI-related symptoms 16 years post-injury?

2. What is the prevalence of early TBI and TBI-related disability in a nationwide general population sample?

3. Which TBI-related and demographic variables predict late outcome?

4. Were participants reporting TBI-related disability awarded or evaluated for compensation?

1.14 Long-term sequelae of early TBI assessed by clinical outcome scales (Paper V)

The main objective of the follow-up study 16 years post-injury was to gain information on the scope of early TBI as a health concern. **Paper IV** presented results regarding symptoms attributed to early TBI. **Paper V** added to the previous findings by assessing the clinical relevance of these self-reported complaints, using clinical outcome scales.

1.14.1 Research questions of Paper V

1. Are self-reported late symptoms attributed to early TBI reflected in results on clinical outcome scales?

2. Which TBI-related and demographic variables predict results on clinical scales?

3. In the ICTBI SG, is non-reporting of early TBI reflected in better outcome?

4. In the group with TBI-related disability, is not being evaluated for compensation reflected in better outcome?

2 MATERIAL AND METHODS

Paper I is based on incidence data that were collected retrospectively in 1992-1993 on the 359 children 0-14 years old diagnosed with TBI (ICD-9 850-854 (see Appendix 2)) and admitted to hospital in Reykjavík during the five-year period 1987-1991 prior to the implementation of the prospective ICTBI research project. **Papers II-V** are based on the ICTBI research project. The total ICTBI SG (n = 550) provided information on the nationwide incidence of pediatric (0-19 years old) TBI during the one-year period from 15 April 1992 to 14 April 1993 (**Paper II**). The sub-group treated in the Reykjavík area (n = 408) was followed-up with a questionnaire 4 years post-injury (**Paper III**) evaluating TBI sequelae and prognostic factors. The total SG participated in a questionnaire study 16 years post-injury together with a newly selected CG (n = 1,232) (**Papers IV** and **V**) assessing the scope of early TBI as a long-term health concern.

As neither CT scanners nor neurosurgical departments were available outside Reykjavík in 1992-1993, all participants of the ICTB SG suspected of moderate/severe TBIs were transported and admitted to RCH in accordance with national guidelines. In addition to the five studies presented here, the 62 patients admitted to RCH, as well as an equal number of controls, were evaluated using neuropsychological measures 6 months, 6 years and 17 years post-injury. Analyses of the neuropsychological data have not been completed and are not included in the present series of studies.

2.1 Paper I

2.1.1 Material and methods

Paper I is based on a retrospective incidence study on pediatric TBI in Reykjavík during the five-year period preceding the implementation of the prospective ICTBI research project in 1992 (Arnarson & Halldorsson, 1995; Halldorsson et al., 1993). The results of the study serve as a baseline and increase the reliability of subsequent findings.

This incidence study included all 359 children 0-14 years old who were admitted to hospital in Reykjavík with TBI diagnosis (ICD-9 850-854) during the five-year period 1987-1991. The estimated number of children receiving rehabilitation because of TBI-related symptoms was based on length of hospitalization and admissions to rehabilitation centers in and around Reykjavík during the same period.

Information was collected retrospectively in 1992-1993 from computerized medical records and archives of the three hospitals in Reykjavík, Reykjavík City Hospital, Landspítali University Hospital and Landakot Hospital. Patient data included TBI-diagnosis and acute severity estimates, cause of TBI, length of hospitalization and admission to intensive care, age at injury and gender.

Incidence rates were calculated based on number of patients and the population at risk in the Reykjavík area. The results were compared to other incidence studies in Iceland and abroad.

2.1.2 Results and discussion

During the five-year period 1987-1991, 359 children 0-14 years old diagnosed with TBI (ICD-9 850-854) were admitted to hospital in Reykjavík, or on average 71.8 each year (Table 1). Of those, 13.9% (n = 50) had received the more severe TBI as indicated by ICD-9 diagnoses 851-854 and 4.7% (n = 17) were admitted to intensive care. The average annual number of mild TBI (ICD-9 850) was comparable across the three age groups (n = 21-28). During the five-year period, the total number of the more severe TBIs (ICD-9 851-854) was evenly distributed across age groups (n = 15-18).

On average, 1-2 children died from the consequences of brain injury each year. Annually, 1-2 children with TBI received rehabilitation, mostly in the form of short-term physiotherapy. Of the total group, boys were 62.4% and girls 37.6%. Boys were more likely to receive the more severe non-fatal TBIs compared to girls (74.0% vs 26.0% respectively). Fatal TBIs were more common among girls, most likely due to a random effect in a small group. Falling was the most common cause of TBI in the two younger age groups combined (74.6%). Traffic and sport-related incidents and unintentional blows became more common with age and reached 62.1% of all TBI-incidents in the oldest age group (Table 2).

Table 1. Number of 0-14 year old children with TBI (ICD-9 850-854), by age, gender and ICD-9 diagnosis, admitted to the three hospitals in Reykjavík (Reykjavík City Hospital, Landspítali University Hospital, and Landakot Hospital) during the five-year period 1987-1991

	0-4 years old		5-9 years old		10-14 years old		
Diagnosis (ICD-9)	Boys	Girls	Boys	Girls	Boys	Girls	Total (%)
Concussion / commotion cerbri (850)	60	38	69	56	58	28	309 (86%)
Cerebral laceration / contusion (851)	2	3	8	1	6	1	21 (5%)
Hemorrhage in cerebral meninges (852)	6	1	3	2	3	2	17 (5%)
Other intracranial hemorrhage (853)	3	1	1	0	1	0	6 (2%)
Other intracranial injury (854)	1	1	0	0	3	1	6 (2%)
Total (%)	72 (20)	44 (12)	81 (23)	59 (16)	71 (20)	32 (9)	359 (100%)

Table 2. Causes of TBI (ICD-9 850-854) by age and gender, among 0-14 year old children in the Reykjavík area during the five-year period 1987-1991

	0-4 years old		5-9 years old		10-14 years old		
Cause	Boys	Girls	Boys	Girls	Boys	Girls	Total (%)
Falls	56	40	55	40	20	11	222 (62%)
Traffic incidents	10	3	14	9	26	7	69 (19%)
Unintentional blows	5	1	8	7	12	5	38 (11%)
Sports	0	0	1	0	7	7	15 (4%)
Intentional blows	1	0	0	2	1	1	5 (1%)
Other	0	0	3	1	5	1	10 (3%)
Total	72	44	81	59	71	32	359 (100%)

During the five-year period 1987-1991, the average annual incidence of pediatric TBI (ICD-9 850-854) leading to hospitalization (1.70 per 1,000), the incidence of the more severe TBI (ICD-9 851-854) (0.28 per 1,000), and the incidence of fatal TBI (0.03 per 1,000) was comparable to corresponding incidence rates reported in the neighboring countries (Davidson & Maguin, 1984; A. W. Engberg & Biering-Sorensen, 1990; Guldvog et al., 1992; Horowitz et al., 1983;

Kraus et al., 1986; Nathorst Westfelt, 1982; SINTEF, 1989; Slutenvårdsregisteret, 1988) (Table 3).

The average annual incidence of pediatric TBI leading to hospitalization in Reykjavík in 1987-1991 was comparable to the corresponding incidence reported in Kristinn R. Guðmundsson's study for the period 1973-1980 (Gudmundsson, 1986) (1.70 and 2.00 per 1,000, respectively). However, the ratio of patients admitted to intensive care was significantly lower (5% vs. 20%) ($p < .005$), presumably indicative of fewer patients with severe TBI. Compared to 1973-1980, the age distribution of patients had changed. Overall, there was a decrease in the percentage of patients in the two older age groups (5-14 years) combined (from 76% to 68%), and a corresponding increase in the percentage of patients in the youngest age group 0-4 years old (from 24% to 32%). In 1987-1991 the ratio of patients with the more severe TBIs (ICD-9 851-854) was slightly higher in the youngest and the oldest age groups (16% and 17% respectively) than in the age group 5-9 years old (11%).

Table 3. The average annual incidence rates per 1,000 population for pediatric traumatic injuries (TI) and traumatic brain injuries (TBI). Results from studies in Iceland and in six other countries

	Type of injury				
Country	TI at EDs	TBI and spinal trauma at EDs	TBI admitted to hospital	Severe TBI	Fatal TBI
Reykjavík, Iceland 1973-1980	299[a]		2.00[b]	0.40[b]	0.03[b]
Reykjavík, Iceland 1987-1991	264[c]	11.0[d]	1.70[d]	0.28[d]	0.03[d]
USA			1.85[e]	0.27[e]	0.10[e]
Israel			1.71[f]	0.26[f]	0.03[f]
Norway	125[g]		2.34[h]		
Sweden	143[i]	9.8[i]	2.62[j]		
France		11.7[k]			
Denmark				0.30[l]	

[a]Reykjavík City Hospital, emergency department 1974-1991 (Stefansdottir et al., 1992); [b]Reykjavík City Hospital, Neurosurgical Ward 1973-1980 (Gudmundsson, 1986); [c]Reykjavík City Hospital, emergency department 1991 (Stefansdottir et al., 1992); [d]Present study (**Paper I**); [e]San Diego County 1981 (Kraus et al., 1986); [f]Israel 1970-1976 (Horowitz et al., 1983); [g]Norway 1992 (Guldvog et al., 1992); [h]Norway 1989 (SINTEF, 1989); [i]Göteborg 1975-1976 (Nathorst Westfelt, 1982); [j]Sweden 1988 (Slutenvårdsregisteret, 1988); [k]France 1981 (Davidson & Maguin, 1984); [l]Denmark 1990 (A. W. Engberg & Biering-Sorensen, 1990).

The decrease in admissions to intensive care indicated that in spite of increased motor vehicle traffic and more traffic-related incidents there were fewer patients with severe TBI. It was proposed that the decrease in the more severe TBIs might be due to preventive efforts, such as increased use of high visibility reflectors, safety seats and restraints in cars, and safety helmets, e.g. for bicycling and horse-riding. The findings suggested that injury prevention had been more effective in the older age groups than in the youngest, 0-4 years old, stressing the need for parental supervision and safer environment for infants, toddlers, and young children.

According to Danish estimates (A. W. Engberg & Biering-Sorensen, 1990), children with TBI receiving rehabilitation and follow-up were far fewer than expected (19 vs 1-2 children). In addition, evidence suggested the need for a broad-based, long-term intervention addressing cognitive, adaptive, and emotional factors, as well as physical factors (Brooke, 1988; H.S. Levin et al., 1989).

2.1.3 Limitations

The study was retrospective, which may have led to underestimation of incidence rates.

2.1.4 The most important contributions

Findings suggested a decrease in the incidence of the more severe TBI in Reykjavík, as compared to the 1970s. Injury prevention appeared to have been least effective in the youngest age group. The incidence of pediatric TBI leading to admission to hospital, the more severe TBI, and fatal TBI in Reykjavík was comparable to incidence rates reported in the neighboring countries. There were strong indications that rehabilitation and follow-up did not match the need, neither in substance nor in number of patients served.

2.2 Paper II

2.2.1 Material and methods

Paper II is based on a prospective incidence study that included a nationwide sample of all 550 individuals 0-19 years old consecutively diagnosed with TBI at all hospitals, EDs and health care centers in Iceland during the one-year period from 15 April 1992 to 14 April 1993 (Halldorsson et al., 2007). This cohort is referred to as the ICTBI SG. The total number of Icelandic children and adolescents at risk was 85,746 (Table 4).

Table 4. Number of Icelandic children and adolescent 0-19 years old in December 1992, by gender, age, and geographical area

	Boys				Girls				
Age in years	0-4	5-9	10-14	15-19	0-4	5-9	10-14	15-19	Total (%)
Reykjavík area[a]	6,639	5,559	6,022	5,775	6,377	5,545	5,799	5,611	47,327 (55%)
Rural areas[b]	5,052	4,792	5,177	4,868	4,682	4,440	4,779	4,629	38,419 (45%)
Total	11,691	10,351	11,199	10,643	11,059	9,985	10,578	10,240	85,746 (100%)

[a] Reykjavík area refers to the city of Reykjavík and the surrounding towns and suburbs from Hafnarfjörður in the south to Mosfellsbær and Kjalarnes in the north. [b]Rural areas refer to other parts of Iceland, small towns, villages, and farmland.

As in **Paper I**, inclusion was based on ICD-9 850-854 diagnoses. Estimate of TBI-severity in the acute phase was based on place of treatment and ICD-9 diagnosis: (1) ED = minimal TBI; (2) hospitalization and ICD9 850 = mild TBI; (3) hospitalization with non-fatal TBI and ICD-9 851-854 = moderate/severe TBI; and (4) fatal TBI. The criteria for hospital admission, comparable to the SNC guidelines (Ingebrigtsen et al., 2000), suggested a difference in severity between TBI/concussion treated at EDs and TBI/concussion leading to hospitalization. Urban residence was defined as living in the Reykjavík area extending from Hafnarfjörður in the south to Mosfellsbær and Kjalarnes in the north. Rural areas were all other parts of Iceland, small towns, villages, and farmland.

In Reykjavík, the first author collected demographic and clinical injury data on all patients diagnosed with TBI during the one-year period prospectively (age, gender, residence, ICD-9 diagnosis, cause of TBI, injury severity, location of traumatic event, and place of treatment). Data on patients with TBI treated outside the Reykjavík area were collected at the end of the one-year period through computerized patient registry. The Icelandic Cause of Death Registry (Statistics Iceland, 2001) provided information on those who received fatal brain injuries during the one-year period.

A log-linear model with two-way interactions was used for statistical analysis of the data. Confidence intervals were calculated for all incidence rates, using the Wilson score procedure (Agresti & Coull, 1998).

2.2.2 Results and discussion

Nationwide, 550 individuals in the age range 0-19 years were diagnosed with TBI (ICD-9 850-854) during the one-year period from 15 April 1992 to 14 April 1993. The number of patients with minimal TBI treated at EDs was 399 (72.5%), mild TBI leading to hospitalization 129 (23.5%), moderate/severe TBI (ICD-9 851-854) 18 (3.3%), and fatal TBI 4 (0.7%). Of the 129 hospitalized patients, 62 were admitted to RCH, including all patients with the more severe injuries according to medical estimates in the acute phase. The results suggested that boys (56.7%) were at a greater risk of sustaining TBI than girls (43.3%) (p = .002). This finding is in agreement with previous reports in Iceland and elsewhere and may be related to the interests and behavioral characteristics of the male gender predisposing boys to greater exposure to environmental hazards (Arnarson & Halldorsson, 1995; Emanuelson & v Wendt, 1997; Jennett, 1998; Kraus et al., 1986; Rivara, 1994).

The overall incidence of pediatric TBI was 6.41 per 1,000 (Table 5). The incidence of TBI leading to hospital admission (1.72 per 1,000), moderate/severe non-fatal TBI (ICD-9 851-854) (0.21 per 1,000), and fatal TBI (0.05 per 1,000) was comparable to corresponding average annual incidence rates previously reported in Reykjavík in 1987-1991 and in the neighboring countries (Arnarson & Halldorsson, 1995).

The nationwide incidence of ‘minimal’ TBI, treated at EDs, was 4.65 per 1,000, which was relatively low compared to previous estimates (Arnarson & Halldorsson, 1995). However, the incidence of minimal TBI was markedly higher in the Reykjavík area (6.87 per 1,000) than in rural areas (1.93 per 1,000) (Table 6). This urban/rural discrepancy was not observed in mild TBI leading to hospital admission or moderate/severe TBI, suggesting that the lower incidence in rural areas might have other explanations than fewer TBIs requiring medical attention. The reason may be that parents in rural areas are less likely to bring their children with TBI to health care services. This should be a public health concern in rural areas, where emergency services may be delayed (Olafsson & Sigurdsson, 2000). It can be complicated to assess accurately the acute severity of TBI in young age, and apparently minimal or mild TBI may in some cases lead to conditions requiring urgent medical intervention (Dietrich et al., 1993; Greenes & Schutzman, 1998; Savitsky & Votey, 2000; Schutzman et al., 2001; Schutzman & Greenes, 2001; Tulipan, 1998). An alternative explanation could be that children dia

Table 5. Incidence rates of TBI (ICD-9 850-854) per 1,000 with 95% confidence intervals by gender, age, and severity of injury. Number of injured patients (n = 550) and the total population at risk (n = 85,746) by gender and age. Number and percentage of patients in each injury severity category

	Boys				Girls					
Age in years / Severity of injury	0-4	5-9	10-14	15-19	0-4	5-9	10-14	15-19	Overall Incidence	Number Injured
Minimal	9.32	3.86	4.20	2.54	6.96	4.11	3.50	2.05	4.65	399 (73%)
95% CI[a]	7.7, 11.2	2.8, 5.3	3.2, 5.6	1.7, 3.7	5.6, 8.7	3.0, 5.6	2.5, 4.8	1.3, 3.1	4.2, 5.1	
Mild	1.71	1.93	1.79	1.41	1.36	1.40	1.04	1.37	1.50	129 (24%)
95% CI	1.1, 2.6	1.3, 3.0	1.2, 2.8	0.9, 2.3	0.8, 2.2	0.8, 2.4	0.6, 1.9	0.8, 2.3	1.3, 1.8	
Moderate/Severe		0.19	0.36	0.38	0.45	0.20		0.10	0.21	18 (3%)
95% CI	0.0, 0.3	0.1, 0.7	0.1, 0.9	0.2, 1.0	0.2, 1.1	0.1, 0.7	0.0, 0.4	0.0, 0.6	0.1, 0.3	
Fatal	0.09		0.09	0.19					0.05	4 (1%)
95% CI	0.0, 0.5	0.0, 0.4	0.0, 0.5	0.1, 0.7	0.0, 0.4	0.0, 0.4	0.1, 0.4	0.0, 0.4	0.0, 0.1	
Total	11.12	5.99	6.43	4.51	8.77	5.71	4.54	3.52	6.41	550(100%)
95% CI	9.4, 13.2	4.7, 7.7	5.1, 8.1	3.4, 6.0	7.2, 10.7	4.4, 7.4	3.4, 6.0	2.5, 4.9	5.9, 7.0	
Number injured	130	62	72	48	97	57	48	36	550	
Total population	11,691	10,351	11,199	10,643	11,059	9,985	10,578	10,240	85,746	

[a] CI = confidence intervals calculated with the Wilson score procedure (Agresti & Coull, 1998).

gnosed with TBI are not recorded in computerized medical records in rural areas. This may also be a matter of concern, as early ‘minimal’ or ‘mild’ TBI can have late consequences and accessible and accurate medical records are important for future reference. The incidence of minimal TBIs treated at EDs in the Reykjavík area (6.87 per 1,000) did not exceed previous reports from neighboring countries (Arnarson & Halldorsson, 1995).

Table 6. Incidence rates of TBI (ICD-9 850-854) per 1,000 with 95% confidence intervals[a] within parentheses, by severity of injury and residence. Number and percentage of injured patients by injury severity category in each of the two geographical areas (n = 550), and the total population at risk (n = 85,746)

	Reykjavík area		Rural areas	
Severity of injury	Incidence	Number Injured (%)	Incidence	Number Injured (%)
Minimal	6.87 (6.2, 7.7)	325 (79.5)	1.93 (1.5, 2.4)	74 (52.5)
Mild	1.52 (1.2, 1.9)	72 (17.6)	1.48 (1.1, 1.9)	57 (40.4)
Moderate/Severe	0.23 (0.1, 0.4)	11 (2.7)	0.18 (0.1, 0.4)	7 (5.0)
Fatal	0.021 (0.0, 0.1)	1 (0.2)	0.080 (0.0, 0.2)	3 (2.1)
Total	8.64 (7.9, 9.5)	409 (100.0)	3.67 (3.1, 4.3)	141 (100.0)
Population	47,327		38,419	

[a] Confidence intervals were calculated with the Wilson score procedure (Agresti & Coull, 1998).

Children in the youngest age group, 0-4 years old, living in the Reykjavík area, were at greatest risk of minimal TBI treated at EDs (Tables 5 and 7), indicating a need for increased parent/teacher supervision and a safer environment for the youngest children. This difference related to age at injury was not as obvious in rural areas, suggesting that outside Reykjavík, children in the youngest age group were less likely to be brought to medical attention because of TBI than older children and adolescents. This is again a public health concern, as it may be more challenging to estimate the acute severity of TBI in infants, toddlers, and young children than in older children and adolescents.

The incidence of patients with mild TBI leading to admission to hospital and the incidence of moderate/severe TBI was comparable across the four age groups and the two geographical area groups (urban/rural).

Table 7. Incidence rates of TBI (ICD-9 850-854) per 1,000 with 95% confidence intervals, by residence, gender and age. Number and percentage of injured patients by gender and age in each of the two geographical areas (n = 550)

	Boys				Girls				
Age in years	0-4	5-9	10-14	15-19	0-4	5-9	10-14	15-19	Overall
Reykjavík area									
Incidence	16.27	8.63	8.64	4.50	11.45	6.85	6.04	5.17	8.64
95% CI[a]	13.5, 19.6	6.5, 11.4	6.6, 11.3	3.1, 6.6	9.1, 14.4	5.0, 9.4	4.4, 8.4	3.6, 7.4	7.9, 9.5
Number injured	108 (26%)	48 (12%)	52 (13%)	26 (6%)	73 (18%)	38 (9%)	35 (9%)	29 (7%)	409 (100%)
Rural areas									
Incidence	4.35	2.92	3.86	4.52	5.13	4.28	2.72	1.51	3.67
95% CI	2.9, 6.6	1.7, 4.9	2.5, 6.0	3.0, 6.8	3.5, 7.6	2.7, 6.7	1.6, 4.7	0.7, 3.1	3.1, 4.3
Number injured	22 (16%)	14 (10%)	20 (14%)	22 (16%)	24 (17%)	19 (14%)	13 (9%)	7 (5%)	141 (100%)

[a] CI = confidence intervals calculated with the Wilson score procedure (Agresti & Coull, 1998).

According to information from Landspítali University Hospital and the Icelandic Cause of Death Registry, the annual incidence of moderate/severe (ICD-9 851-854) and fatal pediatric TBI in Reykjavík has been relatively stable from 1992 to 2006.

2.2.3 Limitations

Collection of patient data was not supervised in rural areas in the same way as it was in the Reykjavík area, and the data from rural areas were not as detailed, e.g. regarding causes, location, and severity of TBI.

2.2.4 The most important contributions

In the ICTBI SG, the incidence of minimal (treated at EDs), mild (hospitalized), moderate-severe (ICD-9 851-854), and fatal pediatric TBI in Iceland was comparable to previous findings in Iceland and in neighboring countries. The incidence of minimal pediatric TBI treated at EDs was low in rural areas, indicating a degree of under-diagnosis of such injuries, especially in the youngest age group. In the Reykjavík area, the youngest children were at greatest risk of sustaining minimal TBI. The hospitalized and the more severe TBIs were evenly distributed across geographical areas and age groups. Recent reports suggest stability in the number of Icelandic children and adolescents as regards the more severe TBI. Findings based on nationwide representative samples are important for injury prevention and public health, taking into account geographical region, age, gender, and cultural and socio-economic factors.

2.3 Paper III

2.3.1 Material and methods

The questionnaire study aiming at parent/self-reported TBI-related consequences four years post-injury (**Paper III**) was based on a sub-group of the ICTBI SG, i.e. the 408 children and adolescents diagnosed with TBI and treated at EDs or hospitalized in Reykjavík (Halldorsson et al., 2008). One of the reasons for excluding from this study patients treated in rural areas was that the available medically confirmed TBI data on the rural group were less detailed than the data on the group treated in the Reykjavík area.

As in **Papers I** and **II**, inclusion was based on ICD-9 850-854 diagnoses. The severity of TBI was based on medical findings in the acute phase, and estimated and scored according to the HISS criteria (Stein & Spettell, 1995) and the SNC guidelines (Ingebrigtsen et al., 2000). Estimated force of impact to the head was a variable based on combined information from cause of TBI and where TBI took place (i.e. at home, outside home or motor-vehicle-related). Urban/rural residence was defined in the same way as in **Paper II**. Severity of parent-/self-reported complaints of late TBI-related symptoms was estimated and scored according to a modified criteria of the Glasgow Outcome Scale (GOS (see Appendix 2)) (Barlow et al., 2005; Ewing-Cobbs et al., 1998; Jennett & Bond, 1975).

Injury data were collected as in **Paper II**. A short questionnaire was sent to participants or their parents (if participant was younger than 18 years old) in Reykjavík four years post-injury. The participation rate was 59.6% (n = 243).

Data were collected from the Social Insurance Administration (SIA) regarding participants who had sought the SIA’s services since the time of injury.

Binary logistic regression analysis was used to predict complaints of TBI-related symptoms four years post-injury. The final model contained the three main effects: location of event, injury severity, and age at injury. Statistical significance was calculated with chi-squares based on likelihood ratio.

2.3.2 Results and discussion

Four years post-injury, 39 (16.0%) of 243 participants still suffered symptoms that they or their parents attributed to the early TBI. Complaints of late symptoms were more common in the group of patients with medically confirmed moderate/severe TBI than in the group with minimal/mild TBI. However, close to half (n = 19) of the 39 participants with late sequelae had sustained medically diagnosed minimal/mild TBI and the rest (n = 20) had sustained moderate/severe TBI. Not including the four patients who died, 16 of the 39 individuals reported late TBI-related physical, cognitive, and adaptive symptoms indicating disability according to the GOS criteria. The findings suggested a need for a broad-based rehabilitation effort and follow-up for a substantial number of children and adolescents each year.

Location of event (at home, outside home, or motor-vehicle-related), injury severity (HISS), and age at injury had prognostic value for complaints of symptoms attributed to TBI four years post-injury.

Controlling for injury severity (HISS) and age at injury, symptoms reported were related to location of event ($\chi^2 = 6.5$, df = 2, $p = 0.039$). Complaints of symptoms were more common following TBI sustained outside the home than at home, and most common following motor-vehicle-related TBI, possibly reflecting the effect of increased force of impact to the head. The findings suggested that patients with motor-vehicle-related TBI need special consideration independent of TBI severity (Figure 2).

Age at injury had a curvilinear effect, where parents of the youngest children were least likely to report symptoms, followed by participants in the oldest age group, 15-19 years old at injury (Figure 2). It was suspected that the relatively few complaints of symptoms attributed to TBI in the youngest age group did not accurately reflect post-traumatic health, but was indicative of problems related to assessing the severity of TBI and TBI-related sequelae at very young age. This hypothesis is supported by the finding that six of the younger children had been diagnosed with developmental disorders at the SIA without mention of previously having sustained TBI.

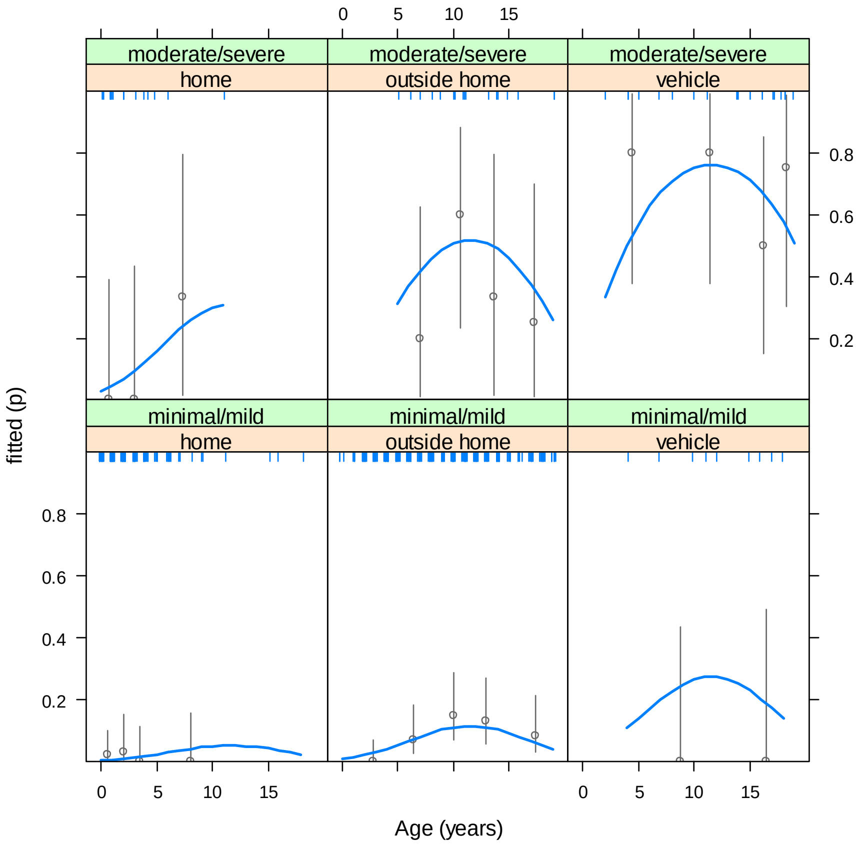

Figure 2. The fitted values of the model of the three main effects, traumatic head injury severity, location of event, and age at injury. The lines show empirical probabilities with CI for sub-ranges of age. The rug plots show the age distribution of participants in each panel, one tick for each participant.

Controlling for the remaining independent variables, no evidence was found that gender or urban/rural residence had an appreciable predictive value for late complaints of symptoms.

2.3.3 Limitations

The validity of the dependent variable (symptoms reported) may be questioned, and there may have been a response bias. However, the association between the more serious TBI and reports of complex symptoms supported the validity of the dependent measure. A larger number of participants in some of the sub-groups would have been preferable for the statistical analyses. Inaccurate or missing information may have affected medical estimates of TBI severity in the acute phase.

2.3.4 The most important contributions

Pediatric TBI had consequences four years post-injury. Although TBI-severity is positively related to late symptoms, even TBI considered ‘minimal’ or ‘mild’ in the acute phase may have long-term sequelae. As ‘minimal’ or ‘mild’ TBIs are relatively common, the number of individuals with late consequences following such injuries may be substantial. The number of individuals with late complaints and complaints indicating disability suggested that the previously reported rehabilitation effort of the late 1980s and the early 1990s had not met the need. A variable presumed to assess force of impact to the head had prognostic value independent of TBI severity. Parents of children in the youngest age group were least likely to report late symptoms, possibly underestimating the consequences of TBI and the need for intervention. Gender or urban/rural residence did not have obvious predictive value for late outcome.

2.4 Paper IV

2.4.1 Material and methods

Paper IV is based on a study conducted in 2008-2009 on the prevalence and scope of early TBI as a health concern and factors of prognostic value for late consequences (Halldorsson et al., 2012). The study included two independent nationwide samples, the ICTBI SG and a CG (n = 1,232) selected in 2008 from the Icelandic National Registry using a stratified random sampling method.

Participants responded to 16 questions on TBI, specifically written for the study. The reported acute severity of TBI was scored according to the HISS criteria. The reported outcome of TBI was scored with reference to the King’s Outcome Scale for Childhood Head Injury (KOSCHI (see Appendix 2)) (Crouchman et al., 2001), the GOS (Jennett & Bond, 1975), and the Extended Glasgow Outcome Scale (GOS-E) (Jennett & Bond, 1975; Wilson et al., 1998). Force of impact to the head was based on answers to TBI question 12: ‘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 graphic examples of traumatic impact to the head (TIH) (see Appendix 1).

A questionnaire was sent by mail to the ICTBI SG approximately 16 years post-injury, in 2008-2009. The same questionnaire was sent to the CG. Participants were not informed as to which group they belonged. The questionnaire was neutral with reference to the TBI-status of respondents. A modified version of the Tailored Design Method for sending out questionnaires was used (Dillman, 2006). Those not participating by mail were reached by telephone and requested to respond to the questionnaire. Overall participation was 67.3%.

The CG was divided into two groups: participants not reporting to have sustained TBI (CG without TBI) and participants reporting to have sustained TBI (CG with TBI). Binary logistic regression analysis was used to predict reported TBI-related late symptoms in the SG and the CG with TBI combined. Model selection was based on the Akaike Information Criterion (AIC) and statistical comparisons of models.

2.4.2 Results and discussion

Of the 331 participants of the SG, 79 (23.9%) reported having sustained moderate/severe TBI according to the HISS criteria (LOC > 5 min or PTA ≥ 1 hour). Sixteen years post-injury, 39 (11.8%) of the 331 respondents described TBI-related symptoms indicating moderate disability according to the KOSCHI/GOS/GOS-E criteria (symptoms interfering with daily life). Minimal/mild TBI led to disability in 7.1% of cases and moderate/severe TBI in 26.6% of cases. Thus, even 'minimal/mild' TBI may have long-term consequences. The findings suggest the need for rehabilitation and follow-up.

In the CG, the prevalence of self-reported early TBI (49.5%) was higher than previously documented in a general population sample (Body & Leathem, 1996; McKinlay et al., 2008; McKinlay et al., 2010; Segalowitz & Brown, 1991). For comparison, in the Christchurch study 32% of participants had sustained medically confirmed TBI by 25 years of age (McKinlay et al., 2008; McKinlay et al., 2010). However, controlling for age, a higher prevalence may be expected in the present study compared to the Christchurch study, as medically non-confirmed TBI was included. Previous reports have suggested that the number of TBIs sustained without being brought to medical attention may be substantial (Setnik & Bazarian, 2007; Sosin et al., 1996).

Suggesting complicated or more severe TBI in the CG, 7.6% reported having been hospitalized with TBI and 9.1% reported moderate/severe TBI according to the HISS criteria. As regards late sequelae in the CG, 7.0% reported TBI-related symptoms indicating disability, as compared to 0.3-2.0% in previous estimates outside Iceland (Corrigan et al., 2010; Langlois et al., 2006; Summers et al., 2009; Tagliaferri et al., 2006; Winqvist et al., 2007; Zaloshnja et al., 2008). However, only 2.4% reported having been evaluated for or awarded compensation.

The finding that 7.6% of participants in the CG reported having been hospitalized with TBI compares with 4-12% reported in other countries (Corrigan et al., 2010; McKinlay et al., 2008; Winqvist et al., 2007), supporting the relevance and representativeness of the findings in the international context.

The two clinical groups, i.e. the SG and the CG with TBI, were remarkably similar in several aspects, such as the ratio of having sustained moderate/severe TBI (23.9% vs 18.4%), moderate disability (11.8% vs 13.0%), minimal/mild TBI leading to disability (7.1% vs 9.0%), moderate/ severe TBI leading to disability (26.6% vs 30.8%), more than one TBI (35.0% vs 41.6%), and having been evaluated for compensation (3.3% vs 4.5%).

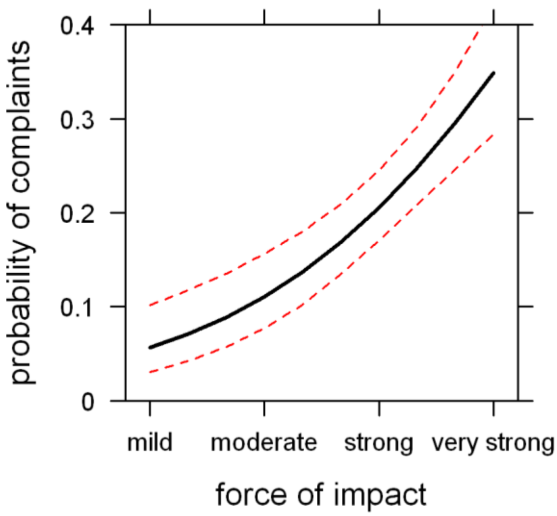

Figure 3. Greater force of impact increases the probability of long-term TBI-related complaints. The unbroken line shows the predicted probability and the dotted lines indicate 95% pointwise confidence envelope.

Overall, 75% of participants with moderate disability had not been evaluated for or awarded compensation. Being evaluated for compensation was related to age at injury. In the age range older than 14 years at injury, 9.9% reported to have been evaluated for compensation while the corresponding ratio for the younger age groups combined was 2.2%. The ratio was lowest in the youngest age group, 0-4 years old, 1.0%.

Close to one fifth (21.1%) of participants in the SG did not report ever having sustained TBI. This was more likely in the youngest age group at injury (35.7%) than in older age groups (12-16%). All had sustained minimal or mild TBI as medically estimated in the acute phase. The reasons for not reporting medically confirmed TBI sustained at a very young age, 16 years post-injury, are speculative and may in part be of an idiosyncratic nature.

The event-related variable, force of impact to the head, had strong prognostic value for late reports of symptoms attributed to early TBI ($\chi^2(1) = 31.4$; ΔAIC = 29.4; odds ratio [OR] = 2.1; 95% CI = 1.6-2.7; $p < 0.001$). Considering that force of impact had values from 1-4, potentially the effect was very large as can be seen in Figure 3. More than one TBI sustained also had significant effect ($\chi^2(1) = 8.3$; ΔAIC = 6.3; OR = 1.9; 95% CI = 1.2-2.9; $p < 0.01$). Severity (HISS) had substantially less effect on symptoms reported and close to none for females. Females appeared more sensitive to the effects of mild TBI than males. Group (SG vs CG with TBI), age at injury, and urban/rural residence had limited or non-existent effect.

2.4.3 Limitations

Findings were based on self-report concerning events that took place several years before and even very early in life. Late recall may, however, be enhanced by the emotional significance of pediatric traumatic events (Cordon et al., 2004; Peterson, 1999; Peterson et al., 2005). Although care was taken to avoid medical terminology, participants may in some instances have misunderstood the phrasing of questions. Mode of answering, i.e. by mail vs by telephone, may have affected responses to questions. However, statistical analysis did not indicate a significant effect. A higher participation rate would have been preferable. However, SG respondents and non-respondents were comparable in terms of age distribution, gender, urban/rural residence, and medically estimated severity of TBI in the acute phase. In the CG participants and non-participants had comparable demographics.

2.4.4 The most important contributions

Pediatric TBI had considerable consequences 16 years post-injury. Based on two independent nationwide samples the prevalence of TBI and TBI-related ‘moderate’ disability in young age was higher than previously documented. The event-related variables, force of impact to the head and number of TBIs sustained, had greater prognostic value than TBI severity (HISS). Females appeared more sensitive to the effects of mild TBI than males. Other demographic variables had limited predictive values. A minority of participants reporting moderate disability had been evaluated for or awarded compensation. The youngest children were least likely to have been evaluated for compensation. Very early TBI may not be recalled or reported 16 years post-injury. Based on previous reports on the incidence of TBI in Iceland and the present prevalence of TBI leading to hospitalization, the findings are representative in the international context.

2.5 Paper V

2.5.1 Material and methods

Paper V is based on further analyses of the questionnaire data collected in 2008-2009 as reported in **Paper IV** (Halldorsson et al., 2012; Halldorsson et al., 2013). The study evaluates the late effects of early TBI assessed by four clinical outcome scales. It includes the same SG and CG as described in **Paper IV**.

Participants responded to four clinical outcome scales, questions on SES of self and parents, questions on demographics, and the 16 questions on TBI used for analyzes in **Paper IV**. The clinical outcome scales, assessing aspects of cognition, mental health, behavior and adaptation, were the Memory Complaint Questionnaire (MCQ) (Schnurr & MacDonald, 1995), the General Health Questionnaire (GHQ-12) (Goldberg, 1972), the Frontal Systems Behavior Scale (FrSBe) (Grace & Malloy, 2001), and the European Brain Injury Questionnaire (EBIQ) (T. W. Teasdale et al., 1997). Those not answering by mail were requested to respond to a shorter version of the questionnaire and the clinical scales by telephone. Selection of items from the four clinical scales was based on results from factor analyses of scales (Martin et al., 2001; Shevlin & Adamson, 2005; Stout et al., 2003), clinical judgment and practical considerations regarding the length of the telephone interview. Table 8 shows the content of the unabridged version and the abbreviated version of the questionnaire.

Table 8. Contents of the questionnaire answered by mail (unabridged version) and by telephone (abbreviated version)

Section	Mail (unabridged version) Questions' numbers	Telephone (abbreviated version) Questions' numbers
Questions on traumatic brain injuries[a]	1-16	1-16
Questions on demographic and socio-economic variables[a]	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

[a] See Appendix 1.

Self-reported acute severity of TBI, force of impact, and late outcome was estimated in the same way as presented in **Paper IV**.

Linear regression analysis was used to develop a prognostic model for each of the four clinical outcome scales in the two clinical groups combined. The main findings of the analyses were based on items common to the unabridged (mail respondents) and abbreviated (telephone respondents) versions of the questionnaire. Due to missing values for the variable 'age at injury', multiple imputation was performed to reduce bias and increase power (J. W. Graham, 2009). As presented in **Paper IV**, model selection was based on AIC and statistical compare-isons of models. The Bonferroni correction method was used to counter-act type-I error due to more than one dependent variable (Rice, 1989).

2.5.2 Results and discussion

On each of the four clinical outcome scales, assessing mental health, cognition, behavior and adaptation, the CG without TBI did better than the SG with medically confirmed TBI (p-values < 0.05) and the CG with self-reported TBI (p-values < 0.01). The CG with TBI did not do better than the SG on any of the four clinical outcome scales, but worse in the case of EBIQ.

In the two clinical groups combined, the event related variable force of impact to the head 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 salient in the case of more than one TBI sustained than in one TBI sustained.

Age at injury, gender, urban/rural residence, parental SES, and group (SG vs CG with TBI) had limited, nominal or non-existent effect.

In the SG, not recalling/reporting very early medically confirmed TBI was associated with better outcome on EBIQ (t (323) = –2.5; p = 0.01) and GHQ (t (323) = –3.5; p < 0.001) but not on MCQ (t (325) = –1.3; p = 0.21) and FrSBe (t (320) = –0.2; p = 0.83). Considering the content of items of the abbreviated scales, this may indicate that not recalling/reporting very early TBI is related to better emotional well-being in spite of similar cognitive consequences. Not reporting early TBI was especially associated with very early age at injury (0-4 years old).

In the group of all SG and CG participants reporting TBI-related symptoms indicating moderate disability, not being evaluated for or awarded compensation was not associated with better outcome on any of the four clinical scales (lowest p-value = 0.21). As stated earlier, being awarded or evaluated for compensation was related to age at injury.

Using the EBIQ as an example, findings suggested that poor outcome on clinical scales related to early TBI was likely to reach clinical significance for a substantial proportion of individuals reporting strong or very strong force of impact to the head.

2.5.3 Limitations

Limitations are comparable to those presented in **Paper IV**. In addition, the present findings are predominantly based on abbreviated versions of the four clinical scales. However, items were selected with reference to factor analyses of scales, and in the group participating by mail the correlation of each scale between the summed scores of the selected items and the summed scores of all remaining items was very high, validating this approach.

2.5.4 The most important contributions

Medically confirmed and self-reported TBI was reflected in worse results on each of the four clinical outcome scales. Force of impact to the head and more than one TBI had predictive value. 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. Parental SES and other demographic variables had limited effect. Results validated previous findings on self-reported late symptoms attributed to early TBI and the scope of TBI as a health concern presented in **Paper IV**. Not reporting early TBI was not related to fewer cognitive symptoms but to better emotional well-being. In the group with self-reported moderate TBI-related disability, not having been evaluated for compensation was not related to better or worse outcome on the clinical scales.

2.6 Summary of main findings

2.6.1 Early TBI may have long-term consequences

TBI is common in pediatric populations. Fortunately, in the majority of cases pediatric TBI is ‘minimal’ or ‘mild’ and the recovery is complete as far as can be seen. However, the present findings indicate that early TBI may have long-term consequences. In some cases ‘minimal’ or ‘mild’ TBI may have long-term consequences but late sequelae are more common following ‘moderate’ or ‘severe’ TBI. In the present studies sequelae were manifested both as complaints of late symptoms attributed to early TBI and functional reduction on clinical outcome scales. In the more severe cases, consequences were likely to reach clinical significance.

2.6.2 Force of impact to the head had predictive value

The present findings suggest that in a parent-/self-report study 4 years and 16 years post-injury, force of impact to the head may have the greatest prognostic value for late sequelae. Having sustained TBI more than once had an independent effect. TBI severity (HISS) had predictive value as a two-way interaction with the two event-related variables, force of impact and number of TBIs sustained. Age at injury, gender, urban/rural residence, and parental SES had a limited, nominal or non-existent effect.

Evidence suggests that force of impact to the head is positively associated with diffuse axonal injuries and the superimposing cerebral contusions and lacerations (Lux, 2007). The present findings have demonstrated cognitive impairment as a function of force of impact.

2.6.3 Incidence of pediatric TBI was representative in an international context

In 1987-1991 and 1992-1993, the annual incidence of minimal, mild, moderate, severe and fatal pediatric TBI in Iceland was comparable to corresponding incidence rates reported in the neighboring countries. The same was true for the ratio of young patients with TBI admitted to hospital. Those results indicated that the present prevalence findings are representative in an international context.

Recent retrospective findings based on computerized patient records at Landspítali University Hospital do not indicate a reduction in the annual number of young patients with the more severe TBIs (ICD-9 851-854/ICD-10 S06.1-S06.9 (see Appendix 2)) compared to 1987-1993. This is in line with findings abroad that although fewer children and adolescents are admitted to hospital, the number of those with moderate and severe non-fatal TBIs has not decreased (Bowman et al., 2008).

2.6.4 The prevalence of early TBI and TBI-related disability was high

The prevalence of self-reported early TBI and TBI-related disability in Iceland was higher than previously estimated and documented in general population samples abroad.

As reported in **Papers I** and **II**, Iceland is no exception as regards severe and fatal pediatric TBI. However, in the present questionnaire study in 2008-2009 there were few, if any, cases of reported severe disability. In terms of numbers, the late consequences of early TBI are more related to ‘moderate’ disability than to ‘severe’ disability. Pediatric TBI may be a threat to cognitive health at all ages.

2.6.5 Rehabilitation does not match the need

The prevalence of early TBI and TBI-related consequences and 'moderate' disability was greater than previously reported. However, the scope of early TBI as a health concern was not reflected in rehabilitation and follow-up efforts in Iceland. On average, only 1-2 children received rehabilitation following TBI each year. The number of individuals with late symptoms attributed to early TBI and poor outcome on clinical scales indicated that the rehabilitation effort was far from meeting the need in terms of number and substance. The findings indicate the need for the development of systematic intervention procedures and follow-up.

2.6.6 Injury prevention may have led to fewer severe pediatric TBIs

In the late 1980s and early 1990s, fewer hospitalized children with TBI required admission to intensive care compared to the 1970s in Reykjavík. It was suggested that the development reflected the success of injury prevention efforts of the 1980s, e.g. resulting in increased use of safety seats and child restraints in cars and protective helmets for pedal cyclists and horse riders. Injury prevention appeared to have been especially successful in the older pediatric age groups.

Paper II presented findings indicating that based on ICD-10 diagnoses of hospitalized individuals and information from the Icelandic Cause of Death Registry the annual incidence of moderate, severe and fatal pediatric TBI in Reykjavík had been relatively stable from 1990-2006, suggesting no less need for prevention and intervention in recent years than in 1992-1993.

2.6.7 SG and CG with TBI were comparable in several respects

In several respects the SG and the CG with TBI were remarkably similar, e.g. as regards the ratio of sustaining moderate/severe TBI, moderate disability, more than one TBI, and having been evaluated for or awarded compensation. These findings may contribute evidence of the validity of participants' reports.

2.6.8 In the majority of cases early TBI-related disability was not evaluated for or awarded compensation

In the majority of cases (75%) children and adolescents with self-reported TBI-related disability had not been evaluated for or awarded compensation. Evaluation was more associated with older than younger age at injury, i.e. 15 years or older. In the group with self-reported moderate disability, not being evaluated for or awarded compensation was not related to better (or worse) results on the clinical outcome scales.

2.6.9 Not recalling/reporting early medically confirmed TBI did not exclude cognitive sequelae

A number of participants in the SG did not report ever having sustained TBI, most common in the youngest age at injury group. The findings indicated that this sub-group had less emotional sequelae but not less cognitive consequences 16 years post-injury.

2.6.10 The youngest age group (0-4 years old) is in need of special attention

1. Injury prevention appeared to have been least effective in the youngest age group.
2. The youngest age group was at greatest risk of sustaining minimal TBI treated at EDs in the Reykjavík area.
3. The youngest age group seemed to be at greatest risk of not being brought to medical attention or included in medical records in rural areas.
4. The incidence rates of hospitalized mild, moderate and severe TBI in the youngest age group was comparable to the corresponding incidence rates in the older age groups.
5. Parents of children in the youngest age group were least likely to report symptoms attributed to TBI four years post-injury.
6. Four years post-injury, six young children in the SG had been diagnosed with developmental disorders at the SIA without reference to the early TBI.

7. In the SG, the youngest participants were most likely not to report to have sustained TBI. Not reporting the very early medically confirmed TBI, was not associated with better cognitive outcome on clinical scales 16 years post-injury.

8. Only 1% of participants with TBI-related disability in the youngest age group had been evaluated for or awarded compensation. Absence of evaluation was not associated with better outcome on clinical scales.

9. Age at injury did not predict late outcome.

2.6.11 Boys were at greater risk than girls of sustaining TBI

Boys were at greater risk of sustaining non-fatal TBI than girls (**Papers I** and **II**). In 1987-1991 this was true both for the milder and the more severe non-fatal TBI. The gender difference was inconsistent in the case of fatal TBI (**Papers I** and **II**), most likely in part due to random variation in small samples. Findings regarding the predictive effect of gender for late outcome were inconclusive (**Papers III**, **IV** and **V**). Four years post-injury gender did not predict complaints of symptoms attributed to the early TBI as reported by parents in most cases (**Paper III**). In the predominantly self-report study 16 years post-injury, females appeared to be more sensitive to the effects of mild TBI than males (**Paper IV**). However, this was only nominally reflected in results on clinical outcome scales (**Paper V**). These findings may be congruent with recent reports suggesting that girls may be more likely to report post-concussion symptoms following TBI than boys (Taylor et al., 2010), but that there may be no gender effect for the course of recovery and outcome (Renner et al., 2012).

2.6.12 Causes of TBI were related to age at injury

Fall was the most common cause of TBI in the youngest age group. With increased age, unintentional blows, and sport- and traffic-related injuries became more common (**Paper I**).

2.6.13 Urban/rural differences should be considered in pediatric TBI

Findings have indicated that pediatric non-fatal and fatal injuries may be more common in rural than urban areas (Eberhardt & Pamuk, 2004; Reid et al., 2001; Stefansdottir & Mogensen, 1997; Vane & Shackford, 1995; Zietlow & Swanson, 1999). In the present study, the incidence rates of mild TBI leading to hospitalization and moderate/severe TBI were comparable in the Reykjavík area and rural areas. The incidence of minimal TBI treated at EDs, however, was lower in rural areas, especially in the youngest age group at injury. Evidence was not found that urban/rural residence had a predictive value for late outcome. Nationwide samples provided information, e.g. related to incidence and age at injury that local samples would not have given.

3 DISCUSSION

The ICTBI research project is broad-based and aimed at addressing questions of clinical relevance for TBI prevention and intervention. Its strengths relate to its nationwide scope and repeated, long-term follow-up. It includes a one-year nationwide cohort of pediatric patients diagnosed with TBI (n = 550) in 1992-1993 (the ICTBI SG) as well as the relatively large CG (n = 1,232), selected from the Icelandic National Registry in 2008.

In the 1980s and the early 1990s, the emerging literature suggested that pediatric TBI was a significant health concern in terms of numbers and sequelae (Boll & Barth, 1983; Johnson, 1992; Montgomery et al., 1991; Scharli & Weber, 1981; Telzrow, 1987). Recent laboratory studies have outlined how the forces involved in minimal, mild, moderate and severe blunt TBI may elicit a cascade of pathological changes in the brain which in some cases may cause axonal damage and long-term symptoms (Bigler, 2008; Bigler & Maxwell, 2012; Giza & Hovda, 2001; Lux, 2007). In several respects, the present findings reflect the concerns expressed in previous reports in the field of pediatric TBI.

According to the findings of the present questionnaire studies, four years and sixteen years post-injury (**Papers III**-**V**), early ‘minimal/mild’ and ‘moderate/severe’ TBI may have late sequelae. Close to 40 individuals in the ICTBI SG reported symptoms meeting the criteria for moderate disability 16 years post-injury. At the launch of the ICTBI research project in 1992, 1-2 children were referred to rehabilitation each year due to acute and post-acute TBI-related sequelae. These findings appear comparable with the estimate from the US Committee on Trauma Research in 1985 that 1 in 20 patients with TBI receives appropriate rehabilitation (CTR, 1985; Greenspan & MacKenzie, 2000). Appropriate early intervention is important, as it may improve outcome (Chevignard et al., 2010; Galbiati et al., 2009; Kirkwood et al., 2008; Ponsford et al., 2001). Unverified reports from clinical services indicate that in recent years in Reykjavík, 1-3 children have been referred to rehabilitation and follow-up annually. In consultations with parents and teachers, there may have been an increasing emphasis on cognitive training in addition to physical therapy. The present findings underline the need for a new estimate of the number of children and adolescents receiving rehabilitation and follow-up following TBI in Iceland, and an evaluation as to how the intervention effort meets the need based on TBI severity and prognosis.

In the ICTBI CG selected in 2008 there was a relatively high percentage of participants reporting to have sustained TBI (CG with TBI). The CG without TBI did significantly better on each of the four clinical outcome scales, MCQ, GHQ-12, FrSBe, and EBIQ, than the SG with medically confirmed TBI and the CG with self-reported TBI. The two clinical groups, i.e. the SG and the CG with TBI, compared well on each of the four scales and were remarkably similar as regards several of the independent TBI-related variables, such as the ratio of moderate/severe TBI and moderate TBI-related disability. The findings support the validity of the self-report of non-medically confirmed TBI sustained and TBI-related sequelae.

The present series investigated the prognostic value of force of impact to the head for late TBI-related symptoms and outcome. In **Paper III**, the estimated force of impact to the head was based on information on causes and location (e.g. at home, sports facility, or street) of TBI as recorded in patient records. In **Papers IV** and **V**, force of impact was based on self-report (mild, moderate, strong, or very strong). As reported in **Paper III**, the effect of force of impact to the head was greater than the effect of medically confirmed severity of TBI in the acute phase, based on GCS, LOC, PTA, cerebral CT, and neurological examination. In **Papers IV** and **V**, force of impact had a stronger effect for late symptoms and outcome than parent- or self-reported severity of TBI (estimated length of LOC and PTA). Studies have shown a positive association between force of impact to the head and diffuse axonal injury (Lux, 2007).

The effect of more than one TBI sustained for late symptoms compares well with recent reports on the consequences of repeated pediatric TBI (Bigler, 2008; Giza & Hovda, 2001; Lux, 2007; Prins & Giza, 2012). The effects of age at injury, gender, urban/rural residence, and parental SES for late outcome appear less clear, which does not diminish their obvious relevance for intervention and rehabilitation during the recovery process.

The present findings suggest that the event-related variables force of impact to the head and number of TBIs may improve the prognostic value of scales of TBI severity in the acute phase.

Previous studies have indicated a higher incidence of pediatric injuries and pediatric fatal TBIs in rural areas, as compared to urban areas (Eberhardt & Pamuk, 2004; Reid et al., 2001; Stefansdottir & Mogensen, 1997; Vane & Shackford, 1995; Zietlow & Swanson, 1999). In the case of non-fatal TBIs the findings have not been as conclusive (Andelic et al., 2012; Reid et al., 2001). The difference between the urban and rural incidence of minimal pediatric TBI, reported in **Paper II**, exemplifies the advantages of nationwide samples in epidemiological research. Differences in incidence rates from one geographical area to another may be expected, due to environmental and cultural factors and access to medical services. These differences are important for emphases in public health and injury prevention. However, the present findings suggest that the need for intervention and rehabilitation is no less in rural than in urban areas and that the same applies for males and females, younger and older age groups at injury, and individuals of lower and higher SES.

The present self-reported prevalence of early TBI in a nationwide random sample is higher than previously reported prevalence of TBI based on adolescent self-reports (Body & Leathem, 1996; Segalowitz & Brown, 1991) and the prevalence of medically confirmed TBI at age 25 (the Christchurch study) (McKinlay et al., 2008). However, the discrepancy in the prevalence of TBI between the ICTBI research project and the Christchurch study may be augmented by differences in inclusion criteria (i.e. self-reported vs medically confirmed TBI). The present prevalence of TBI is lower than the prevalence of self-reported TBI in higher-risk groups of university athletes (Delaney et al., 2002). The prevalence of TBI-related disability was higher than previously reported (Summers et al., 2009). However, the incidence rates of pediatric TBI in Iceland suggest that the prevalence findings may be representative in the international context.

The present findings suggest that the preventive efforts of the 1980s resulted in lower incidence of severe TBIs leading to admission to intensive care, as compared to the 1970s (**Paper I**). Overall, injury prevention appeared to have been more successful in the older age groups than in the youngest, 0-4 years old. The effects of the injury prevention efforts in recent years as regards TBI have not been documented in Iceland. However, both the present findings and findings from abroad have not indicated a reduction in the incidence of minimal/mild or moderate/severe TBI (Bowman et al., 2008; Coronado et al., 2012; Powell et al., 2008).

Important findings of the present series of the ICTBI research project are based on parent- or self-report questionnaires and clinical outcome scales. Such data may be affected by misunderstanding, exaggeration, under-estimation or lack of insight or information. Although not unprecedented in self-report studies of injury prevalence (Locker, 2007; Williams et al., 2010), long recollection periods may have affected detailed recall. However, the phrasing of questions providing examples and contexts, the intense emotional reactions related to medical emergencies (Cordon et al., 2004; Hop et al., 1999; Peterson, 1999; Peterson et al., 2005), the probable absence of compensation issues, and the possible increased insight with longer time since TBI (Vanderploeg et al., 2007), may have enhanced the accuracy of reports. In addition, the consistency in findings based on different data sets in the present series of studies supports the validity and reliability of late parent- and self-report.

For research purposes, different methods are available for delineating the course of recovery following early TBI. In the case of ‘moderate/severe’ TBI, quantitative neuropsychological testing is an objective approach to obtain detailed information on congenital and acquired neuropsychological strengths and weaknesses. In relatively large pediatric groups with ‘minimal/mild’ TBI, the possible long-term effects of TBI on neuropsychological test results may be lost in non-injury-related individual variation (Fay et al., 1993; Yeates & Taylor, 2005; Yeates et al., 2009). Several years post-injury, in groups with predominantly minimal/mild TBI, self-report questionnaires and clinical outcome scales may be a practical approach in terms of clinical relevance and ecological validity (Rabin et al., 2007), and resources related to time and funding.

In general, the self-report and questionnaire data may reflect individual memories and experiences as regards TBIs sustained early in life and their consequences for cognitive factors, physical and mental health, behavior and adaptation. Although less objective than neuropsychological tests, questionnaires and ecologically oriented clinical scales (Rabin et al., 2007) may provide a unique insight into the late effects of early TBI.

The findings of the present series suggest that there is still a tendency to minimize early TBI. Pediatric TBI appears under-reported, under-diagnosed or under-recorded, under-treated and its consequences underestimated. This may be especially so in the youngest age group. Pediatric TBI is a relatively common occurrence and its prevalence is high. A substantial number of young people complain of symptoms attributed to early TBI that meet the criteria for moderate disability. Only a minority receives the intervention or rehabilitation required or is awarded or evaluated for compensation.

Landspítali University Hospital has implemented an Icelandic translation/adaptation (NICE, 2011) of the clinical guidelines presented in ‘Head Injury: triage, assessment, investigation and early management of head injury in infants, children and adults. Quick reference guide’ published by the National Institute for Health and Clinical Excellence in September 2007 (NICE, 2007). In the context of the present findings, it is important that such guidelines are comprehensive as regards referral to specialized services based on accurate estimates of pediatric TBI severity and prognosis.

4 CONCLUSIONS

The present research has provided information on the incidence and prevalence of early TBI in Iceland, as well as its sequelae and factors of prognostic value.

The incidence of pediatric TBI in this country is comparable to the incidence rates reported in neighboring countries. The prevalence of early TBI and late TBI-related sequelae is higher than previously reported in general population samples. However, differences in inclusion criteria may help explain the discrepancies.

The prevalence of TBI-related moderate disability suggests the importance of TBI prevention, particularly in young age. Children are dependent on parents and close others, teachers and coaches, for care and supervision, to keep their environment safe, to teach them the use of safety devices and to avoid hazardous actions and circumstances, and to react according to medically recommended criteria in the case of TBI.

The present reports indicate the relevance of appropriate, effective, broad-based intervention, rehabilitation and follow-up following TBI. A prerequisite for such services is: (1) awareness and knowledge as regards the significance of early TBI for physical, mental and cognitive health, and behavior and adjustment; (2) accurate estimates of TBI-severity and prognosis in the acute and post-acute phase; and (3) recording of TBI-instances and precise diagnoses in accessible medical files.

The present series of studies of the ICTBI research project provides a database that may serve in developing a goal-oriented and comprehensive service in TBI prevention and intervention for children, adolescents, and young adults with TBI in Iceland.

5 SUGGESTIONS FOR FURTHER RESEARCH

Long-term effects of early TBI on mental health in two nationwide samples in Iceland (further analyzes of the questionnaire data).

The subgroup admitted to hospital at RCH (n = 62) and a control group (n = 53): neurocognitive development across 17 years as assessed by neuropsychological tests 6 months, 6 years and 17 years post-injury, in addition to questionnaire follow-up 4 years and 16 years post-injury.

Changes in cognitive and motor functions late in life in individuals with TBI as compared to age, gender and SES matched controls.

A study of hormonal imbalance ≥ 20 years post-injury in the subgroup admitted to hospital at RCH with the more severe TBI. It is hypothesized that the effects of moderate/severe pediatric TBI may in some cases be manifested in late hormonal imbalance.

A study of differences between urban and rural areas with respect to TBI sustained at a very early age (0-4 years).

The high prevalence of TBI in the Reykjavík area makes it suitable for a prospective birth-cohort study on the cognitive and socio-economic development of affected and non-affected individuals.

6 CLINCAL IMPLICATIONS

It is important to diagnose pediatric TBI, to record the diagnosis in the patient's medical records, to estimate the severity and prognosis accurately, to provide information on possible symptoms and how to respond to them and to refer to intervention, rehabilitation and follow-up as needed.

Even 'minimal/mild' pediatric TBI may have long-term consequences. Parents should receive an information booklet at discharge. Complaints of post-concussion symptoms indicate the need for evaluation, intervention and follow-up.

Parents of very young children in rural areas should be encouraged to bring their children with TBI to medical attention and such instances should be recorded in accessible computerized and written medical files, and follow-up recommended.

Strong impact to the head and/or repeated 'minimal/mild' TBI requires special consideration and follow-up.

There is a need for a nationwide broad-based cognitive and mental as well as physical rehabilitation and follow-up.

Injury prevention, not the least for very young children, is indicated.

It is important to protect, promote and improve cognitive health in young age.

It is important to find ways to support and treat those who are at a disadvantage due to TBI-related cognitive health problems affecting learning, work, social adaptation, and physical and mental health.

7 ETHICS

The studies were approved by the Data Protection Authority, the Medical Ethics Committee, the National Bioethics Committee, and the medical directors concerned. Permission was obtained from Statistics Iceland regarding use of data from the Icelandic Cause of Death Registry.

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APPENDIX 1

Questionnaire

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?

<u>Write the year if you select the latter option.</u>

- ☐ 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?

- ☐ 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 Reykjavík area (from Hafnarfjörður to Kjalarnes)
- ☐ In a town or village outside the Reykjavík 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.

<u>Write the answer if you select the last option.</u>

- ☐ 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 reinbursements because of this
- ☐ Yes, I have received compensation, or been evaluated regarding disability pension or reinbursement 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 Reykjavík area (from Hafnarfjörður in the south to Mosfellsbær and Kjalarnes in the north)
- ☐ In a small town or village outside the greater Reykjavík 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 (½-2 school years)
- ☐ 5-8 semesters (2½-4 school years)
- ☐ 9-16 semesters (4½-8 school years)
- ☐ 17 semesters or more (8½ 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 to 2.9
- ☐ 3.0 to 4.9
- ☐ 5.0 to 6.9
- ☐ 7.0 to 8.9
- ☐ 9.0 to 10.0

*28. Please, answer the following statements.

I received remedial teaching in reading in grade school

☐ No ☐ Yes

I received remedial teaching in mathematics in grade school

☐ No ☐ Yes

I received remedial teaching in spelling in grade school

☐ No ☐ Yes

I received remedial teaching in hand-writing in grade school

☐ No ☐ Yes

Questions on your occupation

29. Please, answer the following questions.

a) Are you an employee? ☐ No ☐ Yes

b) Are you an employer? ☐ No ☐ Yes

c) Are you a student? ☐ No ☐ Yes

d) Is household work your main job? ☐ No ☐ Yes

e) Are you on maternity/paternity leave? ☐ No ☐ Yes

f) Are you ill or temporarily unable to work? ☐ No ☐ Yes

g) Are you unemployed? ☐ No ☐ Yes

h) Are you on 50-74% disability pension? ☐ No ☐ Yes

i) Are you on 75% disability pension? ☐ No ☐ 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

APPENDIX 2

Definitions, scales and criteria

ICD-9 850-854, diagnostic codes for traumatic brain injury

850 = Concussion

851 = Cerebral laceration and contusion

852 = Subarachnoid, subdural, and extradural hemorrhage following injury

853 = Other and unspecified intracranial hemorrhage following injury

854 = Intracranial injury of other and unspecified nature

ICD-10 S06.0-S06.9, diagnostic codes for traumatic brain injury

S06.0 = Concussion

S06.1 = Traumatic cerebral edema

S06.2 = Diffuse brain injury

S06.3 = Focal brain injury

S06.4 = Epidural hemorrhage

S06.5 = Traumatic subdural hemorrhage

S06.6 = Traumatic subarachnoid hemorrhage

S06.7 = Intracranial injury with prolonged coma

S06.8 = Other intracranial injuries

S06.9 = Intracranial injury, unspecified

Glasgow Coma Scale (GCS)

The total score is the sum of the scores in each of the three categories: A, B, and C. Its range is 3-15.

For adults the scoring is as follows:

A. Opens eyes

Spontaneous	4
To verbal command	3
To pain, not applied to face	2
None	1

B. Verbal response

Oriented	5
Confused conversation, but able to answer questions	4
Inappropriate responses, but words are discernible	3
Incomprehensible speech	2
None	1

C. Motor response

Obeys commands for movement	6
Purposeful movement to painful stimulus	5
Withdraws from pain	4
Abnormal (spastic) flexion, decorticate posture	3
Extensor (rigid) response, decerebrate posture	2
None	1

For children under 5 years of age the Verbal response is adjusted as follows:

0-23 months of age

Smiles or coos appropriately	5
Cries but consolable	4
Persistent inappropriate cries/screams	3
Grunts or is agitated or restless	2
No response	1

2-4 years of age

Appropriate words or phrases	5
Inappropriate words	4
Persistent cries/screams	3
Grunts	2
No response	1

Glasgow Outcome Scale (GOS)

1 DEATH	
2 PERSISTENT VEGETATIVE STATE	Patient exhibits no obvious cortical function.
3 SEVERE DISABILITY	Conscious but disabled. Patient depends upon others for daily support due to mental or physical disability or both.
4 MODERATE DISABLITIY	Disabled but independent. Patient is independent as far as daily life is concerned. The disabilities found include varying degrees of dysphasia, hemiparesis, or ataxia, as well as intellectual and memory deficits and personality changes.
5 GOOD RECOVERY	Resumption of normal activities, even though there may be minor neurological or psychological deficits.

The GOS extended version (GOS-E) divides “Good recovery”, “Moderate disability”, and “Severe disability” into “Upper” and “Lower” categories, obtaining an 8-level outcome.

King’s Outcome Scale for Childhood Head Injury (KOSCHI)

1 Death

2 Vegetative

The child is breathing spontaneously and may have sleep/wake cycles. He/she may have non-purposeful or reflex movements of limbs or eyes. There is no evidence of ability to communicate verbally or non-verbally or to respond to commands.

3 Severe disability

(a) The child is at least intermittently able to move part of the body/eyes to command or to make purposeful spontaneous movements. He/she may be fully conscious and able to communicate but not yet able to carry out any self-care activities.

(b) Implies a continuous high level of dependency, but the child can assist in daily activities. He/she is fully conscious but may still have a degree of post-traumatic amnesia.

4 Moderate disability

(a) The child is mostly independent but needs a degree of supervision/actual help for physical or behavioral problems. He/she has overt problems, e.g. with moderate hemiplegia or dyspraxia, insecure in stairs or needing help with dressing.

(b) The child is age appropriately independent but has residual problems with learning, behavior or neurological sequelae affecting function. He/she probably should have special needs assistance but his/her special needs may not have been recognized or met. Children with symptoms of post-traumatic stress are likely to fall into this category.

5 Good recovery

(a) The head injury has resulted in a new condition which does not interfere with the child’s well being and/or functioning, e.g. minor headaches not interfering with school functioning, unsightly scarring of face likely to need cosmetic surgery, and mild neurological asymmetry but no evidence of effect on function of limbs.

(b) Apparently complete recovery with no detectable sequelae from the head injury.

The Head Injury Severity Scale (HISS)

Minimal head injury

GCS score 15, no loss of consciousness (LOC), no amnesia.

Mild head injury

GCS score 14 or brief (< 5 min) LOC or amnesia or impaired alertness or memory, no focal neurologic deficit.

Moderate head injury

GCS score 9-13 or LOC (≥ 5 min) or focal neurologic deficit.

Severe head injury

GCS score 5-8.

Critical head injury

GCS score 3-4.

The Scandinavian Guidelines for the Initial Management of Minimal, Mild, and Moderate Head Injury (SNC)

Minimal head injury

Discharge with head injury instructions.

Mild head injury

CT (recommended). If CT is normal discharge with head injury instructions. If CT is abnormal admit for observation for ≥12 hours. If CT is unavailable admit for observation for ≥ 12 hours.

Moderate head injury

CT (mandatory). Admit for observation ≥ 12 hours.

The WHO Collaborating Centre Task Force on Mild Traumatic Brain Injury Definition of Mild TBI

Mild TBI includes TBI from the mildest forms of concussion, characterized by brief confusion or disorientation to complicated or more serious TBI with LOC up to 30 minutes, PTA up to 24 hours, and intracranial lesion (e.g. cerebral contusion), not requiring surgery.

Papers I-V

Paper I

Acta Pædiatr 84: 96–9. 1995

Head trauma among children in Reykjavík

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The incidence of head trauma (ICD9 850–854) among children in the Reykjavík area, aged 0–14 years, was studied over a 5-year period, 1987–1991, using hospital records. On average, 72 children with head trauma were admitted to hospital each year, indicating an annual incidence of 1.70 per 1000 population. Fourteen percent of children admitted to hospital with head trauma suffered the more severe forms of brain injury (ICD9 851–854) (annual incidence of 0.28 per 1000). Seven children died from brain injury, indicating an annual death rate of 0.03 per 1000. Falls were the most common cause of head trauma (62%), followed by traffic accidents (19%). On average, one to two severely brain-injured children received rehabilitation each year. □ *Brain, causes, child, incidence, injury, rehabilitation, trauma*

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Head trauma is a major cause of morbidity and mortality in children in the western world (1). In the USA it is estimated that the annual incidence of head trauma among children is 2–3 per 1000 population, and approximately 10% of these are severe injuries. It is estimated that 0.10 per 1000 children die each year of brain trauma (2).

Recent research indicates that Iceland is no exception when it comes to pediatric injuries. During the period 1974–1991, the annual incidence of accidents among children aged 0–14 years in Reykjavík was 299 per 1000 children (3), which is high compared with neighboring Scandinavian countries Norway (4) and Sweden (5). During the 5-year period, 1987–1991, the annual incidence of head or spinal trauma among 0–14-year-old children diagnosed at the Emergency Unit of Reykjavík City Hospital was 11 per 1000 (data from hospital records), which is similar to Sweden (5) and France (6).

Guðmundsson (7) studied head trauma among children in Reykjavík during the period 1973–1980. On average, 84 children aged 0–14 years were admitted to hospital each year diagnosed with head trauma (diagnostic numbers 850–854 according to the *International Classification of Diseases, ninth edn* (ICD9) (8)), indicating an annual incidence of 2 per 1000 population. Twenty-four percent of children were 0–4 years old, 44% were 5–9 years and 32% were 10–14 years. Twenty percent of all children were admitted to the Intensive Care Unit, Reykjavík City Hospital, with severe brain injury.

There have been many social and economic changes in Iceland over the past decade involving, among other things, a greater number of motor vehicles and traffic accidents (data from Icelandic Traffic Commission, 1993). At the same time, there has been increased emphasis on preventive measures with regard to childhood accidents, and in 1988 the use of seat belts in cars was made obligatory by law. The hypothesis of this research was that in spite of an increase in the number of car accidents, with and without injuries, protective measures had led to a reduction in the number of the more severe forms of head trauma among children needing hospital admission and intensive care.

In the present study, we focused on the incidence and causes of head trauma (ICD9 850–854) among children admitted to hospital in Reykjavík during the 5-year period 1987–1991. The study did not deal with population estimates but with all cases. Because of the limited size of the Icelandic population and an advanced health care system with reliable recording methods, it is possible to identify and follow-up virtually all Icelandic individuals with a specific diagnosis or treatment during a defined period of time. In the case of head trauma, the work is made easier still by the fact that only one emergency unit, located at Reykjavík City Hospital, serves the Greater Reykjavík Area. The same hospital houses the only neurosurgical ward in the whole of Iceland.

Patients and methods

The study included all 359 new cases of head trauma (ICD9 850–854) among children aged 0–14 years admitted to hospital in Reykjavík during the 5-year period 1987–1991. All children were admitted to a

Table 1. Number of 0–14-year-old children with head trauma, by age, sex and ICD9 number, admitted to the three hospitals in Reykjavík (Reykjavík City Hospital, National University Hospital and Landakot Hospital) during the 5-year period 1987–1991.

	Age (years)							
	0–4		5–9		10–14			
Diagnosis (ICD9)	Boys	Girls	Boys	Girls	Boys	Girls	Total	%
Concussion/commotio cerebri (850)	60	38	69	56	58	28	309	86
Cerebral laceration.contusion (851)	2	3	8	1	6	1	21	5
Hemorrhage in cerebral meninges (852)	6	1	3	2	3	2	17	5
Other intracranial hemorrhage (853)	3	1	1	0	1	0	6	2
Other intracranial injury (854)	1	1	0	0	3	1	6	2
Total (%)	72(20)	44(12)	81(23)	59(16)	71(20)	32(9)	359	100

hospital ward for at least overnight observation, following medical evaluation at an emergency unit. A diagnosis was made by a neurosurgeon or a child neurologist. Care was taken not to double-count children who were transferred from one hospital to another. Data on cause of accident, injuries and incidence were obtained through the archives of the three hospitals in Reykjavík: Reykjavík City Hospital, National University Hospital and Landakot Hospital.

The severity of head trauma was estimated by medical diagnosis according to the *International Classification of Diseases, ninth edn* (ICD9) (8). While ICD9 850, concussion, denotes a relatively milder form of trauma, the ICD9 codes 851–854 indicate severe injuries. ICD9 851 = cerebral laceration and contusion; ICD9 852 = subarachnoid, subdural and extradural hemorrhage following injury; ICD9 853 = other and unspecific intracranial hemorrhage following injury; and ICD9 854 = intracranial injury of unspecified nature.

Information was obtained regarding the number of brain-injured children receiving rehabilitation during the period 1987–1991. This was done by examining length of hospitalization and by counting the number of brain-injured children receiving services at every rehabilitation centre in and around Reykjavík.

Results

During the five year period 1987–1991, 359 (224M (62%), 135F (38%)) children aged 0–14 years were admitted to hospital in Reykjavík, diagnosed with head trauma (ICD9 850–854); that is an average of 72 children each year, or an annual incidence of 1.70 per 1000 population in the Reykjavík area. The number of children by age, sex and ICD9 number is shown in Table 1. The 5–9-year-old age group was the largest, followed by the youngest age group (0–4 years old). Fourteen percent of children had the more severe forms of head trauma (ICD9 diagnoses 851–854). The annual incidence of severe head trauma (ICD9 851–854) was 0.28 to 1000. A relatively high percentage (16%) of children in the youngest age group suffered the more severe forms of head trauma. Only 17 (5%) children were admitted to the intensive care unit.

During the 5-year period, 7 Icelandic children died from brain injury, indicating an annual death rate of

Table 2. Causes of head trauma (ICD9 850–854) by age and sex, among 0–14-year-old children in the Reykjavík area during the 5-year period 1987–1991.

	Age (years)						
	0–4		5–9		10–14		
Cause	Boys	Girls	Boys	Girls	Boys	Girls	Total (%)
Falls	56	40	55	40	20	11	222 (62)
Traffic accidents	10	3	14	9	26	7	69 (19)
Accidental blows	5	1	8	7	12	5	38 (11)
Sport			1		7	7	15 (4)
Assaults	1			2	1	1	5 (1)
Other			3	1	5	1	10 (3)
Total	72	44	81	59	71	32	359

Table 3. Results from studies in Iceland and six other countries regarding the incidence of trauma among children.

	Annual incidence per population of 1000				
	Trauma at EUs	Head and spinal trauma at EUs	Head trauma admitted to hospital	Severe head trauma	Death due to brain injury
Reykjavík 1973–1980	299[a]		2.00[b]	0.40[b]	0.03[b]
Reykjavík 1987–1991	264[c]	11.0[d]	1.70[d]	0.28[d]	0.03[d]
USA			1.85[e]	0.27[e]	0.10[e]
Israel			1.71[f]	0.26[f]	0.03[f]
Norway	125[g]		2.34[h]		
Sweden	143[i]	9.8[i]	2.62[j]		
France		11.7[k]			
Denmark				0.30[l]	

[a] Reykjavík City Hospital, Emergency Unit 1974–1991 (3); [b] Reykjavík City Hospital, Neurosurgical Ward 1973–1980 (7); [c] Reykjavík City Hospital, Emergency Unit 1991 (3); [d] Present study; [e] San Diego County 1981 (1); [f] Israel 1970–1976 (9); [g] Norway 1992 (4); [h] Norway 1989 (10); [i] Göteborg 1975–1976 (5); [j] Sweden 1988 (11); [k] France 1981 (6); [l] Denmark 1990 (12).

0.03 per 1000. Six of these children were younger than 10 years of age, and five were girls.

Table 2 shows the causes of head trauma. With increasing age, there was a reduction in the number of head traumas caused by falls, while there was an increase in the number of injuries from other causes, such as traffic accidents, accidental blows and sport.

On average, one to two children were referred to rehabilitation each year.

Discussion

Table 3 compares the results of studies conducted in Iceland with six other countries on the incidence of childhood injuries and pediatric head trauma. In spite of the high incidence of childhood injuries diagnosed at emergency units in Iceland, the annual incidence of hospitalizations due to head trauma (ICD9 850–854), the incidence of severe head trauma and the annual incidence of deaths due to brain injury reported in the present study were all similar to other countries.

During the 8-year period 1973–1980, on average 84 children were admitted to hospital in Reykjavík each year diagnosed with head trauma (ICD9 850–854). Twenty percent of these children were admitted to the Intensive Care Unit, Reykjavík City Hospital, with severe brain injuries. The present study showed, that during the 5-year period 1987–1991, on average 72 children were admitted to the three hospitals in Reykjavík each year diagnosed with head trauma, and only 5% of these received intensive care. The reduction in hospital admissions due to pediatric head trauma in Reykjavík is not statistically significant. However, the decrease in the number of children admitted to the intensive care unit of the City Hospital is significant ($p < 0.005$), indicating a reduction in the incidence of severe brain injuries among Icelandic children. As traffic becomes heavier and as the number of traffic accidents with and without injuries increases in Iceland (information from Icelandic Traffic Commission, 1993), the decrease in hospital admissions due to pediatric head trauma may be attributed to greater emphasis on protective measures which have been adopted in recent years, such as the increased use of child restraints in cars, and protective helmets and high visibility reflectors for pedal cyclists and horse riders. These preventive measures seem to have been especially effective in reducing the incidence of head trauma among older children. However, a relatively high incidence of head trauma and severe brain injuries among young children (0–4 years) is of particular concern. For preventive purposes it is important to note that in this age group 83% of head traumas are caused by falls.

Admission to intensive care, diagnosis according to ICD9 or number of individuals receiving rehabilitation may not encompass all cases of severe head trauma among Icelandic children. Studies in other countries have suggested that mild and moderate head trauma can, in some cases, have considerable short- and long-term effects on the child and the child's family (13, 14). Deficits caused by head injuries are not limited to physical factors. Pediatric brain injury may also lead to deficient cognitive and academic functioning, social and emotional difficulties, behavioral disturbances, poor self-control, reduction in adaptive abilities and lack of concentration and initiative (14). All these factors can affect the maturing and developing child in many ways. The harmful effects of pediatric brain injury may not be fully recognized until later, even in late adolescence. Studies indicate that two out of every three children with severe brain injury will need prolonged support and special services (13). Long-term follow-up is therefore indicated.

The sex ratio in the present study (38% girls and 62% boys) was comparable to previous studies on pediatric head trauma in Iceland and in other countries (1, 7). Of the 50 children suffering from the more severe forms of head trauma, only 13 (26%) were girls. However, more girls than boys died from brain injury during the study period. The reason for this is not clear; most likely it is a random effect in a small group.

On average, only one to two children were referred for rehabilitation each year. Rehabilitation was reserved for children who had suffered the most severe injuries and showed signs of serious physical and mental deficits. Rehabilitation was limited to short-term physical therapy. A broad-based, long-term rehabilitation program and support for brain-injured children and their families are not available in Iceland.

In Denmark it has been estimated that 283 children per year may be in need of support or rehabilitation due to deficits caused by head injuries (12). By simple arithmetic this would imply 19 Icelandic children each year, indicating that the rehabilitation effort in Iceland does not match the need.

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Paper II

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Urban–rural differences in pediatric traumatic head injuries: A prospective nationwide study

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Aims: To estimate differences in the incidence of recorded traumatic head injuries by gender, age, severity, and geographical area.

Methods: The study was prospective and nationwide. Data were collected from all hospitals, emergency units and healthcare centers in Iceland regarding all Icelandic children and adolescents 0–19 years old consecutively diagnosed with traumatic head injuries (N = 550) during a one-year period.

Results: Annual incidence of minimal, mild, moderate/severe, and fatal head injuries (ICD-9 850–854) was 6.41 per 1000, with 95% confidence interval (CI) 5.9, 7.0. Annual incidence of minimal head injuries (ICD-9 850) treated at emergency units was 4.65 (CI 4.2, 5.1) per 1000, mild head injuries admitted to hospital (ICD-9 850) was 1.50 (CI 1.3, 1.8) per 1000, and moderate/severe nonfatal injuries (ICD-9 851–854) was 0.21 (CI 0.1, 0.3) per 1000. Death rate was 0.05 (CI 0.0, 0.1) per 1000. Young children were at greater risk of sustaining minimal head injuries than older ones. Boys were at greater risk than girls were. In rural areas, incidence of recorded minimal head injuries was low.

Conclusions: Use of nationwide estimate of the incidence of pediatric head injury shows important differences between urban and rural areas as well as between different age groups.

Keywords: incidence, nationwide, pediatric, prospective, traumatic head injuries, urban-rural differences

Introduction

Traumatic brain injury is a major cause of death and disability in children and adolescents, more so among boys than girls (Kraus et al 1986; Rivara 1994; Arnarson and Halldorsson 1995; Emanuelson and Wendt 1997; Jennett 1998). Young children are at relatively high risk of minimal and mild traumatic head injuries (Rivara 1994; Jennett 1998; Lovasik et al 2001). An increase in the more severe and fatal traumatic brain injuries has been found in late adolescence (Kraus et al 1986; Rivara 1994; Kraus and McArthur 1996; Jennett 1998; Lovasik et al 2001).

Most children receive head injuries. Many slight injuries may never reach the attention of healthcare personnel. Fortunately, most recorded head injuries are minimal or mild with fast recovery and no apparent complications (Kraus and McArthur 1996). Nonetheless, every head injury may have the potential of leading to serious damage (Jennett 1998). Estimating the severity of traumatic head injuries in the acute phase is therefore critical. However, it can be problematic, especially in infants and young children, due to less marked clinical signs and different responses to trauma compared with older individuals (Bernardi et al 1993; Dietrich et al 1993; Quayle et al 1997; Greenes and Schutzman 1998; Savitsky and Votey 2000; Schutzman et al 2001). Pediatric head injuries, even those considered mild, irrespective of cause, may in some cases have debilitating long-term consequences (Jennett 1998). Sometimes the consequences of early brain injury do not fully manifest until adolescence or early

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adulthood (Brooke 1988; Eslinger et al 1992). The previously held assumption that young children recover better from brain injury than older children due to developmental plasticity has not been substantiated. To the contrary, early brain damage disrupts normal maturation and development, and neuronal plasticity may not always lead to optimal outcome (Chapman and McKinnon 2000). Due to unpredictable, hidden, and sometimes serious consequences, prevention of traumatic pediatric head injuries is imperative.

Epidemiological studies are an important step towards goal-directed organized injury prevention. Bearing in mind methodological considerations when comparing results (Rivara 1994; Kraus and McArthur 1996; Emanuelson and Wendt 1997; Jennett 1998), previous studies on the epidemiology of pediatric traumatic head injuries have indicated that each geographical area may have its special characteristics with regard to incidence, age and gender distribution, and severity of injury, important from a prophylactic point of view (Kraus et al 1986; Rivara 1994; Arnarson and Halldorsson 1995; Kraus and McArthur 1996; Emanuelson 1997; Jennett 1998; Lovasik et al 2001).

At the time of the present study, the Icelandic population numbered 262,202. The environment was diverse, with one major urban area, small towns, villages, and farmland.

Because of a social security system, Icelanders have had good access to comprehensive medical services with healthcare insurance for all, including the underprivileged. Standard of living is overall similar to the neighboring Scandinavian countries. However, working days are longer, for both men and women (Olafsson 1990).

Compared with the Scandinavian countries, Iceland has the highest incidence of childhood injuries and pediatric accident mortality rate (Stefansdottir and Mogensen 1997). The mortality rate is higher for rural than urban areas (Stefansdottir and Mogensen 1997). The reasons for the high incidence of childhood injuries are open to speculation. They may be related to less parental supervision, due to long working hours, certain values and views characteristic of the Icelandic population, emphasizing the need for independence and personal freedom, even at a young age, and underestimating environmental hazards (Stefansdottir and Mogensen 1997).

In spite of the high incidence of childhood injuries in Iceland, the annual incidence of hospitalizations due to pediatric head trauma in the Reykjavik area has been comparable with other countries (Arnarson and Halldorsson 1995). Falls have been the most common cause of traumatic head injuries among the youngest children, with an increase in traffic-related injuries with age (Arnarson and Halldorsson 1995).

In the present study, we had the opportunity to collect information for one year on all recorded cases of pediatric traumatic head injuries nationwide. A national sample has the advantage of being geographically representative. The study was prospective, which enhanced the control of data collection, classifications, and recordings. A search of the literature did not reveal any other prospective nationwide studies on the incidence of traumatic pediatric head injuries, with the same inclusion criteria, definitions, and methodology for comparison.

The aims of the study were to estimate the incidence of recorded head injuries by gender, age, severity, and geographical area. The uniqueness of the study is related to its prospective, nationwide scope, including all recorded traumatic head injuries of different severity in both urban and rural areas.

Material and methods

Patients

This study comprised all 550 children and adolescents 0–19 years old, consecutively recorded for head injury, ICD-9 850–854 (World Health Organization [WHO] 1977), at all hospitals, emergency units, and healthcare centers in Iceland during the period April 15 1992 to April 14 1993. The total population in the 0–19 year age range was 85,746. Table 1 shows the population at risk by gender, age, and geographical area.

Although by law, Icelandic adolescents receive most adult responsibilities at 18 years of age, we decided to have the upper age limit at 19 years instead of 17. The majority of Icelandic adolescents do not complete grammar school or trade school until age 20 and are living with their parents and are still reliant on their support during that time, not in the least when traumatic events occur.

Procedures

At the time of the study, the only neurosurgical unit and the only computed tomography (CT) scanners in Iceland were located in Reykjavik. Practically all patients in Iceland diagnosed with or suspected of moderate or severe brain injury (ICD-9 851–854) were brought there by ambulance, helicopter, airplane, or by sea. When the diagnosis and degree of severity was uncertain, expert advice was available by telephone and transport to Reykjavik encouraged.

By the end of the one-year period, all healthcare institutions outside the city of Reykjavik supplied available information from their computerized patient registry

Table 1 Number of Icelandic children and adolescent 0–19 years old in December 1992, by gender, age, and geographical area

	Boys				Girls				Total (%)
Age in years	**0–4**	**5–9**	**10–14**	**15–19**	**0–4**	**5–9**	**10–14**	**15–19**	
Reykjavik area[a]	6,639	5,559	6,022	5,775	6,377	5,545	5,799	5,611	47,327 (55%)
Rural areas[b]	5,052	4,792	5,177	4,868	4,682	4,440	4,779	4,629	38,419 (45%)
Total	11,691	10,351	11,199	10,643	11,059	9,985	10,578	10,240	85,746 (100%)

Notes: [a]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. [b]Rural areas refer to other parts of Iceland, small towns, villages, and farmland.

regarding age, gender, diagnosis, and residence of head injury patients. In the city of Reykjavik, the primary author, through information provided by neurosurgeons, other hospital personnel, and written and computerized hospital records ascertained the information daily. Care was taken not to count twice patients who were transferred from one healthcare institution to another. Private practitioners or health clinics were not contacted, as they did not provide emergency medical services for patients with traumatic head injuries.

Data were collected from the Icelandic Death Register (Statistics Iceland 2001) on patients who received fatal traumatic brain injuries during the same period. Included were patients who died after being admitted to hospital and those who died at the scene or during transport to hospital.

Classifications

All patients were classified according to International Classification of Diseases 9 (ICD-9) (WHO 1977) diagnostic codes 850–854: ICD-9 850 denotes concussion; 851 cerebral laceration and contusion; 852 subarachnoid, subdural, and extradural hemorrhage following injury; 853 other and unspecified intracranial hemorrhage following injury; and 854 intracranial injury of unspecified nature.

Patients with more than one ICD-9 diagnosis were included if at least one of the diagnoses was in the 850–854 range. Patients with more than one 850–854 diagnosis were recorded according to the most serious one.

Physicians diagnosed concussion following traumatic head injury, based on clinical symptoms, such as loss of or reduced consciousness, confusion, dizziness, somnolence, nausea, or amnesia. ICD-9 851–853 diagnoses were made by neurosurgeons, based on cerebral CT findings.

According to Icelandic guidelines, concussed patients with Glasgow Coma Scale (GCS) (Teasdale and Jennett 1974) score 15, no loss of consciousness (LOC) and no signs of skull fracture or other complications, were not admitted to hospital, but discharged from emergency units with head injury instructions. Concussed patients with GCS scores lower than 15, LOC, amnesia, signs of skull fracture, or other complications were hospitalized. Referral to cerebral CT was based on neurosurgical consultation and expert opinion on injury severity and complications.

Concussions (ICD-9 850) treated at emergency units and subsequently discharged were classified as minimal head injuries. Concussions leading to hospitalization were classified as mild head injuries, and nonfatal ICD-9 851–854 diagnoses as moderate/severe injuries.

A distinction was made between patients living in the Reykjavik area, the only major urban area in Iceland, including the city of Reykjavik and the surrounding towns and suburbs (total population 0–19 years: 47,327), and patients living in the rural areas and small towns and villages in other parts of Iceland (total population 0–19 years: 38,419) (see Table 1). The largest town outside the Reykjavik area was Akureyri with total population of 0–19 years: 4,903.

Statistical analysis

A log-linear model with two-way interactions was used for statistical analysis of the data. Inspection of residuals supported the validity of the log-linear assumption and showed no alarming outliers.

Confidence intervals (CI) were calculated for all incidences in Tables 2–4. While total population numbers were high, incidence rates were extremely low. Therefore, confidence intervals were computed with the Wilson score procedure (Agresti and Coull 1998).

Ethics

The Icelandic Data Protection Commission, the Icelandic Medical Ethics Committee, and the medical directors concerned approved the protocol. Permission was obtained from Statistics Iceland regarding use of data from the Icelandic Death Register.

Results

Table 2 shows the annual incidence with calculated confidence intervals of minimal, mild, moderate/severe, and

Table 2 Incidence rates of traumatic head injuries (ICD-9 850–854) per 1000 with 95% confidence intervals by gender, age and severity of injury. Number of injured patients (N = 550) and the total population at risk (N = 85,746) by gender and age. Number and percentage of patients in each injury severity category

	Boys				**Girls**				**Overall**	**Number**
Age in years	**0–4**	**5–9**	**10–14**	**15–19**	**0–4**	**5–9**	**10–14**	**15–19**	**Incidence**	**Injured (%)**
Severity of injury										
Minimal	9.32	3.86	4.20	2.54	6.96	4.11	3.5	2.05	4.65	399 (72.5%)
95% CI[a]	7.7, 11.2	2.8, 5.3	3.2, 5.6	1.7, 3.7	5.6, 8.7	3.0, 5.6	2.5, 4.8	1.3, 3.1	4.2, 5.1	
Mild	1.71	1.93	1.79	1.41	1.36	1.40	1.04	1.37	1.50	129 (23.5%)
95% CI	1.1, 2.6	1.3, 3.0	1.2, 2.8	0.9, 2.3	0.8, 2.2	0.8, 2.4	0.6, 1.9	0.8, 2.3	1.3, 1.8	
Moderate/Severe		0.19	0.36	0.38	0.45	0.20		0.10	0.21	18 (3.3%)
95% CI	0.0, 0.3	0.1, 0.7	0.1, 0.9	0.2, 1.0	0.2, 1.1	0.1, 0.7	0.0, 0.4	0.0, 0.6	0.1, 0.3	
Fatal	0.09		0.09	0.19					0.05	4 (0.7%)
95% CI	0.0, 0.5	0.0, 0.4	0.0, 0.5	0.1, 0.7	0.0, 0.4	0.0, 0.4	0.1, 0.4	0.0, 0.4	0.0, 0.1	
Total	11.12	5.99	6.43	4.51	8.77	5.71	4.54	3.52	6.41	550 (100.0%)
95% CI	9.4, 13.2	4.7, 7.7	5.1, 8.1	3.4, 6.0	7.2, 10.7	4.4, 7.4	3.4, 6.0	2.5, 4.9	5.9, 7.0	
Number injured	130	62	72	48	97	57	48	36	550	
Total population	11,691	10,351	11,199	10,643	11,059	9,985	10,578	10,240	85,746	

Note: [a]Confidence intervals (CI) were calculated with the Wilson score procedure (Agresti and Coull 1998).

fatal traumatic head injury by gender and age. The total annual incidence of head injuries was 6.4 (CI 5.9, 7.0) per 1000 population.

Boys (7.1 per 1000) were more likely to sustain head injury than girls (5.7 per 1000) ($\chi^2 = 9.987$, df = 1, p = 0.002).

There was an interaction between age and severity ($\chi^2 = 24.920$, df = 9, p = 0.003), mainly due to a relatively high incidence of minimal head injuries among the youngest children. The oldest age group was least likely to suffer head injury. This was not statistically significant.

There was a decrease in incidence with increased severity of injuries. Moderate/severe and fatal brain injuries were 4% of all head injuries.

Table 3 provides information on the incidence of traumatic head injuries in the city of Reykjavik and the surrounding urban area compared with the more rural areas of Iceland.

The results show an interaction between place of residence and severity ($\chi^2 = 37.799$, df = 3, p = 0.000). Considering the confidence intervals, there was clear evidence of a significant difference between minimal head injuries in the Reykjavik area and in rural areas. This was not so for mild, moderate/severe, or fatal injuries (Table 3).

In rural areas, age-related differences were less marked than in the Reykjavik area, although not statistically significant. Clinically this rural–urban difference was most striking in the youngest age group and related to minimal head injuries (Tables 3 and 4).

There was no significant two-way interaction. In particular, there was no evidence of different severity by gender.

No three-way interactions of age, gender, severity, and residence were significant.

In the Reykjavik area, 49% of the head injured patients were admitted during the six winter months, October to March. This ratio was 41% in rural areas.

Discussion

In this one-year nationwide sample in the 0–19 years age range, the total incidence of traumatic head injuries was 6.4 (CI 5.9, 7.0) per 1000 population. The national incidence of mild, moderate/severe, and fatal head injuries was 1.8 (CI 1.5, 2.1) per 1000 population. This compared well with the average annual incidence in the Reykjavik area 1987–1991, and in neighboring countries, while the incidence of minimal head injury, 4.7 (CI 4.2, 5.1) per 1000 was considerably lower (Arnarson and Halldorsson 1995).

The incidence of traumatic head injuries was lower in rural (3.7, CI 3.1, 4.3 per 1000) than urban (8.6, CI 7.9, 9.5 per 1000) areas, predominantly due to relatively few recorded minimal head injuries. The incidence of minimal head injuries was 1.9 (CI 1.5, 2.4) per 1000 in rural areas, but 6.9 (CI 6.2, 7.7) in the Reykjavik area. As age differences were less marked outside the Reykjavik area, young head injured children may have been less likely to be brought to medical attention than were older children.

Table 3 Incidence rates of traumatic head injuries (ICD-9 850–854) per 1000 with 95% confidence intervals[a] within parentheses, by severity of injury and residence. Number and percentage of injured patients by injury severity category in each of the two geographical areas (N = 550), and the total population at risk (N = 85,746)

Severity of injury	Reykjavik area Incidence	Reykjavik area Number Injured (%)	Rural areas Incidence	Rural areas Number Injured (%)
Minimal	6.87 (6.2, 7.7)	325 (79.5)	1.93 (1.5, 2.4)	74 (52.5)
Mild	1.52 (1.2, 1.9)	72 (17.6)	1.48 (1.1, 1.9)	57 (40.4)
Moderate/Severe	0.23 (0.1, 0.4)	11 (2.7)	0.18 (0.1, 0.4)	7 (5.0)
Fatal	0.021 (0.0, 0.1)	1 (0.2)	0.080 (0.0, 0.2)	3 (2.1)
Total	8.64 (7.9, 9.5)	409 (100.0)	3.67 (3.1, 4.3)	141 (100.0)
Population		47,327		38,419

Note: [a]Confidence intervals were calculated with the Wilson score procedure (Agresti and Coull 1998).

A low incidence of minimal pediatric head injuries in rural areas was not anticipated. Studies have shown higher rates of the more severe head trauma and fatal injuries in rural compared with urban areas (Vane and Shackford 1995; Triebel et al 1998; Zietlow and Swanson 1999; Reid et al 2001; Eberhardt and Pamuk 2004). As the incidence of mild, moderate/severe, and fatal brain injuries was comparable to the Reykjavik area, it may be inferred that children and adolescents in rural areas with "minimal" head injuries were less likely to be brought to the attention of medical personnel and receive diagnosis and treatment. The reasons for this may be related to cultural, parental, socio-economic status, and seasonal factors, as well as accessibility to healthcare services.

Evidence emphasizes alertness in the case of traumatic pediatric head injuries. Head trauma that seems to be minimal or mild in the acute phase can lead to intracranial injury and long-term consequences (Tulipan 1998; Schutzman and Greenes 2001). These injuries can be difficult to detect in the acute phase, especially in young children and infants, calling for careful observation of clinical signs, and in selected cases radiographic imaging (Greenes and Schutzman 1998; Schutzman et al 2001). Delayed identification of intracranial injuries can lead to secondary injuries due to intracranial hemorrhage, cerebral swelling and elevated intracranial pressure, causing progressive irreversible brain damage, permanent disability, and death (Dietrich et al 1993; Savitsky and Votey 2000). Due to the increased likelihood of delayed emergency services in rural areas (Olafsson and Sigurdsson 2000), medical evaluation is even more urgent than in urban areas.

In the present study, we have no evidence suggesting that a low incidence of recorded minimal head injuries in rural areas led to increased morbidity or mortality. Nonetheless, the findings presented have implications for public healthcare services. In rural areas, there may be increased need for providing information on dangers related to primary and secondary brain injuries and to emphasize preventive strategies. People should be made aware of clinical symptoms, signs of deterioration, and the effects of repeated minimal or mild head injuries. Caregivers should be encouraged

Table 4 Incidence rates of traumatic head injuries (ICD-9 850–854) per 1000 with 95% confidence intervals, by residence, gender, and age. Number and percentage of injured patients by gender and age in each of the two geographical areas (N = 550)

	Boys				Girls				Overall
Age in years	0–4	5–9	10–14	15–19	0–4	5–9	10–14	15–19	
Reykjavik area									
Incidence	16.27	8.63	8.64	4.50	11.45	6.85	6.04	5.17	8.64
95% CI[a]	13.5, 19.6	6.5, 11.4	6.6, 11.3	3.1, 6.6	9.1, 14.4	5.0, 9.4	4.4, 8.4	3.6, 7.4	7.9, 9.5
Number injured	108 (26.4%)	48 (11.7%)	52 (12.7%)	26 (6.4%)	73 (17.8%)	38 (9.3%)	35 (8.6%)	29 (7.1%)	409 (100.0%)
Rural areas									
Incidence	4.35	2.92	3.86	4.52	5.13	4.28	2.72	1.51	3.67
95% CI	2.9, 6.6	1.7, 4.9	2.5, 6.0	3.0, 6.8	3.5, 7.6	2.7, 6.7	1.6, 4.7	0.7, 3.1	3.1, 4.3
Number injured	22 (15.6%)	14 (9.9%)	20 (14.2%)	22 (15.6%)	24 (17.0%)	19 (13.5%)	13 (9.2%)	7 (5.0%)	141 (100.0%)

Note: [a]Confidence intervals (CI) were calculated with the Wilson score procedure (Agresti and Coull 1998).

to seek medical evaluation regarding acute pediatric head injuries and ensure easy and fast access to services. Because of the possibly long-term consequences of head injuries, healthcare personnel should keep records of medical advice provided via telephone regarding such instances.

There was an increased risk for minimal traumatic head injury in the 0–4 year age range. The reasons for this may be cultural, lack of parental supervision (Stefansdottir and Mogensen 1997), and related to physical characteristics of young children (Brudvik 2000). For mild, moderate/severe, and fatal head injuries, young age was not a specific risk factor, and there was not a marked increase in incidence in the oldest age group, which has been found in the USA (Kraus et al 1986; Rivara 1994; Kraus and McArthur 1996; Lovasik et al 2001). Increased parental supervision, safety awareness and safer environment for infants and young children should be encouraged.

Boys were at greater risk than girls were of sustaining traumatic head injuries. This is a common finding in similar studies, in both Iceland and elsewhere (Kraus et al 1986; Rivara 1994; Arnarson and Halldorsson 1995; Emanuelson and Wendt 1997; Jennett 1998), and may reflect a behavioral pattern and increased exposure to environmental hazards related to the male gender (Rivara 1994). Preventive measures should be adapted to the behavioral characteristics of the two genders.

The data presented show the value of using a nationwide estimate of the incidence of pediatric head injury, to highlight important differences between urban and rural areas as well as between different age groups. These differences, important for public health planning, may be missed in studies relying solely on local samples.

Limitations and future directions

In the present study, information on the causes of traumatic head injuries was not available for the total group of patients. This was also the case for more detailed information on injury severity.

The study took place prior to a formal introduction and implementation of the Head Injury Severity Scale (HISS) (Stein and Spettell 1995) and the Scandinavian Guidelines for the Initial Management of Head Injuries (Ingebrigtsen et al 2000). In the present study, the criteria for hospital admissions following concussion are identical to those suggested by HISS and the Scandinavian guidelines, but due to lack of detailed information related to injury severity for the total group corresponding criteria for mild and moderate head injuries could not be adopted.

In recent years, there has been increased awareness in Iceland regarding the importance of injury prevention and safety measures. In 1999, legislation was passed requiring children under 15 years of age to wear helmets when riding bicycles. In spite of this, there are indications that the annual incidence of moderate, severe, and fatal traumatic brain injuries has been stable in the Reykjavik area from 1990 until 2006.

The design of the present study, including a nationwide sample of all recorded instances of pediatric traumatic head injuries of different severity during a one-year period, provides the opportunity to study the long-term consequences of such injuries.

Conclusion

Care should be taken when estimating nationwide traumatic head injury incidences from local samples. Urban/rural differences are to be expected.

There may be urban/rural differences regarding the discrepancy between actual and recorded traumatic head injury incidences.

The findings of the present study have implications for public health policy and practice in rural areas, where increased awareness regarding "minimal" pediatric traumatic head injuries should be encouraged.

Preventive effort should consider geographical location, age, gender, and cultural and socio-economic factors.

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Paper III

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The prognostic value of injury severity, location of event, and age at injury in pediatric traumatic head injuries

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Aims: To estimate the prognostic value of injury severity, location of event, and demographic parameters, for symptoms of pediatric traumatic head injury (THI) 4 years later.

Methods: Data were collected prospectively from Reykjavik City Hospital on all patients age 0–19 years, diagnosed with THI (n = 408) during one year. Information was collected on patient demographics, location of traumatic event, cause of injury, injury severity, and ICD-9 diagnosis. Injury severity was estimated according to the Head Injury Severity Scale (HISS). Four years post-injury, a questionnaire on late symptoms attributed to the THI was sent.

Results: Symptoms reported were more common among patients with moderate/severe THI than among others ($p < 0.001$). The event location had prognostic value ($p < 0.05$). Overall, 72% of patients with moderate/severe motor vehicle-related THI reported symptoms. There was a curvilinear age effect ($p < 0.05$). Symptoms were least frequent in the youngest age group, 0–4 years, and most frequent in the age group 5–14 years. Gender and urban/rural residence were not significantly related to symptoms.

Conclusions: Motor vehicle related moderate/severe THI resulted in a high rate of late symptoms. Location had a prognostic value. Patients with motor vehicle-related THI need special consideration regardless of injury severity.

Keywords: follow-up, pediatric, symptoms, traumatic head injury

Introduction

Traumatic head injury (THI) leading to brain damage is a major cause of death and disability in childhood and youth (Kraus et al 1986; Rivara 1994; Arnarson and Halldorsson 1995; Emanuelson and Wendt 1997; Jennett 1998; Halldorsson et al 2007).

Most children receive THI at some time. Many minor injuries may never receive attention from healthcare personnel. Fortunately, most recorded THI are minimal or mild with fast recovery and no apparent complications (Kraus and McArthur 1996). Nonetheless, every THI may potentially lead to serious damage (Jennett 1998). Estimating the severity of THI in the acute and sub-acute phase is therefore critical, but can be problematic especially in infancy and early childhood, when clinical signs may be less marked and responses to trauma may differ from those of older individuals (Bernardi et al 1993; Dietrich et al 1993; Quayle et al 1997; Greenes and Schutzman 1998; Savitsky and Votey 2000; Schutzman et al 2001). Pediatric THI, irrespective of cause, and even if considered mild in the acute phase, may have debilitating long-term consequences (Jennett 1998).

Research has shown that force of impact is positively correlated with injury severity. High velocity motor vehicle-related collisions are among the leading causes of severe and fatal injuries in childhood (Vane and Shackford 1995; Boswell et al 1996; DiMaggio and Durkin 2002). Infants and young children are at a relatively high risk of minimal and mild THI caused by falling (Arnarson and Halldorsson 1995; Halldorsson et al 2007). Evidence suggests that craniofacial injuries in young children caused by slipping, tripping, or falling most often take place at home and are rarely serious or fatal (Chang and Tsai 2007). However, THI involving relatively mild impact, eg, caused by stumbling and falling, or falling from a table, may lead to moderate or severe brain injury, especially in infants and young children (Emanuelson and Wendt 1997).

The previously held assumption that young children recover better from brain injury than older children, because of developmental plasticity has not been substantiated. On the contrary, early brain damage disrupts normal maturation and development, and neuronal plasticity may not always promote an optimal outcome (Chapman and McKinnon 2000; Giza and Prins 2006).

Recent research findings have indicated that development of infants and young children may be more adversely affected by brain injury than the development of older children and adolescents (Taylor and Alden 1997; Anderson et al 2000; Eslinger et al 2004). Recovery of intelligence quotient (IQ) in young children 3–7 years old who suffered severe brain injury has been found to be minimal 12 months post-injury. Recovery of IQ in older children was better and similar to that of adults (Anderson et al 2000). In children 6–12 years old with moderate and severe brain injury, sequelae related to cognition had not resolved four years post-injury (Yeates et al 2004).

Pediatric traumatic brain injuries can have significant and persistent sequelae, affecting intellectual and other cognitive functions, prefrontal executive functioning, social adaptation and behavior, academic performance, emotion, and personality (Levin et al 1993; Anderson et al 2004; Eslinger et al 2004; Ewing-Cobbs et al 2006; Max et al 2006).

The social and cognitive functions of those who have suffered childhood brain injuries may even decline with age, as indicated by repeated assessments post-injury (Jonsson et al 2004; Yeates et al 2004; Levine et al 2005). Some sequelae of early brain injury may not be fully manifested until adolescence or early adulthood (Brooke 1988; Eslinger et al 1992).

Boys are at greater risk of sustaining THI than girls (Halldorsson et al 2007). Due to greater adaptability associated with the female gender in infancy and early childhood (Prior et al 1993), girls may make a better recovery from early THI than boys. Groswasser and colleagues (1998) found that in a group of patients with severe brain injury aged 5–65 years old, female patients had a better predicted outcome at the time of discharge from an in-patients rehabilitation program than male patients.

Both in the US and in Iceland, the pediatric accident mortality rate has been found to be higher in rural compared with urban areas, and motor vehicle crashes have been a common cause of fatal injuries (Vane and Shackford 1995; Stefansdottir and Mogensen 1997; Eberhardt and Pamuk 2004). In addition, looking at the incidence of fatal THI in Iceland, specifically, its rate seems to be higher in rural areas than in the Reykjavik area (Halldorsson et al 2007). This may suggest that THI resulting from high force on impact is more common in rural areas than in the Reykjavik area, leading to more serious injuries and more long-term sequelae. The Icelandic environment is diverse, with one major urban area, and rural areas with small towns, villages, and farmland. The low population density, and thus significant distance to healthcare providers in rural areas, increases the likelihood of delayed emergency services (Olafsson and Sigurdsson 2000).

The present study was part of a larger, prospective, longitudinal research project, aimed at assessing the nationwide incidence and long-term cognitive and socioeconomic consequences of early THI.

In the present study, our aim was to estimate the prognostic value of injury severity, location of event, age at injury, gender and urban/rural residence, for reported symptoms of THI 4 years post-injury. An additional aim was to obtain information on what characterizes young THI patients who need specialized intervention in the sub-acute phase and long-term follow-up.

Material and methods

Patients

This prospective study comprised all 408 children and adolescents, 0–19 years old, consecutively diagnosed with THI, International Classification of Diseases 9 (ICD-9) 850–854 (WHO 1977), at Reykjavik City Hospital during the year from April 15, 1992 to April 14, 1993. Of the 408 patients, 343 were treated at the emergency unit of Reykjavik City Hospital and subsequently discharged, while 61 were hospitalized. Four received fatal THI.

By law, Icelandic adolescents take on most of the responsibilities of adults at 18 years of age, but we decided on an upper age limit of 19 rather than 17 years. The majority of Icelandic adolescents do not complete grammar school or trade school until age 20, are living with their parents, and rely on their support, almost certainly when traumatic events occur.

Procedures

At the time of the study, the only neurosurgical unit and the only computed tomography (CT) scanners in Iceland were located in Reykjavik. Practically all patients in Iceland diagnosed with or suspected of moderate or severe THI (ICD-9 851–854) were brought to the Reykjavik City Hospital by ambulance, helicopter, airplane, or by sea. When the diagnosis and degree of severity were uncertain, expert advice was available by telephone and transport to Reykjavik encouraged. Medical services were provided for minimal or mild THI by local hospitals and healthcare centers. The emergency unit of Reykjavik City Hospital served mainly the Reykjavik area. The study group included a nationwide sample of patients 0–19 years with moderate/severe THI, and a sample of same age patients with minimal/mild THI, the majority living in the Reykjavik area.

Information was collected on the age, gender, and urban/rural residence of THI patients, as well as the location of the traumatic event, cause of injury, injury severity, and ICD-9 diagnosis. The primary author ascertained new admissions daily, through information provided by neurosurgeons, other hospital personnel, and written and computerized hospital records.

Data were collected from the Icelandic Death Register (Statistics Iceland 2001) on patients who received fatal THI during the same period. Included were patients who died after being admitted to hospital and those who died at the scene or during transport to hospital.

We sent a short questionnaire 4 years post-injury to the custodial parents of the THI patients, or to the patients themselves if they had reached 18 years of age. The patient version of the questionnaire included three questions. Question one: Do you still have any symptoms that you attribute to the traumatic head injury you suffered 4 years ago? Answer “Yes” or “No”. Question two: If the answer to question one is “Yes”, please describe those symptoms in a couple of sentences. Question three: Have you sought professional advice regarding those symptoms. Answer “Yes” or “No”. The focus in the present study is on the results of answers to Question one.

The overall response rate to the questionnaire was 60%, comparable across sub-groups of age and gender. Approximately 58% of patients with minimal/mild THI and 66% of those with moderate/severe THI answered the questionnaire. Responders and nonresponders were comparable in age and gender distribution.

Four years post-injury, data were obtained from the State Social Security Institute (SSSI), to see if and why any of the 405 patients had been added to the list of children and adolescents receiving benefits intended for the disabled or chronically ill, since the time of injury. Patients’ identification numbers were sent to the SSSI without any reference to THI. The data from the SSSI could not be linked to patients’ names or identification numbers.

Classifications

All patients were classified according to ICD-9 (WHO 1977) diagnostic codes 850–854: ICD-9 850 denotes concussion; 851 cerebral laceration and contusion; 852 subarachnoid, subdural, and extradural hemorrhage following injury; 853 other and unspecified intracranial hemorrhage following injury; and 854 intracranial injury of unspecified nature. Corresponding diagnostic codes can be found in ICD-10, S06.0–S06.9 (WHO 1992).

Patients with more than one ICD-9 diagnosis were included if at least one of the diagnoses was in the 850–854 range. Patients with more than one 850–854 diagnosis were identified according to the most serious one.

Physicians diagnosed concussion following THI, based on clinical symptoms, such as loss of or reduced consciousness, confusion, dizziness, somnolence, nausea, or amnesia. ICD-9 851–853 diagnoses were made by neurosurgeons, based on cerebral CT findings.

In accordance with the Scandinavian Guidelines for Initial Management of Minimal, Mild, and Moderate Head Injuries (SNC Guidelines) (Ingebrigtsen et al 2000), concussed patients with Glasgow Coma Scale (GCS) (Teasdale and Jennett 1974) score 15, no loss of consciousness (LOC) and no signs of skull fracture or other complications, were not admitted to hospital, but discharged from the emergency unit with head injury instructions. Concussed patients with GCS scores lower than 15, or LOC, or amnesia, or signs of skull fracture, or other complications were hospitalized. Referral to cerebral CT was based on neurosurgical consultation and expert opinion on injury severity and complications.

We estimated injury severity according to the Head Injury Severity Scale (HISS) (Stein and Spettell 1995), and the SNC Guidelines (Ingebrigtsen et al 2000). Concussion with GCS score 15, no LOC, and no amnesia was classified as minimal THI. Concussion with GCS 14 or 15, brief (<5 minutes) LOC or amnesia, or impaired alertness or memory, was categorized as mild THI. The criteria for moderate THI were GCS 9–13, or LOC ≥ 5 minutes, or focal neurological deficit, or abnormal cerebral CT, or skull fracture. GCS 3–8 was classified as severe THI.

As the variables “Cause of THI” and “Where the THI took place” were related, we made a new variable based on the two, called “Location of event”. This variable had three categories: In the first category, “Home”, THI occurred at home, mainly caused by fall; in the second category, “Outside home”, THI occurred outside the home, for example in playgrounds, schools, sports facilities, including all causes other than motor vehicle or heavy machinery; and in the third category, "Motor vehicle", THI caused by motor vehicles and heavy machinery.

A distinction was made between patients living in the greater Reykjavik area (total population 0–19 years: 47,327), and patients living in rural areas and small towns and villages in other parts of Iceland (total population 0–19 years: 38,419). Reykjavik with its surrounding towns and suburbs is the only major urban area in Iceland. The largest town outside the Reykjavik area was Akureyri with a total population 0–19 years of 4,903.

The study group was divided according to gender. Boys were 58% of the total group of patients, 57% in the minimal/mild THI group and 63% in the moderate/severe group.

We converted answers to Question two of the questionnaire, Description of symptoms, into Glasgow Outcome Scale (GOS) scores (Jennett and Bond 1975), with criteria modified for infants and children (Ewing-Cobbs et al 1998; Barlow et al 2005): 1) Good Outcome: Return to age appropriate or pre-injury levels of functioning, even though there may be minor neurological or psychological deficits; 2) Moderate Disability: Significant reduction in cognitive functioning from estimated premorbid levels and personality changes; and/or motor deficits interfering with activities of daily living; and/or referral to outpatient rehabilitation or special education therapies; 3) Severe Disability: (Conscious but disabled). Cognitive functioning in the deficient range; and or severe motor deficits. Patient depends upon others for daily support due to mental or physical disability or both; 4) Persistent Vegetative State: Patient exhibits no obvious cortical function; and 5) Death.

Statistical analysis

Binary logistic regression was used to predict symptoms of pediatric THI 4 years post-injury. The full model contained the five plausible main effects, injury severity, location of event, age at injury, gender, and urban/rural residence. Backward elimination from the full model removed two nonsignificant effects, gender and urban/rural residence, leading to a model of the three remaining main effects. Statistical significance was calculated with chi-squares based on likelihood ratio. Age was coded as a second-degree polynomial allowing for a curvilinear effect for age. SPSS for Windows, Release 15.0.0 (SPSS Inc., Chicago, IL, USA), was used for the statistical analyses.

Ethics

The Icelandic Data Protection Commission, the Icelandic Medical Ethics Committee, and the medical directors concerned approved the protocol. Permission was obtained from Statistics Iceland regarding use of data from the Icelandic Death Register.

Results

The cross-classification by injury severity, location of event, age, and symptoms reported, resulted in uneven distribution of data. This led to sparse data in some subgroups, particularly for minimal/mild THI involving a motor vehicle. Overall, 49 patients suffered moderate/severe THI, about 12% of the total sample (Table 1).

The model adopted, containing the three main effects, severity of injury, location of event, and age at injury, was statistically significant ($\chi^2 = 63.9$, df = 3, $p < 0.001$). Figure 1 gives the fitted values of the model.

Symptoms reported 4 years post-injury were more common among patients with moderate/severe THI than among those with minimal/mild THI (odds ratio [OR] = 8.3, 95% confidence interval [CI] = 3.4–20.3, $\chi^2 = 20.9$, df = 1, $p < 0.001$).

Controlling for the two other effects of the main model, injury severity and age at injury, symptoms reported were related to location of event ($\chi^2 = 6.5$, df = 2, p = 0.039). Symptoms reported were least likely when injury took place at home, but increased when it took place outside the home (OR = 2.4, 95% CI = 0.5–10.5), and were most likely when motor vehicles and heavy machinery were involved (OR = 7.0, 95% CI 1.4–35.7).

Symptoms were least likely in the youngest age group (0–4 years), and substantially more likely in the 5–9 years and 10–14 years age groups than in the 15–19 years age group, resulting in a curvilinear age trend, $\chi^2 = 7.5$, df = 2, p = 0.024, as depicted in Figure 1.

We neither found an effect for gender ($\chi^2 = 0.003$, df = 1, p = 0.957) nor urban/rural residence ($\chi^2 = 1.7$, df = 1, p = 0.197).

One two-way interaction was significant: severity of injury by location of event ($\chi^2 = 6.1$, df = 2, p = 0.047). This interaction suggested that minimal/mild THI related to motor vehicles had fewer sequelae than minimal/mild THI from other causes outside the home, which we found implausible. Despite nominal significance, considering the few patients in the minimal/mild motor vehicle subgroup, as well as the theoretical intractability, we regarded the interaction as an instance of overfitting of random variations in the somewhat sparse data.

No three-way interactions were significant.

Of 19 patients who reported symptoms following minimal/mild THI, 13 (68%) complained of chronic headache. The remaining six (32%) reported physical, as well as

Table 1 Number of patients diagnosed with traumatic head injury (THI) (ICD-9 850–854) by age at injury, injury severity, location of event, and by symptoms, four years post-injury

Type of THI	0–4 years	5–9 years	10–14 years	15–19 years	Total
Moderate/severe THI[a]					
At home – symptom	0	1	0	0	1
At home – no symptom	11	1	1	0	13
Outside home – symptom	0	1	4	1	6
Outside home – no symptom	0	4	4	3	11
Motor vehicle – symptom or fatal	2	3	3	5	13
Motor vehicle – no symptom	1	0	1	3	5
Total number with symptoms	2	5	7	6	20
Total number injured	14	10	13	12	49
Minimal/mild THI					
At home – symptom	2	0	0	0	2
At home – no symptom	114	17	1	3	135
Outside home – symptom	0	5	9	3	17
Outside home – no symptom	52	49	61	34	196
Motor vehicle – symptom	0	0	0	0	0
Motor vehicle – no symptom	1	1	3	4	9
Total number with symptoms	2	5	9	3	19
Total number injured	169	72	74	44	359

Note: [a]All four cases of fatal THI were related to motor vehicle collisions. Fatal THI were included with symptoms following moderate/severe, motor vehicle-related THI.

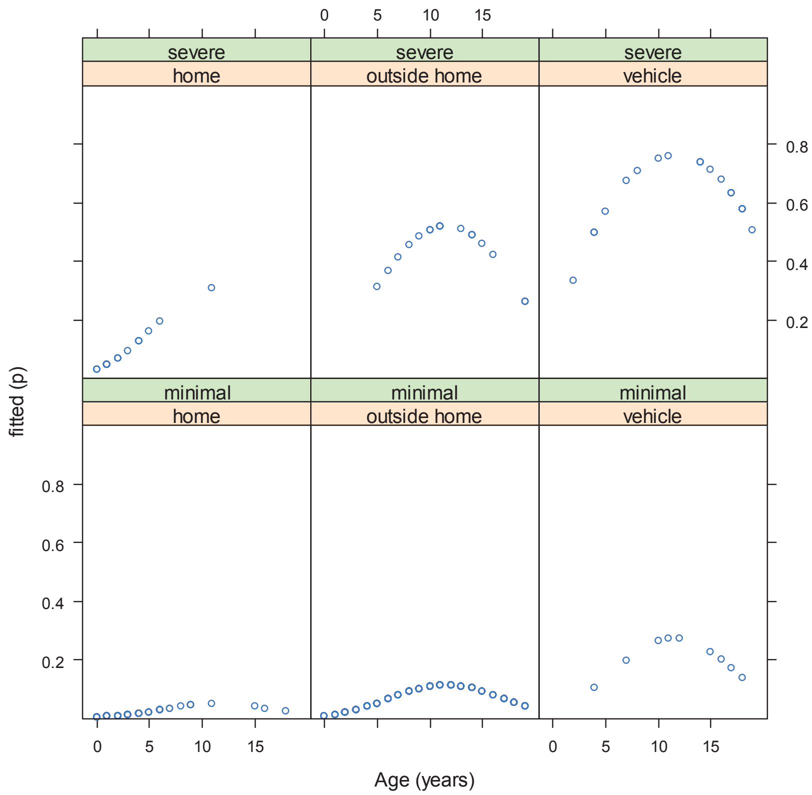

Figure 1 The fitted values of the model of the three main effects, traumatic head injury severity, location of event, and age at injury.

cognitive and adaptive symptoms, such as chronic headache, sleep disorder, motor problems, lack of concentration, problems with verbal expression, and obsessive-compulsive traits. Professional advice about symptoms had been sought in eight (42%) cases. According to GOS, 14 (74%) patients had a good outcome and five (26%) had moderate disability. Of the total group of patients with minimal/mild THI (n = 359), all but five (1%) had a good outcome.

In the group of 20 patients who reported symptoms following moderate/severe THI, three (15%) had physical complaints limited to chronic headache or loss of hearing. The rest of the patients reported a variety of physical, cognitive, and adaptive symptoms, such as sleep disorder, epileptic episodes, tic disorder and stuttering, motor problems and indications of hemiparesis, general slowness, lack of concentration, attention and stamina, problems with memory and verbal expression, change of personality and temper, lack of self-restraint, dependence, emotional problems, and depression. Fifteen (75%) patients had sought professional advice because of their symptoms. According to the GOS, five (25%) of the 20 patients had a good outcome, nine (45%) had moderate disability, two (10%) had severe disability, and four (20%) died. In the total group of 49 patients with moderate/severe THI, 34 (69%) had a good outcome, while 15 (31%) had moderate/severe disability or died.

Discussion

Results support the validity of symptoms reported, with more severe THI resulting in greater frequency of symptoms than less severe THI. The high risk of symptoms reported 4 years post-injury in moderate/severe THI, outside the home and motor vehicle related, indicates a need for specialized intervention and assessment in the sub-acute phase and subsequent follow-up for patients at risk of long-term sequelae.

We included fatal THI in the statistical analysis so that we would not run the risk of underestimating the severity of THI among children and adolescents. While admittedly not a reported symptom, death may be seen as an indicator of severe injury sequelae. For prevention purposes, it is important to note that all cases of fatal THI were related to high velocity motor vehicle collisions.

In line with previous research (Jennett 1998; Yeates and Taylor 2005), the present findings suggest that minimal/mild THI may lead to long-term sequelae. Nineteen (5%) of the 359 patients with minimal/mild THI reported late sequelae, stressing the need for instructions to parents on post concussion symptoms. Although assessment of THI severity in the acute phase provides valuable information regarding prognosis, based on well established criteria such as the HISS (Stein and Spettell 1995), it may not fully address the extent of neurological disruption and late neuropsychological sequelae.

Symptoms reported were positively related to the location of event 4 years post-injury. We suggest that this increase in symptoms reflects in part the increased force of impact, resulting in more extensive injuries. We propose that the majority of THI at home are low impact injuries, that there is an increase in force when THI takes place outside the home, for example in playgrounds, schools, and sport facilities, and that highest impact THI is most often related to motor vehicles and heavy machinery.

Previous research (Vane and Shackford 1995; Boswell et al 1996; DiMaggio and Durkin 2002) has shown that motor vehicle collisions are a common cause of serious brain injury, and that THI in young children caused by slipping, tripping or falling in the home is most often minimal or mild (Chang and Tsai 2007). Obviously, there are exceptions; even a relatively low fall in the home, the most common cause of THI in early age, may cause cerebral contusion or hemorrhage in infants and toddlers (Emanuelson and Wendt 1997). In our study, three 0–3 year old children were diagnosed with ICD-9 851–854, caused by falls in the home. These findings are important for injury prevention purposes.

There was a significant curvilinear age effect ($p < 0.05$), where symptoms reported were least likely in the youngest age group 0–4 years old, and most likely in the two age groups 5–9 and 10–14 years.

The relatively few cases of symptoms reported among children in the youngest age group, sustaining moderate/severe THI, were unanticipated, because the number of moderate/severe THI was identical across the four age groups, as was the parents' response rate to the questionnaire. Young children have not been found to recover better from brain injury than older children (Taylor and Alden 1997; Anderson et al 2000; Chapman and McKinnon 2000; Eslinger et al 2004; Giza and Prins 2006). In the present study, young children may, however, have received less extensive neurological injury than older ones. The actual severity may not have been fully captured in the injury severity variable. A later follow-up study is indicated to help clarify the age effect.

It may be speculated that other reasons than injury severity contribute to the low frequency of symptoms reported in the 0–4 year old. For example, healthcare professionals have more difficulty detecting THI severity in infants and young children than in older ones in the acute and sub-acute phase (Bernardi et al 1993; Dietrich et al 1993; Quayle et al 1997; Greenes and Schutzman 1998; Savitsky and Votey 2000; Schutzman et al 2001). Parents may also have greater difficulty discerning THI sequelae in infants and young children, than in older children and adolescents. Professional awareness regarding the sequelae of moderate/severe THI in infants and young children is indicated, as is support and instructions to parents.

In this vein, it may be added that 4 years post-injury, six of the younger children had been added to the SSSI records because of hyperkinetic disorder, conduct disorder, social adaptation disorder, sleep disorder, or tic disorder, without referring to the previous THI. Misdiagnosis may lead to less than optimal intervention and outcome.

Controlling for injury severity, location of event, and age at injury, we did not establish any relationship between gender and symptoms reported. In particular, we did not find evidence for the earlier finding that females recover better than males from THI (Groswasser et al 1998). While THI is more common in boys than girls, the results indicate that given the same severity, location of event and (possibly) age, similar specialized intervention and follow-up may be recommended regardless of patient gender.

In our study group, no significant differences were found between the Reykjavik area and rural areas in the incidence of moderate/severe THI (Halldorsson et al 2007), and in the present study, symptoms reported 4 years post-injury were not significantly related to urban/rural residence. This suggests that specialized intervention and follow-up must be accessible, in both urban and rural areas.

Limitations and future directions

The validity of the dependent variable, symptoms reported, may be open to question. In addition, there is the possibility of response bias. However, the content analysis of symptoms, and classification of symptoms according to GOS scores, suggesting that more complex symptoms and more serious outcomes on GOS relate to the more serious THI, lends increased support to the validity of the dependent measure.

A larger number of patients in some of the subgroups, such as minimal/mild, motor vehicle-related THI, would have been preferable for the statistical analyses. The proportional distribution of participants in the study, however, reflected the incidence of pediatric THI in Iceland. A validation of the present results in a larger sample is indicated.

There are uncertainties related to the classification of THI severity in the acute phase. For example, accurate information may be lacking with respect to length of loss of consciousness, and the extent of neurological injury may at times be underestimated. However, the HISS was applicable to the present data according to the SNC Guidelines in a consistent manner.

The wide age range makes interpreting our data more complicated, but at the same time, the age range and injuries of different severity are the strength of the study.

A follow-up of the study group is presently being planned, as well as a detailed questionnaire, and more objective measures of outcome. A large control group will be included. A subgroup of 50 patients with the more severe THI will undergo neuropsychological evaluation. The study may provide additional information regarding the late effects of early THI, its relationship to age at injury, and early prognostic symptoms.

Conclusions

The present study indicates the long-term consequences of pediatric THI. Our findings suggest that minimal/mild THI may in some cases lead to late sequelae, stressing the need for instructions to parents on post concussion symptoms. Because of increased risk of late sequelae, children and adolescents diagnosed with moderate/severe THI should receive specialized evaluation in the sub-acute phase with respect to their need for intervention and long-term follow-up. Patients with minimal/mild and moderate/severe motor vehicle-related THI need special consideration. Further research is needed on late sequelae of moderate/severe THI in the youngest age group, 0–4 years. Misdiagnosis may lead to less than optimal intervention and outcome.

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Paper IV

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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,

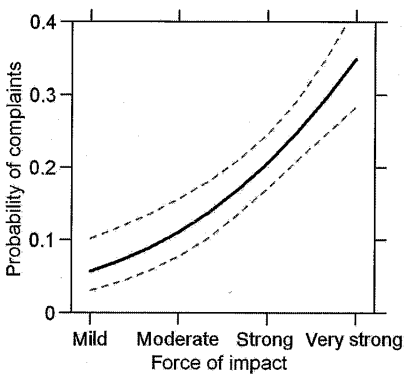

Figure 1 Greater force of impact increases the probability of long-term TBI-related complaints. The unbroken line shows the predicted probability and the dotted lines indicate 95% pointwise confidence envelope.

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.

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 reimbursements because of this
- ☐ Yes, I have received compensation or been evaluated regarding disability pension or reinbursement because of TIH consequences

Paper V

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

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Keywords: *Adolescents, children, longitudinal, nationwide, outcome, paediatric, prognosis, traumatic brain injury, young adults*

Running head: Long-term outcome of early traumatic brain injury

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 one-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 approximately 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.

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 pathophysiolgic 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 specialised intervention and follow-up may improve outcome [3-6]. In the absence of accurate data on pathophysiologic, 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 unrecognised or unmet need for health care 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 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 specialised 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.

Material 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 April 15, 1992 to April 14, 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 health care 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 years old (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 minimise 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 computerised patient records, on a daily basis during the one-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 one-year period, the first author collected computerised patient TBI data from all rural hospitals, EDs and health care 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 computerised 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 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 subgroup 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 (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 judgment 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.

Insert Table I about here

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).

Insert Table II about here

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 7 (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 six months and six years post-injury and 409 had been included in a mail questionnaire study four 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 approximately 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 percent 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') one 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, or problem with memory and concentration, or 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 $r = 0.75$ to $r = 0.86$, 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 Landspitali 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 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 = < 0.001) and GHQ (t (770) = 4.4; p = < 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 late 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, the symptom was only one. 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 min or PTA ≥ 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, coordinated 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 underestimation 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, underestimation, 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 specialised 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 specialised 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 six months, six 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 underestimated 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, <u>without being</u> transported to an emergency department (ED) or hospital?

☐ No

☐ Yes, once

☐ Yes, more than once

4. Have you been <u>transported to an ED</u> 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 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 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 reinbursement 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 specialised 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)
- Specialised employee (not with university degree)
- Office worker, clerk
- Attendant, salesman, or shop assistant
- Farmer
- Fisherman, sailor
- Tradesman
- Specialised 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 specialised 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)
- Specialised employee (not with university degree)
- Office worker, clerk
- Attendant, salesman, or shop assistant
- Farmer
- Fisherman, sailor
- Tradesman
- Specialised 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 Kjalarnes 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 specialised 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 (½-2 school years)

□ 5-8 semesters (2½-4 school years)

□ 9-16 semesters (4½-8 school years)

□ 17 semesters or more (8½ 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 to 2.9

□ 3.0 to 4.9

□ 5.0 to 6.9

□ 7.0 to 8.9

□ 9.0 to 10.0

*28. Please, answer the following statements.

I received remedial teaching in reading in grade school	□ No	□ Yes
I received remedial teaching in mathematics in grade school	□ No	□ Yes
I received remedial teaching in spelling in grade school	□ No	□ Yes
I received remedial teaching in hand-writing in grade school	□ No	□ Yes

Questions about your occupation

29. Please, answer the following questions.

a) Are you an employee?	☐ No	☐ Yes
b) Are you an employer?	☐ No	☐ Yes
c) Are you a student?	☐ No	☐ Yes
d) Is household work your main job?	☐ No	☐ Yes
e) Are you on maternity/paternity leave?	☐ No	☐ Yes
f) Are you ill or temporarily unable to work?	☐ No	☐ Yes
g) Are you unemployed?	☐ No	☐ Yes
h) Are you on 50-74% disability pension?	☐ No	☐ Yes
i) Are you on 75% disability pension?	☐ No	☐ Yes

30. Which of the following best describes your occupation?

☐ Elected public representative, highest officeholder, or chief administrator

☐ Specialist (with university degree)

☐ Specialised employee (not with university degree)

☐ Office worker, clerk

☐ Attendant, salesman, or shop assistant

☐ Farmer

☐ Fisherman, sailor

☐ Tradesman

☐ Specialised worker

☐ Worker

☐ I take care of the home

☐ I am a student with no paid job

☐ I have no paid job

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

Section	*Mail (unabridged version) Questions' numbers*	*Telephone (abbreviated version) Questions' 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.

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

	Individuals contacted		
Response	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.