Participation of children and youth with acquired brain injury

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Chapter 2
Youth with Acquired Brain Injury in The Netherlands: a multi-centre study

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ABSTRACT

Aim To describe the occurrence and causes of acquired brain injury (ABI), including traumatic brain injury (TBI) and non-traumatic brain injury (NTBI), among Dutch youth and estimate incidence rates from the data.

Patients Aged 1 month-24 years, hospital diagnosed with ABI in 2008 or 2009.

Methods In three major hospitals in the southwest region of the Netherlands patients with ABI were retrospectively identified by means of diagnosis codes and specific search terms.

Results One thousand eight hundred and ninety-two patients were included: 1476 with TBI and 416 with NTBI. Causes of TBI and NTBI varied among the age groups 0-4, 5-14 and 15-24 years, with accidents (in traffic or at home) being the most common cause of TBI and hypoxic-ischemic events for NTBI, in all groups. The estimated yearly incidence rates per 100 000 for mild-moderate-severe TBI were 271.2-15.4-2.3 (0-14 years) and 261.6-27.0-7.9 (15-24 years), for mild-moderate-severe NTBI 95.7-11.8-1.3 (0-14 years) and 73.8-6.1-1.6 (15-24 years), respectively.

Conclusion More than 15% of TBI and NTBI in children and youth is classified as moderate or severe, with causes of TBI and NTBI varying among age groups. Based on the occurrence of ABI in three hospitals, the estimated incidence of ABI in children and youth in the southwest region of the Netherlands is substantial.

INTRODUCTION

Acquired brain injury (ABI) in children, youth and young adults may result from events with an external cause (traumatic brain injury, TBI) or internal cause (non-traumatic brain injury, NTBI) such as a brain tumour, stroke or infections such as meningitis or encephalitis.[1]

ABI in children and youth has been designated as a neglected area in medicine[2] and a 'silent epidemic'.[3] TBI is considered to be the most common cause of death or disability among children, youth and young adults.[4] Epidemiological studies in youth have mainly focused on TBI in the age group up to 14 years, reporting annual rates varying from 70 to 798 per 100 000 persons per year in the age group 0-14 years.[4-12]

Data on the incidence of NTBI in children, youth and young adults are only available for specific causes. The reported incidence of stroke varied from 2.1 (Hong Kong)[13] and 2.7 (USA)[14] to 13.0 (France)[15] per 100 000 persons per year in the age group 0-14 years. The incidence of brain tumours varies in the literature from 2.8 (USA)[16] to 25 (UK)[17] per 100 000 persons per year in the age group 0-14 years. To our knowledge, data on the incidence of TBI and NTBI taking the age group of 15-24 years and older into account are not yet available.

Concerning the causes of ABI, several studies have focused on accidents as the cause of TBI in children and youth,[3,5,6,8,9,12] with a number of other studies addressing specific causes as: shaken baby syndrome,[18] violence[19] or alcohol intoxication.[20] All of these studies included different age groups.

More exact figures on the incidence and outcome of ABI resulting from all possible causes in children and youth are needed to raise awareness on the large number of young patients with ABI. These data will help to underscore the need of facilitation and planning of prevention, screening and the provision of care, including both educational facilities as well as rehabilitation care, with a focus on social and societal participation.[21-26] The availability and provision of care for patients with ABI was found to be highly variable and a considerable proportion of cases appear to remain undiagnosed and thus may not receive adequate treatment and follow-up.[1,12,22-26]

Given the lack of knowledge on ABI in children, youth and young adults, the aim of this study was to determine the occurrence and causes of TBI and NTBI in children and youth up to 24 years of age. An additional aim was to estimate the incidence rates for the southwest region of the Netherlands.

METHODS

Design

This study was a multicentre, retrospective hospital-based cohort study. Part of this study, including data from patients with TBI from one centre (Erasmus University Medical Centre in Rotterdam, the Netherlands) in a different time period (2007 and 2008) has been recently published.[27]

The present study was done using a cohort in 2008 and 2009 in three large tertiary care hospitals in two large cities in the southwest region of the Netherlands, including TBI as well as NTBI. The hospitals involved were a university hospital (Erasmus University Medical Centre, Rotterdam, including the Sophia Children's Hospital) and two large teaching hospitals (Haga Hospital, including the Juliana Children's Hospital, The Hague and Medical Centre Haaglanden, The Hague).

This study was approved by the medical ethical committee (METC) of the Erasmus University Medical Centre Rotterdam (MEC-2009-440).

Patients

Patients aged 1 month-24 years with a diagnosis of ABI who presented between 1 January 2008 and 31 December 2009 were retospectively identified in one of the three hospitals.

For this purpose, we used the electronic medical databases of the Intensive Care Units and all outpatient and inpatient wards.

Patients were first selected by age and subsequently a search was performed using diagnosis codes (diagnosis treatment combination (DBC)-codes) and search terms related to ABI. DBC-codes are used in the Netherlands to specify finances in health care. They are derived from the International Statistical Classification of Diseases and Related Health Problems (ICD-codes).[28] The computer-based search strategy included the following terms found in the medical records: minor head injury, traumatic brain injury, concussion, skull/brain trauma, neurological trauma, epilepsy, brain tumour, stroke, infections (meningitis/ encephalitis), post anoxia and otherwise (non-traumatic diagnosis).

Fatal injuries, i.e. patients that died after an incident before arrival at the hospital, were not included in our study. Patients with TBI categorized as Trauma Capitis (abnormalities of the skull without brain symptoms) were recorded but excluded from this study. If patients appeared to have repetitive head injuries, only the first incident was included, to assure an independent sample. The selection procedure was identically performed in all hospitals, except for the patients aged 15-24 years of age with NTBI, of whom the medical records of the University Medical Centre in Rotterdam were not available for this study.

Data collection

This study collected characteristics of patients with ABI for the age groups 0-14 en 15-24 years of age, to facilitate comparisons with the international literature. In addition, the youngest age group was split in two subgroups to describe the causes of ABI. This subdivision is based on general accepted developmental stages and corresponds reasonably with transitions in school systems and hospital care: preschool children (0-4 years), children (5-14 years) and youth (15-24 years).

Data were collected from the selected patient files by four trained research assistants under supervision of the principal investigator, using a standardized registration form including sociodemographic and disease characteristics. Data were registered anonymously.

Sociodemographic data

Gender was recorded and age in years at presentation was calculated using the date of birth and the date of ABI diagnosis recorded in the patient file. Postal code was recorded to determine whether patients were living in the referral area of the hospitals.

Severity

Severity of TBI was scored using the description at the time of presentation in the emergency room, as scores at the site of trauma were usually not available. The Glasgow Coma Scale (GCS)[29] was used in patients older than 2 years of age and the paediatric version of the GCS was used in young pre-verbal children (2 years or younger).[30] TBI was considered mild if the GCS was 13-15, moderate if the GCS was 9-12 or severe if the GCS was <9.[31]

The severity of NTBI, determined at the time of discharge after the first admission to the hospital for this particular problem, was scored by means of an adapted version of the modified paediatric Rankin Scale (mRS)[32] (school performance not taken into consideration):

1. Mild injury: no limitations (mRS 0,1).
2. Moderate injury: mild motor impairments and/or mild problems with learning (mRS 2,3).
3. Severe injury: severe motor impairments and/or severe problems with learning (mRS 4,5).

In addition, mRS 6 was used in case of death during hospitalization.

Causes

For TBI the following causes of injury were registered: 1. traffic accident, 2. accident at home, 3. sport accident, 4. accident at (pre)school, 5. accident playing outdoors, 6. (suspicion of) physical abuse, 7. fall under influence of alcohol or drugs intoxication, 8. fall under influence of epileptic seizure or syncope or 9. unknown.

For NTBI, the following causes were recorded: 1. tumour, 2. meningitis or encephalitis, 3. stroke, 4. ADEM (Acute Disseminated Encephalo Myelitis), MS (Multiple Sclerosis) or acute CNS (Central Nervous System) demyelinating disease otherwise, 5. hypoxic-ischemic, or 6.

otherwise. All relatively rare causes, e.g. Hashimoto encephalopathy and missing causes were classified as 'otherwise'.

Estimated incidence rates

In order to estimate incidence rates, we proportionally assigned missing data regarding severity of TBI (13 cases) and NTBI (54 cases) to a category of severity, according to known valid percentages and calculated the mean number of patients per year (average of 2008 and 2009). We divided the number of patients identified by the number of age-matched young people of the population living in the referral areas of the hospitals, and the result was multiplied by 100 000. The total number of young people (0-14 years and 15-24 years) living in the referral areas in 2008 and 2009 was extracted from data of the research departments of the hospitals, the Regional and Central Institutes of Statistics.[33-36] For this purpose, the variation for three levels of care provided (standard, specialized and intensive care) and the referral areas of other hospitals in both cities were taken into account. The following figures were used as the denominator:

For standard care (mild TBI, NTBI): Haga and MCH The Hague combined (0-14 years: 84 014; 15-24 years: 59 641),[35] the Erasmus University Hospital Medical Centre Rotterdam (0-14 years: 42 456; 15-24 years: 34 684.[34]

- For specialised care (moderate TBI, NTBI): Haga and MCH combined (0-14 years: 136 112; 15-24 years: 90 904),[34] the Erasmus University Hospital Medical Centre Rotterdam (0-14 years: 90 995; 15-24 years: 74 347).[33]
- Intensive care (severe TBI, NTBI): for 0-14 years old the referral areas of Rotterdam and The Hague were combined, due to the supra-regional function of both children hospitals (0-14 years: 415 034);[33-36] Haga The Hague: 15-24 years: 126 886),[34] the Erasmus University Hospital Medical Centre Rotterdam (15-24 years: 177 195.[33]

As one hospital did not supply data of people in age group 15-24 years with NTBI, results on NTBI in 15-24 years old were registered and analysed in the The Hague cohort only.

To extrapolate results to the Dutch population we calculated using the number of inhabitants on January 1st, 2009; 2 915 000 (0-14 years), 2 015 000 (15-24 years).[36]

Statistical analyses

The study used SPSS statistical software, version 17[37] to analyse the data.

Using percentages, characteristics of the patients and ABI were described separately for the age groups 0-14 and 15-24 years of age. To describe the causes of TBI, the youngest age group was split in two subgroups: pre-school children (0-4 years) and school children (5-14 years). Using the Chi-Square test differences in gender, severity and causes of ABI were determined for the two ages groups, for both TBI and NTBI. To adjust for the large number of tests performed, the level of significance α was set at 0.001.

Confidence intervals for the registered incidence rates were calculated according to the (recommended) Wilson method, using Confidence Interval Analysis (CIA) (2.0.0); 2000 (Trevor R. Bryant).

RESULTS

In total 3930 patients were diagnosed with head injury with or without brain symptoms or NTBI in the electronic registries of the three hospitals in 2008 and 2009.
Of these patients 2036 were excluded because they were diagnosed with trauma capitis without brain symptoms. Two other patients were excluded because they were referred from The Hague to Rotterdam and were registered twice.
Hence, the sample consisted of 1892 patients with TBI or NTBI, including 35 patients who died during hospitalization (16 patients with a diagnosis of TBI and 19 with a diagnosis of NTBI).

Characteristics of patients with TBI and NTBI
The characteristics of the patients are shown in Table 1.

Table 1 Patient characteristic for youth with ABI in 2008 and 2009, in 3 major hospitals in The Hague and Rotterdam, broken down into two age groups

Characteristic	TBI			NTBI		
Age	0-14 yrs	15-24 yrs	p-value	0-14 yrs	15-24 yrs[a]	p-value
Number of included patients	842	634		313	103	
Gender Male	473 (56.2%)	454 (71.6%)	**p<0.001**	185 (59.1%)	55 (53.4%)	p=0.31
Severity[b]						
Mild	726 (86.2%)	489 (77.1%)	**p<0.001**	215 (68.7%)	75 (72.8%)	p=0.24
Moderate	74 (8.8%)	94 (14.8%)		41 (13.1%)	9 (8.8%)	
Severe	37 (4.4%)	43 (6.8%)		19 (6.1%)	3 (2.9%)	
Missing	5 (0.6%)	8 (1.3%)		38 (12.1%)	16 (15.5%)	

[a] based only on cohort The Hague
[b] severity of TBI at presentation in the emergency room; severity of NTBI at discharge from the hospital

Overall, TBI occurred more frequently than NTBI in all age groups. In both patient groups with TBI and NTBI the majority of patients were male. In the patients with TBI there was a difference among age groups regarding gender, with more male patients in the 15-24 year old group as compared with the 0-14 year old group. With respect to severity, the large majority of cases were mild: 82.4% and 81.4% in TBI and NTBI, respectively. In the TBI group, the frequency of mild TBI was higher in the younger group as compared with the older age group. In the NTBI group the age groups did not differ with respect to severity.
Table 2 shows that overall traffic accidents and accidents at home were the most common causes of TBI and hypoxic-ischemic incidents for NTBI.

Table 2 Distribution of causes of Traumatic Brain Injury and Non-Traumatic Brain Injury for 3 age categories

TBI causes frequency (%) n=1422[a]	**1: 0-4 years**	**2: 5-14 years**	**3: 15-24 years**	**p-value**
traffic accident	31 (8.1)	136 (30.1)	237 (40.0)	<.001
accident at home	268 (72.6)	66 (13.1)	36 (5.9)	<.001
sports accident	0 (0.0)	77 (16.6)	59 (10.3)	<.001
accident at (pre)school	15 (4.2)	36 (8.2)	22 (3.6)	.003
accident playing outdoor	51 (13.5)	104 (24.1)	27 (4.3)	<.001
(suspicion of) abuse	4 (0.8)	33 (5.8)	147 (25.6)	<.001
fall under influence alcohol/drugs	0 (0.0)	1 (0.2)	58 (9.5)	<.001
collaps cause unknown	1 (0.3)	9 (1.9)	4 (0.8)	.06

NTBI causes frequency (%) n=313[b]	**1: 0-4 years**	**2: 5-14 years**		
tumour	21 (14.4)	44 (27.5)		.004
meningitis/encephalitis	60 (32.5)	21 (13.1)		<.001
stroke	13 (8.7)	10 (4.5)		.14
neurological disorders otherwise	4 (2.5)	2 (2.0)		.75
hypoxic-ischemic	65 (39.4)	71 (47.7)		.12
otherwise	4 (2.5)	12 (5.2)		.21

[a] cause unknown excluded
[b] NTBI 15-24 years cannot be compared with other age groups: based on cohort The Hague only

In patients with TBI aged 0-4 years, accidents in or around the house were the most common, whereas in patients aged 5-14 and 15-24 years traffic accidents were the most frequent cause. The proportion of patients in whom suspicion of abuse and a fall under influence of

alcohol and/or drugs were recorded as the cause of TBI seemed to increase with age.
Table 2 shows that the differences between the three age groups were significant (df=2; p<0.001) for all causes of TBI except for collapse with unknown cause.
With respect to the causes of NTBI, meningitis and encephalitis were relatively frequent in the 0-4 year old group, whereas brain tumours showed a peak in 5-14 year old group. Stroke occurred with a relatively similar frequency in the three age groups. The differences between the age groups 0-4 and 5-14 years were significant (df=2; p<0.001) for the causes tumour, meningitis/ encephalitis and otherwise. Table 3 shows the estimated incidence rate for TBI and NTBI in the southwest region of the Netherlands, based on different referral areas for standard, special and intensive care.

Table 3 Estimated annual incidence with the 95% Confidence Interval (per 100.000) of Acquired Brain Injury in youth up to 24 years in the south-western region of the Netherlands broken down in two age groups

	Traumatic Brain Injury (TBI)			**Non-traumatic Brain Injury (NTBI)**		
	Estimated incidence rate based on all data	Estimated incidence rate based on The Hague data	Estimated incidence rate based on Rotterdam data	Estimated incidence rate based on all data	Estimated incidence rate based on The Hague data	Estimated incidence rate based on Rotterdam data
0-14 yrs	288.9			108.8		
Mild	271.2	324.4 (288.7-365.8)	217.9 (178.9-268.3)	95.7	99.4 (80.8-123.8)	91.9 (67.2-125.5)
Moderate	15.4	20.9 (14.8-30.6)	9.9 (5.2-18.8)	11.8	4.4 (2.0-9.6)	19.2 (12.5-31.3)
Severe	2.3	0.6 (0.2-2.1)	3.9 (2.4-6.3)	1.3	1.0 (0.5-2.8)[b]	1.5 (0.7-3.2)
15-24 yrs	296.5			81.5[a]		
Mild	261.6	256.5 (219.0-300.5)	266.7 (218.9-328.3)	73.8	73.8 (55.0-99.0)	
Moderate	27.0	41.8 (30.5-57.4)	12.1 (6.4-23.0)	6.1	6.1 (3.0-14.4)	
Severe	7.9	6.7 (3.7-13.5)	9.0 (5.6-14.7)	1.6	1.6 (0.4-5.7)	

[a] based on cohort The Hague 15-24 years only

[b] Intensive care for severe TBI and NTBI 0-14 years in cohorts The Hague and Rotterdam in 1 specialised hospital (Erasmus/Sophia)

Bold point estimations are summed to produce an estimation of the total relative incidence of TBI and NTBI per age group. Extrapolating these estimated incidence rates to absolute numbers in the Dutch population[36] this would imply that more than 12 000 (0-14 years) and 7000 (15-24 years) have a hospital-based diagnosis of TBI or NTBI in the Netherlands each year.

DISCUSSION

This multicentre study shows that the incidence of ABI in patients up to 24 years of age in the southwest region of the Netherlands is substantial, with about 1.6-7.9% of both TBI and NTBI being severe. Causes of ABI were found to vary largely among age groups.

With respect to the causes of TBI our study demonstrated differences in the distribution of causes among age groups. Our study showed in particular a higher percentage (suspicion of) physical abuse in 15-24 years old compared to Guerrero (24.9% vs 8.2%).[6] In the age group 0-4 years we registered (suspicion of) physical abuse as the cause in 0.8% of cases, a lower percentage than reported in other studies,[18] especially referring to Shaken Baby Syndrome.[38] These findings stress that health care providers working at Emergency Room Services and Intensive Care Units should be more alert to the signs and symptoms of abusive head injury; physical abuse should be a standard issue of registration.

Andersson[9] et al. reported frequencies of causes for TBI in children between 7-12 years of age in the western part of Sweden, including accidents during playing outdoors (school, public place, playground) (39%), in traffic (14%), during sports (12%), or at home (5%). This study finds a similar ranking with slightly different proportions in 0-14 year old group, but striking differences between 0-4 and 5-14 year old groups. These results underline the need to tailor prevention of TBI to different age groups according to risk factor based strategies. Regarding the planning of the follow-up of patients with TBI, it should be noted that no evidence was found to suggest a threshold of injury severity below which the risk of late sequelae could safely be discounted.[39] Taking into account the most common causes, prevention should be targeted to accidents at and around home in children younger than 5 years of age, to traffic accidents in primary school children (5-14 years old) and at the usage of alcohol and drugs in youth in secondary or high school (15-24 years old). In addition, the results indicate that awareness and prevention of physical abuse is important in all age groups. In the youngest age group we noticed that inadequate fixation in a car seat, chair or stroller was frequently the cause of mild TBI. Raising awareness in parents and care takers of such risk factors for TBI in the very young is warranted.

Regarding the incidence of ABI, incidence rates were estimated using number of persons in the same age range in the referral areas of the hospitals involved, which can then be compared with rates reported in the literature. For TBI, the estimated incidence rates from the present study (mild 271.2-moderate 15.4-severe 2.3 per 100 000/year) for children aged 0-14 years of age are similar to recent figures from the United Kingdom (280 per 100 000/year),[7] whereas earlier studies reported somewhat lower rates in the Netherlands (243 per 100 000).[8] Higher rates were found in Estonia (369/100 000/year, 0-14 years of age)[11] and Germany (581/100 000/year, 0-14 years of age).[12] Langeois[3] found an incidence rate of 798.8 per 100 000/year (USA, 2004) in TBI 0-14 years of age, but included head injury without brain symptoms as well.

For youth aged 15-24 years of age no comparable data were found in the literature. Regarding the incidence of NTBI in children and youth, the estimated incidence rates from the current study are lower than those of TBI, but still considerable. As in the literature data on the incidence of NTBI in children, youth and young adults are only available for specific causes, no direct comparisons with the present study can be made. Given the scarcity of data on NTBI, the challenge for the future is to gain more insight into the incidence of NTBI in children and youth. The results of the current study suggest that NTBI is a substantial group and should be integrated in ABI policy, education, innovation and research. Differences in estimated incidence rates between the present study and previous studies may be explained by differences in definitions of ABI, classification and methodology. These results underscore the need for experts in this field to initiate consensus meetings and support the process of attaining international consensus. Through this consensus guidelines can be developed and implemented worldwide.

This study has a number of limitations. First, differences in estimated incidence rates were found between the hospitals in two cities. This may be explained by differences in classification of Trauma Capitis and mild TBI as the criteria for Trauma Capitis, mild or moderate TBI are not solidly distinctive or undisputed. The higher number of patients 0-14 years of age with severe TBI in the Rotterdam cohort 0-14 years of age can be explained by the presence of an Intensive Care Unit for children in the Erasmus University Hospital Medical Centre Rotterdam/Sophia Children's Hospital.

The estimation of the magnitude of the source population is arbitrary, hospital-based data about referral areas for ABI up to 24 years were not complete. It should be noted that there are differences between the estimated incidence rates in the present study and those reported in a previous publication presenting only the data on TBI from one region (Rotterdam).[27] In the previous study the estimation was based on a cohort in 2007-2008, with regional statistics, whereas in the present study concerning 2008-2009 more accurate (i.e. distinction in age groups; adherent general practitioners for standard care) data were used to define referral areas.

Moreover, the data were gathered retrospectively. Therefore it is conceivable that data were incomplete or classifications were inconsistent. To diminish observer bias in this study a standardized registration form and trained research assistants were used. To account for variations in incidence, cases were registered over 2 years. Another limitation was that the results in the NTBI 15-24 years of age group were based only on data from hospitals in The Hague.

Although we gathered data from three hospitals, these were all situated in urban regions: The Hague as city with metropolitan region Haaglanden, Rotterdam as city with metropolitan region Rijnmond. The incidence of TBI may be different in rural areas, e.g. because of a different traffic density. The number of hospital registered mild TBI cases may be higher

than in a rural area, where the general practitioner will manage most cases of mild TBI. Furthermore, the cities of Rotterdam and The Hague appeal to students and tourists for study, work and leisure time. However, a postal code check showed that no more than 2% of the included group with moderate TBI and NTBI in both cities had a postal code out of the referral area. It is assumed that a similar percentage of youth from inside the referral area will be diagnosed with ABI yearly in a hospital outside the referral area. Finally, this is a hospital-based and not a population based study. Patients with relatively mild TBI may not always be seen in a hospital, and for a minority of mild NTBI this may also be the case leading to an underestimation of incidence. Brown estimated the 'undiagnosed' incidence of mild TBI to be 3-5 times higher than the diagnosed incidence.[40] Despite the limitations, the results of this study give more insight into the incidence of children and youth with ABI in the southwest region of the Netherlands and may help to facilitate and stimulate planning of prevention, screening and the provision of care, including both educational facilities as well as rehabilitation care for this group.
Considering the incidence of ABI in youth, awareness for this problem should be enlarged, affecting healthcare and society in general. Preventive measures should be taken. Taking into account the enlarged risk for long term health problems, with consequences for psycho-social functioning, participation and quality of life for youth and their families, health policy needs urgent attention.

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Declaration of Interest

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REFERENCES

1. Gillett J. The Paediatric Acquired Brain Injury Community Outreach Program (PABICOP) - an innovative comprehensive model of care for children and youth with an acquired brain injury. Neurorehabilitation 2004;19:207-18.
2. Langeois JA, Rutland-Brown W, Thomas KE. The incidence of Traumatic Brain Injury among children in the United States. Journal of Head Trauma Rehabilitation 2005;20:229-39.
3. Kraus JF, Rock A, Hemyari P. Brain injuries among infants, children, adolescents and young adults. American Journal of Diseases of Children 1990;144:684-91.
4. Javouhey E, Guérin AC, Amoros E, Haddak M, Ndiaye A, Floret D, Chiron M. Severe outcome of children following trauma resulting from road accidents. European Journal of Pediatrics 2005;165:519-25.
5. Guerrero JL, Thurman DJ, Sniezek JE. Emergency department visits associated with traumatic brain injury: United States, 1995-1996. Brain Injury 2000;14:181-86.
6. Hawley CA, Ward AB, Long J, Owen DW, Magnay AR. Prevalence of traumatic brain injury amongst children admitted to hospital in one health district: a population-based study. Injury 2003;34:256-60.
7. Meerhoff SR, de Kruijk JR, Rutten J, Leffers P, Twijnstra A. Incidence of traumatic head or brain injuries in catchment area of Academic Hospital Maastricht in 1997. Nederlands Tijdschrift voor Geneeskunde 2000;144:1915-18.
8. Andersson EE, Lund J, Mansson J. Traumatic brain injury in children between 7-12 years of age. Developmental Neurorehabilitation 2010;13:346-50.
9. Schneier AJ, Shields BJ, Hostetler SG, Xiang H, Smith GA. Incidence of paediatric traumatic brain injury amongst children. Pediatrics 2006;11:483-92.
10. Ventsel G, Kolk A, Talvik I, Väli M, Vaikmaa M, Talvik T. The incidence of childhood traumatic brain injury in Tartu and Tartu County in Estonia. Neuroepidemiology 2008;30:20-24.
11. Rickels E, Wild K von, Wenzlaff P. Head injury in Germany: A population-based prospective study on epidemiology, causes, treatment and outcome of all degrees of head-injury severity in two distinct areas. Brain Injury 2010;24:1491-1504.
12. Chung B, Wong V. Pediatric stroke among Hong Kong Chinese subjects. Pediatrics 2004;114:206-12.
13. Broderick JP, Brott TG, Duldner JE. Stroke in children within a major metropolitan area: the surprising importance of intracerebral haemorrhage. Journal of Child Neurology 1993;3:250-55.
14. Giroud M, Lemesle M, Gouyon JB. Cerebrovascular disease in children under 16 years of age in the city of Dijon, France: a study of incidence and clinical features from 1985 to 1993. Journal of Clinical Epidemiology 1995;48:1343-48.
15. Bunin G. What causes childhood brain tumors? Limited knowledge, many clues. Pediatric Neurosurgery 2000;32:321-26.
16. Cancer Research UK. Population base figures. www.cancerresearchuk.orgbrain/cancerstats/types/incidence.nl; 18-11-2011. Ref Type: Electronic citation.
17. Christian CW, Block R. Abusive head trauma in infants and children. Pediatrics 2009;123:1409-11.
18. Gerhart KA, Mellick DC, Weintraub AH. Violence-related traumatic brain injury: a population-based study. Journal Trauma 2003;55:1045-53.
19. De Guise E, Leblanc J, Dagher J, Lamoureux J, Jishi AA, Maleki M, Marcoux J, Feyz M. Early outcome in patients with traumatic brain injury, pre-injury alcohol abuse and intoxication at time of injury. Brain Injury 2009;23:853-65.
20. Falk AC, Klang B, Paavonen EJ, Wendt L von. Current incidence and management of children with traumatic head injuries: the Stockholm experience. Developmental Neurorehabilitation 2007;10:49-55.
21. Hawley CA. Behavioural and school performance after brain injury. Brain Injury 2004;18:645-59.
22. Todis B, Glang A. Redefining success: Results of a qualitative study of post-secondary transition outcomes for youth with traumatic brain injury. Journal of Head Trauma Rehabilitation 2008;23:252-63.
23. Bedell GM, Dumas HM. Social participation of children and youth with acquired brain injuries discharged from inpatient rehabilitation: a follow-up study. Brain Injury 2004;18:65-82.
24. Barrera M, Schulte F, Spiegler B. Factors influencing depressive symptoms of children treated for a brain tumor. Journal of Psychosocial Oncology 2008; 26:1-16.
25. Galvin J, Hewish S, Rice J, Mackay MT. Functional outcome following paediatric stroke. Developmental Neurorehabilitation 2011;14:67-71.
26. Pelt D van, Kloet AJ de, Hilberink SR, Lambregts SA, Peeters E, Roebroeck ME, Catsman-Berrevoets CE. The incidence of traumatic brain injury in young people in the catchment area of the University Hospital Rotterdam, the Netherlands. European Journal of Paediatric Neurology 2011;15:519-26.
27. World Health Organisation (WHO). International Classification of Functioning, Disability and Health. Geneva 2007.
28. World Health Organization (WHO). International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY). Geneva 2007.
29. World Health Organization (WHO). International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY). Geneva 2001.
30. Teasdale G, Jennett B. Assessment of coma and impaired consciousness: a practical scale. Lancet 1974;13:81-84.

31. Holmes JF, Palchak MJ, MacFarlane T, Kuppermann N. Performance of the paediatric Glasgow coma scale in children with blunt head trauma. Academic Emergency Medicine 2005;12:814-19.
32. Dunning J, Daly JP, Malhotra R, Stratford-Smith R, Lomas JP, Lecky F, Batchelor J, Mackway-Jones K. The implications of NICE guidelines on the management of children presenting with head injury. Archives of Disease in Childhood 2004;89:763-67.
33. Bonita R, Beaglehole R. Modification of Rankin Scale: Recovery of motor function after stroke. Stroke 1988; 19:1497-1500.
34. Statistics Rotterdam. Population base figures. www.cos.rotterdam.nl; 01-09-2011. Ref Type: Electronic citation.
35. Statistics the Hague. Population base figures. www.haaglandenincijfers.nl; 01-09-2011. Ref Type: Electronic citation.
36. Statistics Zeeland. Population base figures. www.cbs.nl; 01-09-2011. Ref Type: Electronic citation.
37. Statistics Netherlands. Population base figures. www.cbs.nl; 01-09-2011. Ref Type: Electronic citation.
38. Statistical Package for the Social Studies, version 17.0. SPSS Incorporated Chicago, December 2008.
39. National Centre on Shaken Baby Syndrome, UTAH (USA). www.dontshake.org; 01-09-2011. Ref Type: Electronic citation.
40. Hawley CA, Ward AB, Magnay AR, Mychalkiw W. Return to school after brain injury. Archives of Disease in Childhood 2004;89:136-42.
41. Gordon W, Brown M. Mild traumatic brain injury: identification, the key to preventing social failure. Brain Injury Professional 2008;5:8-11.
42. Tenovuo O. Centres for treatment, research, education and prevention for Traumatic Brain Injuries. Oral presentation during International Brain Injury Association; Lisboa, Portugal 2010.