Department of Woman and Child Health
Paediatric Neurology
Karolinska Institutet, Stockholm, Sweden

HEAD INJURIES IN CHILDREN; INCIDENCE, SEQUELE AND INFORMATIONAL NEEDS

Ann-Charlotte Falk

Stockholm 2008

Published by Karolinska Institutet and printed by US-AB
Box 200, SE-171 77 Stockholm, Sweden

ISBN 978-91-7357-431-0

"No head injury is too severe to despair of,
nor too trivial to ignore"

Hippocrates (approx. 460 BC – 370 BC)

ABSTRACT

The **aim** is to describe head injury characteristics, assessments, classification and occurrence of head injury symptoms, post head injury symptoms and informational needs among children in the age-group 0-15.9 years and information provided to their families.

Participants were 3,168 children (0-15.9 years) with a head injury, who visited an Emergency Department during one year. Of these children, various samples were included in the different articles.

The **design** was a cross-sectional with a follow-up at three months after the incident.

Methods were: Review of the documented initial diagnosis, symptoms and management at the hospital and questionnaires (Rivermead postconcussion questionnaire (RPQ), Rivermead head injury follow-up questionnaire (RHFUQ), Karolinska postconcussion questionnaire (KPCQ) and a questionnaire about the perception of given information which included one open-ended item) at three month months post injury. Different statistical methods were used in the analysis of the quantitative items and content analyse was used in for the open-ended question.

The Results showed that the annual *incidence* of head injury was 865 /100,000 children with the highest incidence among children less than 18 month of age (2379/100,000). The most frequent *external cause* of injury was falls (68%) followed by road and traffic accidents (9%). Fifty percent of all children were *observed* for some time in the Emergency Department and 12 percent were admitted for further observation. CT scans were performed in 13 percent of the children with 108 positive findings. Very few children required neurosurgical intervention. No connection was found between the documented signs and symptoms and management in the hospital.

The Scandinavian Head Injury Classification (SHIC) more accurately reflected management in the hospital than the ICD-10 discharge diagnosis. Some differences could be seen in the documented initial symptoms between children of different ages. In one percent of all children a planned follow-up appointment was documented.

A *follow-up three months post-injury* showed that 35 percent of the children/parents reported post-concussion symptoms. In the analysis of the documented initial symptoms and the prediction of post-concussion symptoms no such predictors could be identified. The three month post-injury follow-up also showed that the children/parents mostly understood the information that was provided and 69 percent did get the information they needed. There were however, some differences between the age groups. The information they needed was expressed as the need for head injury information concerning symptoms and observations as well as the need for emotional support.

In *conclusion* the incidence of head injuries among children is high in the youngest age group. The methods for assessment and documentation of signs and symptoms do not seem to be helpful in clinical decision making. The initial and late symptoms differ by age-group. No conclusive risk factor was found to be predictive of complications. Informational needs are not always met during the visit at the Emergency Department and there seems to be a need for a structured follow-up for children, independent of the severity of head injury.

Keywords: head injury, children, management, post-concussion symptoms, informational needs.

ISBN: 978-91-7357-431-0

LIST OF PUBLICATIONS

I. Current incidence and management of children with traumatic head injuries: The Stockholm experience. Falk AC, Paavonen J, Klang B, von Wendt L. Developmental Neurorehabilitation. 2007; 10:49-55.

II. Management and classification of children with head injury. Falk A-C, Cederfjäll C, von Wendt L, Klang-Söderqvist B. Childs Nerv Syst. 2005; 21:430-436.

III. Are the symptoms and severity of head injury predictive of clinical findings three months later? Falk A-C, Cederfjäll C, von Wendt L, Klang B. Acta Paediatrica. 2006; 95: 1533-1539.

IV. Families perceptions of information provided in relation to their child's head injury. Falk A-C, Von Wendt L, Klang B. (Submitted)

V. Informational needs in families after their child's mild head injury. Falk A-C, von Wendt L, Klang B. Accepted in Journal of Patient Education and Counselling

CONTENTS

1 INTRODUCTION 1
2 GENERAL BACKGROUND 2
  2.1 Concepts of head injury 2
  2.2 Classification of head injuries 2
  2.3 Definitions of head injury 4
  2.4 Incidence of head injuries 5
  2.5 Management of head injuries 7
  2.6 Outcome of head injury among children 10
  2.7 Informational needs 16
  2.8 Conclusion 17
3 AIM 18
  3.1 Specific aims 18
4 DESIGN, PARTICIPANTS AND METHODS 19
  4.1 Study design 19
  4. 2 Sample 19
  4.3 Participants 19
  4.4 Methods 20
  4.5 Procedure 23
  4.6 Analysis of data 23
  4.7 Ethical considerations 25
5 SUMMARY OF THE RESULTS 26
  5.1 Incidence and management (Paper I) 26
  5.2 Classification and management (Paper II) 27
  5.3 Post-concussion symptoms (Paper III) 28
  5.4 Families perception of received information (Paper IV) 29
  5.6 Families needs for information (Paper V) 30
6 DISCUSSION 31
  6.1 The general study design 31
  6.2 Results 34
7 SUMMARY OF FINDNINGS 38
8 CLINICAL IMPLICATIONS AND FUTURE RESEARCH 39
9 POPULÄRVETENSKAPLIG SAMMANFATTNING PÅ SVENSKA 41
10 ACKNOWLEDGEMENTS 44
11 REFERENCES 46
Appendix 56
  Rivermead frågeformulär symtom efter skallskada, till barn >5 år 56
  Rivermead frågeformulär uppföljning till barn 57
  Karolinska frågeformulär symtom barn <5 år 58

LIST OF ABBREVIATIONS

ABI	Acquired brain injury
CT	Computerized tomography (of the brain)
CNS	Central nervous system
CI	Confidence interval
GCS	Glasgow Coma Scale
ICD-10	International classification of diseases, 10th revision
HI	Head injury
ED	Emergency Department
LOC	Loss of consciousness
MTBI	Mild traumatic brain injury
OR	Odds ratio
PTA	Post-traumatic amnesia
PCS	Post-concussion Syndrome
PCD	Post-concussion Disorder
PTSD	Post-traumatic stress disorder
RHFUQ	Rivermead Head Injury Follow-up Questionnaire
RLS-85	Reaction Level Scale
RPQ	Rivermead Post-concussion Symptoms Questionnaire
SHIC	Scandinavian Head Injury Classification
TBI	Traumatic brain injury

1 INTRODUCTION

Brain disorder accounts for more than a third of the burden of all diseases in Europe (1) and as many as 127 million Europeans suffer from brain disorders which results in a cost estimated to be 386 billion Euros a year. Despite this, brain disorders do not get anywhere near the attention such as heart diseases and cancer (1).
As early as 1970 Rune demonstrated in a Swedish study that childhood head injury is a very common event with as many as 30 percent of all children suffering from at least one episode of concussion before adulthood (2).

In the United States traumatic brain injury (TBI) is the most common cause of morbidity and mortality in children (3). Approximately 100,000 children under 15 years of age are hospitalised for TBI every year in the United States (3) which results in a hospitalisation rate of $80/10^5$. In Sweden with a population of 9 million (USA 270 million), 7,200 children and adolescents (age 0-19 years) are hospitalised every year because of head trauma, which results in a rate of $37/10^5$ (4) and a total annual cost (all age groups included) for acute management of head trauma has been estimated at 100 million Swedish Crowns (approx. 12 million €) (4,5).

The outcome after a head injury can be measured in different ways either by using pathological findings on the CT scan or the incidence of complications. The general opinion has been that children with a head injury recover completely due to the brain's plasticity and greater possibility for brain organisation during childhood. This opinion has been modified during the last decade due to several studies (6-9) where results imply that an injury to the brain disrupts established functions but also may effect functions that are to be developed during maturation.

The goal for the acute management and observation of children with a head injury is to identify children in need of acute intervention as early as possible. Another goal is to identify those at risk for developing sequele (10). The early management plans are mostly adopted from adult emergency medicine and have not taken into consideration children in different age groups and their specific symptoms. However, as the American Academy of Paediatrics concluded (11), early management and follow-up programmes for children, especially with mild head injury, are highly variable and there is an obvious lack of evidence-based studies. Therefore, the aim of this thesis was to fill in some of the gaps by describing head injury characteristics, assessment, classification and occurrence of head injury symptoms, post head injury symptoms and informational needs among children in the Stockholm area in the age-group 0-15.9 years of age, including their families' perceptions of information provided.

2 GENERAL BACKGROUND

2.1 CONCEPTS OF HEAD INJURY

Head injury is a trauma to the head, that may or may not, include injury to the brain. These partly overlapping definitions cause problems in the interpretation of scientific studies. Examples of frequently used concepts of traumatic head or brain injury are listed in Table I.

Table I. Examples of definitions of Head Injury throughout the literature;

Brain concussion	Mild traumatic head injury
Brain injury	an injury towards the head, which result in different characteristics
Closed head injury	Minimal brain injury
Closed head trauma	Minimal traumatic brain injury
Concussion	Minimal head injury
Head injury	Any injury towards the head but not involving the brain
Minimal brain injury	Minor brain injury
Mild brain injury	Minor brain injury
Mild closed head injury	Minor head injury
Mild head injury	Minor head trauma
Mild head trauma	Minor traumatic brain injury
Mild traumatic brain injury	Trivial head injury
Moderate head injury	Moderate brain injury
Severe head injury	Severe brain injury

For this thesis, head injury has been used throughout all articles for all traumatic head injuries including the concept of brain injury.

2.2 CLASSIFICATION OF HEAD INJURIES

Glasgow coma scale (GCS)

The most frequently used tool for assessing the severity of neurological disruption after head injury is the Glasgow Coma Scale (GCS) which was developed by Teasdale and Jennet in 1974 (12). The areas to assess and score are eye opening, motor response and verbal response to stimuli. The scores vary between 3 (severe head injury) and 15 (normal neurological exam) (table II).

Table. II Glasgow Coma Scale

Glasgow Coma Score		
Eye Opening (E)	**Verbal Response (V)**	**Motor Response (M)**
4=Spontaneous	5=Normal conversation	6=Normal
3=To voice	4=Disoriented conversation	5=Localizes to pain
2=To pain	3=Words, but not coherent	4=Withdraws to pain
1=None	2=No words, only sounds	3=Decorticate posture
	1=None	2=Decerebrate
		1=None
Total = E+V+M		

A paediatric version of the GCS is the Paediatric Coma Score which contains the same domains for assessment as for the adult patients but are age specific. In a child 0-23 months old the normal verbal response would be to smile or to react normally according to the situation and in the age group two to five years the responses would be the use of adequate words (13).

Reaction Level Scale-85

Another tool in evaluating consciousness is the Reaction Level Scale (RLS 85), which is in use in Sweden (14) (table III).

Table III. RLS-85

Clinical status	Level
Alert, no delay in response	1
Drowsy or confused, but responds to stimuli	2
Very drowsy or confused, but responds to strong stimulation	3
Unconscious; localizes (moves a hand towards) a painful stimuli but does not ward it off	4
Unconscious; makes withdrawing movements following a painful stimulus	5
Unconscious; stereotypic flexion movements following painful stimuli	6
Unconscious; stereotypic extension movements following painful stimuli	7

A GCS of 15 is equivalent to a RLS of 1.

2.3 DEFINITIONS OF HEAD INJURY

Various definitions have been used to describe head injuries and until today, no conclusive definition has been agreed upon. Usually head injuries are divided into three categories according to their GCS score; mild head injury (GCS 13-15), moderate head injury (GCS 9-12) and severe head injury (GCS <8) (15).

A widespread set of definitions was presented in 1993 by the Mild Traumatic Brain Injury Committee of the Head Injury Interdisciplinary Special Interest Group of the American Congress of Rehabilitation Medicine (16). They concurred on a definition of mild head injury as;
"a patient with mild traumatic brain injury is a person who has had a traumatically induced physical disruption of brain function, as manifested by at least one of the following:

- Any period of loss of consciousness
- Any loss of memory for events immediately before or after the accident
- Any alteration in mental state at the time of the accident (feeling dazed, disoriented or confused)
- Focal neurological deficits that may or may not be transient.

But, where the severity of the injury does not exceed the following:

- Post-traumatic amnesia (PTA) not greater than 24 hours
- After 30 minutes, an initial GCS of 13-15 and
- Loss of consciousness (LOC) of approximately 30 minutes or less" (page 86).

Another definition has been amended by introducing the concept of Post-traumatic Amnesia (PTA) and Loss of consciousness (LOC) into the system as seen in Table IV (12, 17)

Table IV. Classification of head injury according to GCS/LOC/PTA

	Mild	Moderate	Severe
GCS	13-15	9-12	3-8
LOC	Less than 30 minutes	>30 minutes	>30 minutes
PTA	<24 hours	>24 hours	>24 hours

This implies that the duration of unconsciousness seems crucial, and all head injuries with duration of unconsciousness less than 30 minutes would be collapsed into one group.
It is rather obvious that it matters if the duration of unconsciousness is 29 minutes or one minute. In children, PTA can rarely be assessed with certainty (18).

A further development of the classification is represented by the Scandinavian Head Injury Classification System (SHIC) which uses the GCS, LOC and the initial neurological findings (10) (Table V).

Table V. Scandinavian Head injury Classification (SHIC)

	Minimal head injury	Mild head injury	Moderate head injury	Severe head injury
GCS	15	14-15	9-13	3-8
LOC	No LOC	LOC less than 5 minutes	LOC >5 minutes	LOC >30 minutes
Neurologica l findings	No	No	Yes	Yes

The British Society of Rehabilitation Medicine introduced another definition of head injuries in the United Kingdom (19). The classification of severity of traumatic brain injury divides the TBI into three levels; minor brain injury (unconsciousness for 15 minutes or less and a GCS 13-15), moderate brain injury (unconsciousness for more than 15 minutes and a GCS of 9-12) and a severe brain injury (unconsciousness for more than 6 hours and/or GCS of 3-8) (19).

2.4 INCIDENCE OF HEAD INJURIES

Incidence rates for head injuries in all ages vary between 100-1,115.2 /100,000 (3, 20-25). This variation is dependent upon the population under study and the definition used. Most studies on incidence rates use health statistics from several sources for example ICD codes (International Classification of Diseases, WHO (26), Abbreviated Injury Score (AIS) and hospital admission rates. The WHO collaborating centre for mild head injury reports that an ICD-10 code identifies less than 50 percent of all head injury admissions to hospital which could lead to inaccurately low incidence rates (22). There is also a valid case ascertainment when using ICD- codes as the most frequently used code for a mild head injury is the code for concussion which seems to be both under-inclusive and over-inclusive. Tate and co-workers (1998) found that only 23 percent of mild traumatic brain injury (MTBI) cases were classified as ICD code 850 (concussion). At the same time 13 percent of the severe and 29 percent of the moderate traumatic brain injury (TBI) cases were also coded as having a concussion (ICD-9=850). Therefore, reliable statistics are difficult to extract from routinely collected data and therefore the best source should be research surveys (23-24).

In children, most publications base their incidence rates from Kraus and co-workers´ report from 1986 (3) where data was collected from Emergency departments records, hospital records and coroner's reports from children admitted to the hospital (0-15 years of age). The report shows an incidence rate of 185/100,000 (235 for boys and 132 for girls). Eighty–eight percent of the children had a mild head injury, seven percent a moderate head injury and five percent a severe head injury. Forty-four percent of all the children had no evidence of LOC (3).

In United Kingdom (UK) Hawley and co- workers investigated the prevalence of admitted (>24 hours) children (0-15 years of age) with a TBI from one health district between the years 1992-1998 (19). The injury severity was established by using the British Society of Rehabilitation Medicine Classification of Severity of Traumatic Brain Injury. They found 1,553 children, which is equivalent to a yearly estimation of

280 children /100,000 with a TBI serious enough for hospital admission. Out of these children, 232 would have a minor brain injury, twenty-five a moderate and seventeen a severe brain injury and two would die due to the brain injury (19).

In Sweden, Anderson and co-workers investigated the incidence rate of TBI (all ages) in one region in Sweden (25). The classification of injury severity was based on the available information in the medical records and the recommendations of classification based on the American Congress of Rehabilitation Medicine who defined seven categories of TBI severities. During one year they found 753 patients with TBI, which represents a yearly incidence of 546 per 100,000 in the region. In this group of patients with a TBI (all ages), two and a half percent had a moderate or a severe head injury and one percent were dead on arrival at the hospital. The highest number of TBI was found in children 0-9 years (n=175) and in children 10-19 years (n=95) which yields a total number of approximately 170 children with a TBI annually in the region (25).

Depending on the populations studied and the definitions used of head injury the most frequently external cause of injury varies. In the group of severe head injuries, road and traffic accidents are reported as being the most frequent cause (60 %) and twenty-two percent experiencing a severe head injury from falls (44). Whereas for the mild head injury group, falls (31%) are the predominant external cause of injury, motor vehicle related causes (22%) and being struck by an object (20%). These results were extracted from Emergency department records of mild head injury patients of all ages (20).

Emergency departments are important for the management of mild head injury patients as the Emergency departments might be the only hospital contact for these patients. Guerrero and co-workers investigated TBI related Emergency departments visits but with no requirement of hospitalisation in the United States (20). They used the ICD-9 codes for a head injury for inclusion in their investigation. The non-hospitalisation incidence was used to give an estimation of the so called mild head injury incidence rates. They found that children less than 15 years of age (692/100,000) had the highest incidence rates among all age groups. Guerrero points out that the estimated TBI related Emergency departments visits incidence rate of 392/100,000 population per year is more than four times the rate of fatal and hospitalized TBI in 1994 (20).

Others such as Bazarian and co-workers have found incidence rates of Emergency departments visits for mild traumatic brain injury (MTBI) in the United States as 1,115.2 /100,000 in children <5 years and in children 5-14 years: 733.3/100,000. MTBI was defined by ICD-9 codes (skull fracture, concussion, intracranial injury of unspecified nature and head injury, unspecified). Another result of interest was that the greatest proportion of children less than five years of age received a head injury, unspecified ICD-9 code compared to other age groups (21).

2.5 MANAGEMENT OF HEAD INJURIES

Clinical guidelines

Clinical guidelines have been developed in several countries, however, there is no consensus regarding the content of the guidelines. To be useful, clinical guidelines are expected to be sensitive and predictive, and guarantee that any important intracranial lesion that needs a neurosurgical intervention is not overlooked (26).

The WHO task force on MTBI has performed a critical evaluation of the existing guidelines on MTBI (27). The quality was judged by evaluating the methods used by a validated index produced by Shaneyfelt and co-workers (28).The results showed that out of 41 guidelines only five used an approved search strategy and could be used for a critical review. Only one guideline in this review was based on sufficient evidence to consider it to be evidence-based and that was the guideline developed by Jagoda and co-workers (29) concerning neuroimaging and decision making in adult MTBI in the acute setting. Only two reports were considered as appropriate guidelines for children in this review as they were judged to be methodologically sound however, they were based on expert opinion and not on strong empirical evidence. The lack of evidence-based guidelines therefore indicates a need for further studies of the significance of symptoms in children after a head injury (27).

Since the report from the WHO task force (22) on mild head injury guidelines, the National Collaborating Centre for Acute Care (NICE guidelines) was published in 2003 and updated in 2007 (30). This guideline covers head injury: the triage, assessment, investigation and early management of head injury in infants, children and adults and is produced by the National Health System (NHS) in the UK. It was produced by all relevant professional and patient parties and formed in 2001. The focus was a full systematic review of the existing studies including cohort studies, validation designs and those which had used the classification from the Oxford Centre for Evidence-based Medicine levels of evidence (May 2001) for the review.

The review shows that there is a lack of evidence-based studies concerning all areas for the management of the head injured child. Most recommendations are based on expert panels and clinical professionals; therefore the need for strong methodological studies was highlighted (30).

Admission to the Hospital

The majority of patients with head injuries visiting the Emergency departments have a mild head injury (23, 31). Even if the head injury is considered to be mild, several studies showed that approximately 80 percent of all admissions (all ages) are patients with a mild head injury. This has been shown from a study in the San Diego region, USA (31). The results showed that during one year, 709 children were admitted to a hospital due to a brain injury. Ninety-three percent of all children admitted with a head injury were classified as having a mild brain injury and they accounted for 90 percent of all hospital days for brain injury. These admission rates highlight the difficulty in managing patients with head injuries and the extreme caution that is required to avoid complications (31).

The economic aspect is also of interest as unnecessary admissions to a hospital has both an economic impact on the health care system as well as the fact that unnecessary admittance can have an impact on the families (both parents and child's) anxiety level (30,34). The costs for a 24 hour observation in hospital are estimated to be 183-277 UK Pounds (cost estimates 2005-2006 in UK) and acute head injury admissions account for 320,900 bed days in the hospital in the UK. This represents a significant resource burden on the NHS in the UK. Only 1-3 percent of admitted patients actually go on to develop life-threatening intracranial pathologies. Even a small reduction in the proportion of patients requiring admissions would have a substantial beneficial impact on hospital resources (30).

Hawley reported on the prevalence of brain injury among children admitted to one health district in the UK (19) and showed that the number of admissions were similar throughout the years 1992-1998 (N= 250-238-274-292-266 and 206) with a small decline in one year (19).

Diagnostic Procedures

The diagnostic procedure is of importance while managing head injured patients during their stay in hospital. To be able to classify the severity of head injury and to determine the prognosis of the injury are crucial for the ability to identify those with higher risk of developing complications such as intracranial lesions. Therefore, the aim for the acute management of patients with a head injury is to identify patients in need of acute intervention as early as possible. Another aim is to identify patients at risk for developing sequele (10,27). Diagnostic assessments include information taken from the clinical history, the physical and neurological examination and diagnostic imaging (33). To define the severity of head injury two common criteria have been used, the length of time the patient was unconscious after the injury often called loss of consciousness (LOC) and the length of the post-traumatic amnesia (PTA) defined as the time period from when the patient regains consciousness until the patient regains the capacity for continuous memory (33).

Observation

For many years the standard practice for managing patients with head injuries has been observation in a hospital (34). The observations are based on regular neurological assessments using GCS and RLS-85. It is crucial that the observations and documentations are carried out frequently so that any deterioration of the patient's neurological state will be identified as early as possible. However, the observation guidelines including frequency of observation are mostly based on the clinicians' own experience and reports from different work-groups and are not evidence-based (30). Until today (2007), and as far as we know, no trial has been carried out to investigate the importance of the frequency of observations and which observations are really necessary (30).

Radiographic imaging

Skull X-ray has routinely been used to categorise patients with mild head injuries and to diagnose fractures of the skull and an evaluation of risk following a positive skull x-ray has widely been adopted. A meta-analysis of thirteen studies was performed which found that the sensitivity and specificity of a skull x-ray for prediction of the presence of an intracranial haemorrhage were 38 percent and 95 percent respectively. The figures imply that if there is a skull fracture diagnosed on radiography, the risk of an intracranial haemorrhage is elevated about 4.9 times. At the same time one cannot rule out an intracranial haematoma in patients for whom a skull x-ray does not show a skull fracture (30, 35).

Computed tomography (CT) scanning has both sensitivity and specificity of 100 percent for detecting and locating a surgically significant focal intracranial lesion. CT

scan has been established as the definitive diagnostic investigation in patients who have sustained a head injury (29). However, it is only during the last few years that the possibility to perform a CT scan has become more common throughout several countries (27).
Studies in relation to a CT scan show that in patients with a MTBI and with a GCS score of 15, the prevalence of an intracranial CT scan abnormality is about five percent. Several studies showed the prevalence of CT scan abnormalities was higher (20%) in the more severely injured patient (GCS<13-14). In patients with a GCS score of 13 the prevalence of CT scan abnormalities was 30 percent among all patients with a MTBI (27).
In a randomised controlled trial conducted by af Geijerstam and co-workers (36) of the medical outcome after immediate CT on admission for observation in patients with mild head injury, they found that the use of imaging to triage for admission was a safe and feasible management strategy for patients with a mild head injury (36). In their study they included patients (age >6 years) with a mild head injury (according to GCS of 15, any LOC or amnesia and normal neurological findings) who were seen for acute care at any of the participating centres (39 of the acute hospitals in Sweden). The physicians randomised 2,602 patients; 1,316 to immediate CT and 1,286 for observation in hospital. This strategy revealed no impact on patient outcome and also reduced the cost by one third for this group of patients (36).
The WHO task force found only six studies that had investigated the use of CT scans in the MTBI paediatric population. These studies suggested that the prevalence of CT scan abnormalities is similar to that reported from adult patients with a MTBI. However, the results should be interpreted with caution due to the fact that the paediatric studies were based on different study design, inclusion criteria and indications for a CT scan (27).

Biochemical markers
Studies on biochemical markers to predict outcome have been performed on S100B. S100B is a polypeptide that has both intracellular and extracellular functions and exerts an influence depending on its concentration. The effects are neurotrophic as well as toxic (37).
Initial S100B concentrations in blood have been found to significantly correlate with outcomes in neurological disorders like stroke, global hypoxia and in severe head injury (38). However, the short half-life of S100B and the lack of specificity for neural tissue results in conflicting evidence for its usefulness as a prognostic factor in head injury patients (38).

<u>Follow-up regimens</u>
Follow-up after a head injury has been described by authors such as Wade (39), King (40), Ponsford (41) Hawley and co-workers (42) and Bazarian and co-workers (43).
Hawley and co-workers found in their investigation of the outcome following childhood head injury that children in the UK with severe disability due to a head trauma received appropriate follow up, but 64 percent of children with moderate disability received none. They included children who required hospital admission (age 5-15 years) at the time of the injury and carried out a postal follow-up with a mean of 2.2 years post-head injury where the parents of 526 children completed a questionnaire (42).

In a follow up at an average of six years post head injury the participants (children 5-15 years of age) were offered a follow-up by a head injury nurse. The respondents were invited to discuss issues raised by the questionnaire. One third of parents (n=182, 34.6%) accepted this offer: 131 (31.2%) in the mild group, 23 (40.4%) in the moderate and 28 (57.1%) in the severe group. No evidence was found to suggest a threshold of injury severity below which the risk of late sequele could be safely discounted. This could indicate that all families with children who had a head injury should be offered a follow-up regardless of the severity of the injury (42).

In Bazarian and co-workers (43) report about the prediction of follow-up after discharge from an Emergency Department, they stated that a follow-up visit was the key to recognizing and treating post-concussion syndrome in patients with a mild head injury therefore the assessment of risk factors for its development was of importance. Their conclusion is based on a prospective, observational study of 71 mild head injury patients with a follow-up at one month post-injury.
Comparative studies of follow-up regimens are scanty, and thus there is no clear agreement on the optimal procedure.

2.6 OUTCOME OF HEAD INJURY AMONG CHILDREN

Outcome after a head injury can be measured in different ways either by using mortality rates (3) positive findings from radiographic imaging (35, 44-46) or by using post concussion symptoms (7, 54-60).
Children's mortality (at the scene or within 24 hours of admission) after a TBI is low, range from 2.5-5.3/100,000 children a year (3, 23, 47-49). In 1987 Kraus and co-workers reported on a study in the San Diego region in the USA that of 709 children less than 14 years of age, 688 (97%) were discharged alive from the hospital. The overall in-hospital paediatric brain injury case fatality rate was 3/100 children and among those who were classified as having a severe head injury the fatality rate was 59/100 (3).
From a Swedish perspective, Emanuelson and co-workers (48) reported a mean annual incidence of 12/100,000 children (0-17 years) with severe TBI (48). The mean mortality rate was 2.6/100,000 per year. As many as 75 percent (n=34) of the deaths were related to traffic accidents.
Snoek et al. (49) found that 42 children out of 967 developed neurological signs after a lucid period following a minor head injury which revealed an incidence of four percent with delayed deterioration and death after a so called mild head injury.

Intracerebral pathological findings
The frequency of pathological findings on radiographic imaging have been reported by Kraus et al. (44), Qualey et al. (35), Greenes et al. (50), Gruskin et al. (46), Brown et al. (51) and Dunning et al. (45). The incidence of an intracranial injury ranged from three to six percent among children less than 18 years of age with a non trivial head trauma. Of this number less than one percent required neurosurgical intervention (35, 44, 46, 50).

Dunning and co-workers (45) did a meta-analysis of the variables that predicted significant intracranial injury in MTBI in the paediatric population. Sixteen articles were finally selected to be included in the analysis which contained 22,420 children. In this analysis the prevalence of intracranial haemorrhage varied between 1.3-36 percent and was mainly explained by the variability in the inclusion critera (from all head injuries to only children admitted with reported LOC).

Risk factors for intracranial pathologies

There are conflicting resluts concerning the presence of intial predictors for intracranial pathologies (46, 66-67). Dunning and co-workers (45) meta-analysis consisted of a search for articles in Medline and Embase from January 1990 to June 2002 concerning intracranial complications after a head injury in all patients less than 18 years of age. A full review was carried out on 98 articles. Out of these 98 articles, 16 were finally selected to be included in the analysis and contained 22,420 patients. The results showed a significant increased relative risk of intracranial hemorrhage for reduced conscious level (5,51), focal neurology (9,43) skull fracture (6,13) and LOC (2,23). Headache, vomiting and seizures did not show any increased risk of intracranial injury (45).

Teasdale (66) and co–workers reported on the risks of acute traumatic intracranial haematoma in children (<14 years) and in adults who had attended an accident (A) and Emergency Department (ED) and in all patients having an acute intracrainial haematoma evacuated in one neurosurgical unit. Over an eleven year period they found 8,406 adults and children attending the A&ED and 1,007 who had an intracranial haematoma evacuated. The results revealed that children were less at risk than adults (one in 2,100 verus one in 348 respectively). In both age groups the presence of skull fracture and changes in conscious level permitted identification of an intracranial haematoma. However, they concluded that due to exclusion criteria of children less than two years of age in the study the results should be interpreted with caution in applying these findings for all children in this age group. In such children where there is a suspicion of non-accidental injuries being present and other features such as retinal hemorrhages or anemia, these may provide additional clues to an intracranial haemorrage (66).

In the results by Gruskin and co-workers (46), who described predictors for complications (either skull fracture or intracranial injury) in children less than two years with a head trauma (n=278) it was shown that 62 percent of the children with an isolated skull fracture and 58 percent of the children with an intracranial injury had no history of LOC, emesis, seizures or behavioural change. Ninety-two percent of the children with an isolated skull fracture and 75 percent of the children with an intracranial injury had normal LOC and a normal neurological examination at time of diagnosis. The conclusion was that clinical signs were insignificant predictors for both skull fracture and intracranial injury in children less than two years (46).This is in agreement with the result from Greenes et al. (50), who reported that clinical signs of brain injury seemed insensitive indicators of an intracranial injury in infants. This study was of 608 children under two years and with the presence of an intracranial injury (50).

Palshak and co-workers (67) reported that an isolated LOC and/or amnesia or the absence of other clinical findings suggestive of TBI are not predictive of either TBI on CT or TBI requering acute intervention.This conclusion was drawn from a study on children less than 18 years (n=2,043) with a blunt head trauma and the association between the inital LOC and/or amnesia and the presence of a TBI.

Post-concussion symptoms

Whether a mild head injury causes permanent neurological impairments or not has been discussed for many years. Reports of post-concussion symptoms vary between five–fifteen percent of all adult patients with a head injury (6-9, 52). The most common post-concussion symptoms reported after a TBI can be grouped into three categories: Cognitive complaints (decreased memory, attention and concentration), somatic complaints (headache, fatigue, insomnia, dizziness, tinnitus and sensitivity to noise and light) and affective complaints (depression, irritability and anxiety) (51).
There is an emerging literature describing the presence of persistent symptoms following TBI in childhood (42, 54-60).

Mittenberg and co-workers (6-7) stated that post-concussion symptoms occurs in children however, cognitive impairment is unlikely to persist beyond three months after the head injury in the majority of patients who sustained a mild head injury. The conclusion was drawn after a study of 65 children (age range 6-15 years) admitted due to a head trauma (mild n=38, moderate-severe n= 27) (6). An orthopedic control group of 47 hospitalized children (age 5-15 years) was used to compare the frequency of symptoms six weeks post injury. The symptom checklist used was derived from one used in the adult TBI population and was simplified by the authors for use in the pediatric sample. It consisted of twelve questions covering somatic (headache, sensitivity to light and noise and fatigue) cognitive (memory, attention and concentration) and affective symptoms (irritability and anxiety). The head injury groups did differ significantly in incidence of symptoms with more symptoms in the moderate–severe head injury group compared to the mild head injury group. Both head injury groups showed significantly more post-concussion symptoms than the orthopedic injury group. To test the hypothesis that post concussion syndrome occurs less frequently in children than in adults, the children's symptoms were compared to those reported by a consecutive group of adults admitted to the hospital for treatment of mild (n=40) and moderate-severe (n=40) head trauma. The adults reported significantly more symptoms than the mild head injury group in children but no significant difference in symptoms was found between adults and children with moderate-severe head injuries (6).
Casey and co-workers (56) reported physical symptoms and functional morbidity in children six months to 14 years of age after a minor head trauma. Physical symptoms were reported at three months post head injury; headache (7%), vomiting (1%), appetite loss (1%), speaking difficulty (1%), vision difficulty (0.5%), walking difficulty (0.5%) and unsteady balance (0.5%). Functional morbidity such as limitations in daily activities (school or play) was reported in 69 percent of the children and in 27 percent of the children (2-14 years) there were behavioural problems. Included children (n=321) had a mean age of 4.47 years and of these, 204 children were enrolled in the follow-up at one month after the injury. The authors concluded that according to parents, children with a minor head injury manifest with functional morbidity despite the rarity of physical sequelae. Their recommendation to the child's paediatrician was to focus on parental education concerning the rarity of the physical sequele and the importance of the child's return to school.

Hooper and co-workers (57) reported on the most common symptoms in children (age infancy to18 years, n=681) following a TBI in both admitted (n=272) and non-admitted children (n=409) and revealed that caregivers reported at least one neurological symptom in 8.9 percent at one month, in 6.2 percent four month post injury and in 2.8 percent at ten months post injury. At all time points the group of children who were admitted experienced more symptoms in all symptom groups compared to those who were not admitted to hospital. A large group of children from all groups reported persistent symptoms at 10 months post head injury including headache, attention and memory problems, low frustration tolerance, sleep problems, personality changes and new school problems. In the follow-up the children's primary caregiver was asked to report the presence of current symptoms from neurological, neuro-cognitive, behavioural and school problems using dichotomized questions in a telephone interview at one, four and ten months post injury. The majority (83%) of children experienced a mild head injury, 5 percent a moderate and twelve percent a severe head injury (57).
Jaffe and co- workers (59) report of neurobehavioral sequele when comparing groups of children (6-15 years) with mild-moderate and severe bran injuries (according to GCS presenting at the Emergency Department) with matched controls (age, gender, school grade and the classroom teacher's assessment of level of academic performance of reading and arithmetic) showed a strong correlation between the severity of head injury and the degree of impairment on almost all neurobehavioral measures. The children were compared using several neuropsychological assessments covering intelligence, adaptive problem solving, memory, academic, motor and psychomotor measures at three weeks after the date of injury when full orientation was achieved (range 14-261 days). They concluded that moderate and severe brain injured children are at increased risk for school failure and require careful monitoring of neuropsychological, psychosocial and educational progress. In the group of mild brain injured children few deficits were detected however significant differences were found in the speed of motor performance and long-term verbal memory.

Ponsford et al. (9), Necajauskaite et al. (60), and Donders et al. (61) all concluded that children with a mild head injury were more likely to completely recover in comparison to the children with a moderate or severe head injury.
Ponsford and co-workers (9) compared the cognitive and behavioral outcomes following MBTI in children (n=130) age 6-15 years with a control group (n=96) with minor injuries. The most prominent symptoms reported by the parents in the mild head injury group were headaches, dizziness and fatigue compared to the control group. At three month post injury the mild head injury group did not appear to experience any difficulties (9). The children's parents were asked to assess their child's pre- injury behavior, injury related symptom checklist and several neurobehavioral measures at one week post injury and at three months post- injury. The definition of mild traumatic head injury used was produced by the American Congress of medicine of rehabilitation medicine (a history of any period of unconsciousness of less than 30 minutes resulting from a head trauma or a acceleration- deceleration movement of the head, GCS 13-15 and a period of PTA not exceeding 24 hours (9).

These results are well in line with the result from Necajauskaite and co-workers (60) who investigated two groups of children (4-16 years of age), one group (n= 301) who had experienced a single MTBI and one group (n=301) who had experienced any

other mild body injury without head trauma (60). They used a postal follow-up questionnaire concerning symptoms of post concussion syndrome. The period from the injury to the follow up was one-five years (median 27 months). They concluded that more than one year after the trauma the prevalence of the symptoms of post-concussion syndrome was not significantly higher in children with MTBI compared to children with other mild body injuries and was also comparable over time (60).
These results are contrary to what Hawley and co-workers (62) reported in their study concerning outcomes in different groups of children (5-15 years of age) following a mild, moderate or severe head injury (severity according to GCS and /or duration of unconsciousness). The most commonly reported symptoms by the child or parent in the TBI groups were headaches, mood fluctuations, concentration, temper, memory, attitude towards siblings, behavior, tiredness, schoolwork, learning and lost friendships. Hawley's results showed that physical problems seemed to resolve at 12 month follow-up while cognitive and intellectual problems remained. Five hundred and twenty-six parents (419 mild, 58 moderate, 49 severe and 45 controls) completed questionnaires concerning their child's behavior, emotions, memory and attention at 2.2 years post head injury.

In Sweden, outcomes after a severe TBI in adolescents have been investigated by Emanuelson and co-workers (63) seven years after the incident. The results showed that only twenty-eight percent of the group of surviving adolescent TBI victims functioned within normal range. As a group they showed significantly subnormal ($p < 0.0001$) results in gross motor, fine motor, sensibility and perception sub-tests. The most crucial disabling component was poor social integration, which was clearly demonstrated in the WHO score (63).The study included 18 adolescents or young adults with a mean age at injury of 13.9±3.7 years (range 6.4-19.3).

Risk factors for post-concussion symptoms

Anderson investigated the predictors of acute child and family outcome following TBI in children who were hospitalized due to a head injury (age 2-12 years) (68). The outcome was measured by using parent and child questionaire both acutely and at six months post injury. Measures included injury and demographic questionaires, adaptive and behaviour functioning, family functioning and for the children an intellectual evaluation, attention and memory assessment. They found a clear dose-response relationship for physical and cognitive outcomes with a severe TBI associated with greater impairment of physical, intellectual, memory and attentional function as compared to a mild head injury. However, for the psychosocial outcome the results were less clearly linked to injury severity. As expected, children in the mild head injury group demonstrated good outcomes with generally intact abilites in physical and cognitive areas. However fifteen percent reported clinically significant deficiencies in the functional domains (68). One hundred and twelve children were included, divided into three severity groups according to the GCS scores: Mild TBI (n=31), Moderate TBI (n=52) and severe TBI (n=29) (68).
Yeates and co-workers (69) described the correlates of neurobehavioural symptoms in childhood (6-12 years) closed head injuries. They included 31 children with severe closed head injuries, 38 moderate closed head injuries and 53 with orthopaedic injuries as a control group. They found that in most cases the severe closed head injury group displayed more symptoms than the moderate closed head injury group and both head injury groups showed more symptoms than the

orthopaedic injury group. The prediction of neurobehavioural symtoms was significant for injury severity, memory functioning and premorbid child adjustment. However, the findings indicated that the prevalence and correlates of neurobehavioral symptoms in childhood closed head injury varied as a function of symptom type and time since injury. The assessments were made at baseline and repeated at six and twelve months and included neurobehavioural symptoms, cognitive and behavioural functioning and family adjustments. They used regression analysis to examine the prediction of the total number of reported symptoms (69).

Symptom predictors for the development of post-concussion symptoms in the adult head injury patient has been investigated by several authors (70-72). Kruijk and co-workers (70) reported on PCS according to the Rivermead Postconcussive Symptoms Questionnaire (RPQ) after a mild head injury in patients (>15 years) at two weeks (n=103) and six months (n=79) post injury. They found that patients who reported headache, dizziness or nausea in the Emergency Department showed at least a two-fold increase in severity of one or more post concussion complaints after six months. Twenty-two out of seventy-nine patients (28%) were classified as not fully recoverd at six months.
Savola and Hillbom (71) searched for simple measures for the early detection of patients who were at risk of developing post-concussion symptoms after a mild head injury. They investigated 172 patients (16-49 years) admitted to a Emergency Department and the follow-up interviews were conducted two-six weeks after the injury. Assessment of post-concussion symptoms was performed by using the Rivermead post-concussion Questionnaire (RPQ). They found that 37 of the mild head injury patients (22%) reported post-concussion symptoms lasting for one month or more after the injury. The mean number was five symptoms per subject. They further reported that in the adult patient with a mild head injury, skull fracture (OR 8.0 CI 2,6-24,6), elevated S100B (>0.50 ug/L) (OR 5.5, 95% CI 1.6-18.6), dizziness (OR 3.1, 95% CI 1.2-8.0) and headache (OR 2.6, 95% CI 1.0-6.5) were early risk predictors for post-concussion symptoms reported after one month.

In children, Korinthenberg et al. (72) reported results from a prospective study concerning the prediction of post traumatic syndrome in 98 children (3-13 years) with a minor head injury. The assessment of symptoms and neurological/psycho-logical and electroencephalographic findings were done within twenty-four hours of the trauma and four to six weeks later. Out of the 98 children 23 patients still reported headache and fatigue and 18 suffered from psychiatric symptoms such as sleep disorder, increased anxiety and affect instability at four–six weeks post injury. However they found no correlation between the the initial reported symptoms and signs, severity of injury or other neurological findings in the acute phase of the trauma and the presence of post traumatic syndrome at follow-up.
Ponsford and co-workers (9) found no evidence that a more severe injury in children, as measured by the Post-traumatic Amnesia Scale (PTA) (range; seconds to 510 minutes), would cause more sequele identified as cognitive and behavioral outcome than those with a minor head injury.
This is in agreement with Erlanger et al. (73) who in an adult population (n=47) of athletes with a concussion found no useful predictors, i.e., brief LOC or a history of concussion for the presence and duration of post-concussion symptoms. The follow-up of the post-concussion symptoms was performed by a brief internet-based neurocognitive assessment battery at one-two day intervals until all symptoms had

resolved. All post-concussion symptoms had resolved by day sixteen post injury. Despite the finding concerning LOC, they did find that the athletes self-reported memory problems and cognitive impairment at the initial follow-up predicted the number of additional post-concussion symptoms.

Ponsford and co-workers (9) and Anderson and co-workers (68) reported that children who developed sequele such as post-concussion symptoms had pre-disposing factors such as adverse social background or a personality disorder. This is in line with the result from Hawley and co-workers (62) who found that children from deprived areas had an increased risk of poorer outcomes.

Ponsford and co-workers (9) compared the cognitive and behavioural outcomes in children with MTBI in children (n=130) age six-fifteen years of age and a control group (n=96) with minor injuries (9). At three month post injury most of the mild head injury group did not report any difficulties. However, a small portion of children in this group (n=24, 17%) had significant ongoing problems. These 24 children were more likely to have a history of prior head injury, learning difficulties neurological and psychiatric problems or family stressors.

2.7 INFORMATIONAL NEEDS

It is well known that when a child is hospitalised due to an illness the whole family can often react with stress and anxiety (74-77). Parental concern and anxiety are often associated with feelings of insecurity, disempowerment, fear and even guilt. This in itself will increase the child's own level of stress. To reduce these feelings, identification of informational needs due to hospitalisation among children and parents has been investigated by several authors (74-78). As early as 1982, Brewster (74) concluded that access to information is the most important coping mechanism for parents during their child's hospitalisation and both Davies (32) and Edwinson and co-workers (75) have shown that parents who are well informed and well prepared are less anxious, a fact that was found to decrease the child's level of stress.

On the other hand, Taanila (79) found that parents who received only a small amount of information and practical advice on how to cope with a sick child at home, felt insecure and helpless five times more often than parents who were satisfied with the instructions and the advice they had received. In a qualitative and observational study Hallström and Runesson (77) investigated parent's needs during their child's stay in hospital. Four groups of needs were identified: the need for competent-caregiver, communication, confirmation and participation. They concluded that routines should be established and evaluated in an ongoing process to ensure that both children and parents are cared for in an individualised way.

Kai and co-workers (78) who interviewed 95 parents of pre-school children concluded that the parents felt disempowered when dealing with an acute illness in their child. Central to the parents' difficulties were their experiences of inadequate information shared by their general practitioners and variation in their doctors' decisions and behaviour. The parents expressed a need for a range of accessible and specific information in supporting them through the negotiation of their child's illness.

Health care personnel have a major impact on the family health status during their child's stay in hospital and different aspects have been reported by Kristensson-

Hallström et al. (80), Miles et al. (81) Helseth et al. (82), Tomlinson & Hall (83), Hopia et al. (85) and Aitken et al. (86). Helseth et al. (82) described the impact of helping the family by improving their way of coping with their child's illness and Tomlinson & Hall (83) discussed the importance of family care to make life easier for the whole family during the child's illness.

Hopia et al. (85) found that family health is promoted by nursing staff during a child's hospitalisation by; reinforcing parenthood, looking after the child's welfare, sharing the emotional burden, supporting in everyday coping and creating a confidential care relationship (85). This is in accordance with the findings of Aitken et al. (86) and Hallström and Runesson (77). Aitken et al. (86), found in interviews with mothers (n=16) of children (age 5-16) who had sustained a traumatic injury (TBI, fractures, and multiple trauma) parental needs in communication (inconsistent messages by providers), assessment of care (confusion regarding follow-up), parental burden (emotional responses) and social support (social and emotional isolation). The parents' needs emerged through focus groups interviews and they concluded that routines should be established and evaluated in an ongoing process to ensure both children and parents are cared for in an individualised way. However, others believe that it is not only access to information that is important but the quality of the information and the learning process should also be an important focus (83-84).

2.8 CONCLUSION

As far as I know, there is a relatively vast, but partly contradictory bulk of studies of basic epidemiological issues on childhood head injuries. These studies are all based on statistics from different health care systems, they use different classification system of brain injuries and the data are collected from different age groups. Most of the literature also deals with adults, and the youngest age-groups are frequently not included. Therefore, the need for a report on the actual incidence of head injuries both mild and severe in the paediatric population seems obvious.

The current recommendations for early management, including information for the family and follow-up schedules appear to be mainly based on tradition rather than science. The present series of studies were therefore designed to describe head injury characteristics, assessments, classification and occurrence of head injury symptoms, post head injury symptoms and informational needs among children and their families admitted to a single trauma centre in the Stockholm region.

3 AIM

To describe head injury characteristics, assessments, classification and occurrence of head injury symptoms, post head injury symptoms and informational needs among children in the age-group 0-15.9 years and information provided to their families in the Stockholm area.

3.1 SPECIFIC AIMS

I to describe the incidence and management of TBI in children less than 16 years in a level-one trauma centre in the Stockholm region from documentation in the medical records.

II to describe head injury characteristics, management in hospital and to evaluate the feasibility of the Scandinavian Head Injury Classification in the paediatric population

III to describe the occurrence of post-concussion symptoms at three months post head injury and to analyse the relationship between these and the documented initial symptoms among paediatric patients

IV to describe the families' perceptions of information provided in relation to a head injury

V to describe the families informational needs in relation to their child's mild head injury

4 DESIGN, PARTICIPANTS AND METHODS

4.1 STUDY DESIGN

This study was conducted to increase our knowledge of children with head injuries. The clinical series, which formed the basis of this series of studies, was collected retrospectively from 2002-2003. A descriptive and cross-sectional design was conducted with both qualitative and quantitative design. This approach was considered to be advantageous as it incorporated different paradigms and thereby brought different kinds of knowledge to the area of head injuries in children. Thus, quantitative analysis of questionnaire data was used whenever a large sample of the group was studied, whereas the qualitative approach was used whenever an in-depth elucidation was the aim.

4. 2 SAMPLE

The study was conducted at Astrid Lindgren Children's Hospital, which is a level one-trauma centre in the Stockholm region. The entire population in the Stockholm region is 1.8 million inhabitants and 350,000 of those are children between 0-15.9 years of age.

In the region there are a total of four children's hospitals, but the one with a surgical emergency room is the Astrid Lindgren children's hospital, which has a 24-hour emergency service. Families are allowed to bring their child to any of these four hospitals regardless of their home address or state of their child and notes of referral are not required.

4.3 PARTICIPANTS

Participants Paper I

All children (0-15.9 years of age) who were admitted to the Emergency Department during one year (Sept 15 2002 –Sept 14, 2003) with a history of head injury, and with the initial, tentative diagnosis of concussion made by a triage registered nurse (n=3,168). This initial diagnosis was based on the anamnestic data given by the child, parents or other accompanying persons upon arrival.

Participants paper II, III and IV

The participants in Paper II consisted of all children (0-15.9 years) who were admitted during one month (September – October 2002, n=242) to the Emergency Department with a history of head injury, and with the initial, tentative diagnosis of concussion made by a triage registered nurse. Of the initial 242 children, 96 completed the follow-up questionnaire at three months post injury.

Participants paper V

The participants consisted of all the hospitalized children due to a head injury (0-15.9 years) included in paper I and who during a three-month period (March-June, 2003) visited the Emergency Department due to persistent complaints (up to seven days from the head injury such as headache, fatigue or nausea) or was admitted to a hospital ward due to a head injury. Of the 94 families identified during the three months period in this manner as eligible for inclusion, 57 agreed to participate in this study.

4.4 METHODS

Assessment at the emergency care visit. Background data such as age, sex, and duration of unconsciousness, external cause of injury, primary symptoms and symptoms during the observation period in the Emergency Department were collected from the medical record. Data regarding the management of the child in the hospital and discharge diagnosis were also retrieved from the medical records. These data were collected by means of a scoring sheet, which was developed by the authors (A-C F, L v W).

ICD-10 (Paper I-III)

The discharge diagnoses were set by the physician in charge of the child according to the ICD-10 which is an international statistical classification of diseases and related health problems issued by WHO (26) (table VI).

Table VI. ICD-10 discharge diagnosis of head injury

S 009	Head injury
S 020	Skull fracture
S 060	Brain injury

Classification of head injuries

Glasgow coma score (GCS) (Paper II-III).

The GCS was used for assessing the severity of neurological damage after head injury (12). In the examination of the children in the ages of 0-5 years of age we used an age specific paediatric coma scale translated into Swedish and in use at the Astrid Lindgren Children's Hospital (13).

Scandinavian Head injury Classification (SHIC) (Paper II-IV)

The New Scandinavian guidelines for classification and initial management of minimal, mild and moderate head injuries have recently been presented by the Scandinavian Neurotrauma Committee (10). The classification is based on the concept that a history of unconsciousness increases the risk of an intracranial haematoma four times.

The guidelines of the head injury classification are aimed at a better focus on the risk of developing an intracranial haematoma and appearance of post-concussion syndrome (10). The classification makes recommendations about how to manage the different head injury groups concerning observation, CT scan, consulting neurosurgeon and when to discharge the patient. The management includes a patient information sheet that describes common symptoms (for example headache and nausea) and when to return to hospital for a check up regarding post-concussion symptoms (10).

According to the SHIC the following categories are recommended for use (Table. VII):

Table VII. Classification of head injury according to SHIC (10)

Minimal head injury	a history of head injury but no unconsciousness, GCS 15
Mild head injury	short period of unconsciousness <5 minutes and /or amnesia, GCS 14-15
Moderate head injury	GCS 9-13
Severe head injury	GCS <8

Questionnaires

The Rivermead Post Concussion Questionnaire (RPQ)(Paper III-IV) was used for children >5 years and consists of 15 items regarding common symptoms after a head injury (for example headache, dizziness, nausea and sensitivity to noise) with the possibility to add individually experienced symptoms (87). The child and/or the parent were instructed to evaluate the symptoms and compare them with the time before the injury as ”have no symptoms”(0), ”no longer have any symptoms”(1), ”have some symptoms”(2), ”have moderate symptoms” (3), and ”have severe symptoms”(4). Thus, the highest possible summed score for a child is 60 points (variation 0-60) (87). The questionnaire was translated into Swedish for the study and had a Cronbach’s alpha of 0.86.

The Karolinska Post Concussion Questionnaire (KPCQ)(Paper III-IV) was used for children <5 years which was developed by the authors to evaluate change in children under the age of five as the RPQ appeared to be unsuitable for this age group. Young children (<5 years) cannot be expected to report on their own functioning (88) and therefore the reliability of the existing symptom questionnaire is doubtful. The questionnaire consists of seven items regarding changes in sleeping patterns, mood fluctuations, eating habits, global change of behaviour, motor problems and changes in play patterns. The parents were instructed to evaluate the areas that were asked about and to compare them with the time before the injury as “completely agree” (1) “agree somewhat“(2), “minimally agree“(3) or “not at all” (4). The design of this questionnaire was based on the clinical experience of two of the authors because children and/or parents in this age group are more likely to describe changes in major daily activities rather than individual symptoms. In this study, Cronbach’s alpha was 0.59. When the item about other symptoms was deleted the Cronbach’s alpha was 0.67.

The Rivermead Head Injury Follow-up Questionnaire (RHFUQ)(*Paper III-IV)* was used for children of all ages which consists of ten questions regarding functional activities in daily life such as the ability to participate in conversations with more than one person and ability to carry out normal functional activities (89). The child and/or the parent were instructed to evaluate the ability level and compare them with the time before the injury as: “no change” (0), “no change but slightly more difficult” (1), “small change” (2), ”moderate change” (3), and a “severe change" (4). The answers to the questions are totalled and can vary between 0-40 points.

<u>Translation process</u>

The translation process of the Rivermead Post-concussion Symptom Questionnaire (RPQ) and the Rivermead Head Injury Follow-up Questionnaire (RHFUQ) was conducted according to scientific rules about translation of questionnaires (101). We examined the original documents conceptual definitions and made a forward translation from English into Swedish. We used a person who was both Swedish- as well as English speaking.

In this, we used an independent translator to make a backward translation (Swedish to English) to make sure that the translation was done correctly.

We found no evidence of incorrect translation. In stage three, we carried out a pilot study by testing the Swedish translation on a few healthy children and their parents to guarantee that the concept was correctly understood. We made no changes in the questionnaire as understanding was good and no changes for cultural differences were necessary (100). The final translated version had good internal consistency with a Cronbach's alpha of 0.84.

<u>Information</u>

Information that was provided in the Emergency Department *(Paper IV)* to the child/family was addressed with a questionnaire (seven items) that was developed by two of the authors to evaluate perceptions of the information received. The Picker Questionnaire was the source and inspiration for the questions regarding pediatric health care satisfaction (90) and discussed by a multiprofessional team for content validation. The questions were; "Did you understand the information you received concerning the head injury", and "Did you receive the information you needed regarding head injury". The response options were; "in most part" (1)," in some part" (2), and "not at all" (3). One question was "Did you receive information about common symptoms" with the response options of yes (1), no (2) and do not know (3). To address the information directed towards the child we asked "Was the information you received age appropriate for your child" and "Was the information about the head injury addressed to your child specifically". The response options were yes (1), no (2) and do not know (3). We also asked "Who informed you during your stay at the Emergency Department?" The response options were "attending physician" (1), "registered nurse" (2), "both" (3) or "other" (4). "Have you been in contact with any healthcare service due to the head injury after your visit at the Emergency Department?" with yes (1) and no (2) options.

In the questionnaire concerning families own needs (Paper V), one open-ended question was directed towards the child and his/her family; "What questions did you have when your child had injured his/her head"?

4.5 PROCEDURE

Paper I-III

All of the required information was collected within three days after the injury. The initial emergency room documentation in the medical records of children with the tentative diagnosis of a head injury (such as fall, concussion, head trauma or trauma) was scrutinized. The practice at the time of the study was that the triage nurse set the initial tentative diagnosis, which was based on available information from the child, parent or a significant other.

Procedures specific for Paper II-V

Questionnaires

Written information about the aim of the study, the patient's rights and the follow-up questionnaires were mailed to the families three months after the head injury and were returned by a pre-addressed and stamped envelope. For the data presented in articles II and III the data were collected so that for the children under five years of age the parents answered the KPCQ and the RHFUQ (89) questionnaires. For the children five years of age or older the parents and/or the child answered the RPQ (87) and the RHFUQ (89) questionnaires.

4.6 ANALYSIS OF DATA

In the analysis, the ICD-10 based diagnosis set at discharge was compared to the anamnestic duration of unconsciousness, GCS, amount of signs and symptoms and the SHIC. The classification of the children according to the SHIC was carried out in retrospect by the author (A-C. F) on the basis of the available documentation in the medical records and collected for the present study.

The statistical analysis of the questionnaires was carried out using descriptive statistical procedures and computed in Stat View 5.0 programme (paper II-IV),
SPSS version 11.0 program for study III and SPSS version 13.0 program and SAS 9.1 program for paper I.
In paper V, content analysis was used for the analysis.

Paper I

The overall and age-specific incidence rates with 95% confidence intervals were calculated. Chi Square tests were used to compare categorical variables. The incidence of accidents was compared between different months, days of the week, gender and age groups using a Poisson linear regression model. As the univariate data analysis suggested that all these factors were related to the frequency of the accidents, a complete set of multivariate models was constructed to predict the number of accidents. The regression diagnostics (regression diagnostic is a statistical term that refers to the process to identify violations in the model assumptions) did not reveal significant discrepancies related to the model assumptions. The reported models were based on age-stratified analysis in which weighting with respect to the log of the size of the total population was done. All two-way interaction terms were considered. A probability level below 0.05 was regarded as statistically significant.

Paper II- III

Descriptive statistical procedures were computed using categorical variables and was compared by means of Fisher´s exact two-tailed test or Pearson chi-square tests. For these analyses the sample was divided into age groups (<5 and >5 year old). In Paper III, In the statistical analysis of the descriptive procedures, symptom questionnaire-answers were dichotomised into yes (scoring 2-4) and no (scoring 0-1) and categorical variables was compared by means of Fisher´s exact two-tailed test or Pearson chi-square tests.

Univariate associations of continuous variables were tested by Spearman's rank correlation coefficients. Odds ratio (OR) and 95% confidence intervals (CI), before and after adjustment for confounding variables, were calculated by logistic regression. Probability below 0.05 was accepted as statistically significant.

Paper IV

Chi-Square was used to compare categorical variables (age group) and the severity of head injury with the information answers. Cramer's v was used to report the strength of the relationship between the variables. A probability level below 0.05 was accepted as statistically significant.

Paper V

Content analysis was used to categorise the data according to the model described by Krippendorf (91) and Weber (92). Content analysis can be used on any text and for this study had the objective of coding the open-ended answers to the question and was appropriate (91).

The answers to the question "What questions did you have when your child had injured his/her head" were transcribed into a separate document by one of the authors (AF). The transcribed text was read through and validated by another author (BK) to ensure that the text was transcribed correctly.

The analysis began with the decision that the level of analysis was to use the whole set of words and not single words and that the coding process would be open-minded and with no pre-defined concept because of the lack of knowledge within this area (91).

The entire text was divided into units of meaning and was subsequently organized into subcategories, categories and then labelled. The analysis was repeatedly checked against the original transcript of the questions to ensure that no changes were made of the original text.

All text has a degree of interpretation in the approach to the text and to ensure credibility, no relevant data was excluded or irrelevant data included (91). Strategies to achieve credibility or reliability and validity of our data were made by using the concepts of Weber (90) and Lundman & Graneheim (93).

The process was carried out by two of the authors by naive reading of the text separately. The two authors discussed the suggested codes, subcategories and categories until agreement was achieved. As a part of the agreement process the third author read the subcategories and categories and no changes were made.

4.7 ETHICAL CONSIDERATIONS

Children and their parents who seek medical care due to an acute illness in the child are in a vulnerable position and ethical aspects have to receive extra consideration when research includes children. The United Nations, Children's Convention (23) states the rights of every child despite age. This means when a small child due to its age and maturity is not able to communicate or receive information, the parents are considered their guardians with the aim of protecting the child and their rights. In Sweden, the child should be asked for consent if possible and both parents and an ethical committee have to approve the study.

The study was approved by the local ethical committee at the Karolinska Hospital in Stockholm, Sweden (Dnr: 02-292). The study was introduced to both parents and child by providing them written information and informed consent was received from all respondents.

5 SUMMARY OF THE RESULTS

5.1 INCIDENCE AND MANAGEMENT (PAPER I)

During the period September 2002-September 2003, a total of 3,168 children with documentation of a head injury visited the Emergency Department at Astrid Lindgren Children's Hospital. The mean age of the entire group was 5.5 years (range 1 week - 15.9 years). The overall incidence of head injury was 865 per 100,000 children (95% CI $835/10^5$-$895/10^5$).
The highest incidence for TBI, $2{,}379/10^5$ children (95% CI $2218/10^5$-$2538/10^5$) was found in the youngest age group 0 to <18 months, followed by $1704/10^5$ (95% CI $1571/10^5$-$1837/10^5$) in the next age group, 18 months to <3 years. A decrease was found in the next two age-groups; $590/10^5$ (95% CI $538/10^5$-$642/10^5$), 3 to <7 years and $580/10^5$ (95% CI $547/10^5$-$612/10^5$) age group, 7 to <16 years.
In the entire group of children the boys outnumbered the girls with respect to incidence ($p<0.001$). There were significant differences found between months in the number of children visiting the Emergency Department. As compared to December the frequency of visits was highest during January ($p=0.02$), May ($p=0.0001$) and September ($p=0.001$).
Falls was the predominant external cause (68%) of injury in all ages. As few as 269 (9%) out of 3,168 were road and traffic accidents victims. Sport related head injuries accounted for 6.5 percent, and in this subgroup, football accidents (soccer) were most frequently documented.

Concerning the management in the hospital, fifty percent (n=1,591) of all children were observed for some time at the Emergency Department and twelve percent (n=396) were admitted to a hospital ward for further observation. CT scans were used in thirteen percent (n=412) of the children and the most frequent CT scans were performed among children who had a documentation of road and traffic accidents ($p<0.001$) compared to the other external causes of head injury. Positive findings on the CT scan were found in 108 children (13%). In spite of the fact that they had positive findings on the CT scan, twenty- eight percent (n=30) of the 108 children were not admitted to a hospital ward.
The children with documented LOC for more than five minutes were more likely to have a CT scan performed than the children with documentation of no LOC ($p<0.001$). Nine children out of 3,168 (0.3%) required neurosurgical intervention due to an intracranial haematoma (n=2) or intracranial pressure monitoring (n=4) or both interventions (n=3). In our study we found no single initial symptom that predicted the need for neurosurgical intervention.

The physician in charge set the discharge diagnosis and was distributed as follows; Fifty-seven percent (n=1,799) of all children were diagnosed with a concussion, twenty-two percent (n=695) had a contusion cerebri and two percent (n=59) had a skull fracture. Eighteen percent (n=585) had other diagnoses such as post concussion, gastroenteritis, migraine or no diagnosis at all.

One percent of the children (n=41) had documentation of a planned follow-up appointment at different outpatient clinics in the hospital. Only fourteen percent (n=15) out of 108 children with positive findings on the CT scan and one percent (n=3) of the 24 children with documented LOC more than five minutes had a planned follow-up appointment.
However, it was more likely that a child with a more severe ICD-10 discharge diagnosis (S 060) did have a planned follow-up but no significant difference was found between the different ICD-10 discharge diagnoses and a planned follow-up appointment.
Six children were referred to the in-patient rehabilitation ward at the Children's hospital and three of these children were referred later on for further special brain injury rehabilitation.

5.2 CLASSIFICATION AND MANAGEMENT (PAPER II)

During one month, 242 children (105 boys/137girls) visited the Emergency Department due to a head injury. The mean age was 5.3 ± 4.4 years (range 1 month-15 years).
In the children between one and three years of age there were only three different external causes documented (falls, blow to the head and road and traffic accident) compared to five different groups of external causes (road and traffic accident, falls, abuse, blow to the head and sports related) in the older children.

Anamnestic data of unconsciousness at the site of the injury was recorded for thirty children (12%), whereas no unconsciousness was recorded in 162 (67%) children. Documentation of the level of unconsciousness at the site of the injury was missing in 50 children (21%). On the other hand, altered consciousness observed during the stay at the Emergency Department was the most common documented sign or symptom, which was observed in 111 children (46%) of the total series. In the SHIC, altered consciousness in the Emergency Department was observed in 86 children (48%) with minimal head injury, in 18 children (46%) with mild head injury and in four children (80%) with a moderate head injury. In the group of 162 children with no reported anamnestic unconsciousness at the site of injury, altered consciousness in 78 (48%) was observed at the hospital.
The documentation in the medical records revealed that 192 (79%) of the children in the entire series had clinical signs and symptoms after their head injury compared to twenty-eight children who had no signs or symptoms and data were missing for twenty-two children.

In the group of children with minimal head injury (n=179) according to the SHIC there were 33 children (18%) with no documented symptoms during the visit to the Emergency Department compared to three children (8%) in the mild head injury group and one child (2%) in the moderate head injury group (data were missing for 13 children). There were 54 children (30%) in the minimal head injury group that had two documented symptoms as compared to nine children (23%) in the mild head injury group. In the children with moderate head injury three out of five children had two to three different signs and symptoms documented.

One hundred and fifty-seven children (65%) had no documentation of GCS. Out of those with documentation of GCS, a total of 66 children (79%) had a GCS score of 15, fourteen children (16%) a GCS of 14 and five children (1%) had a GCS of 13.
There were no correlations found between GCS scores and the SHIC, admission to the hospital or to the ICD-10 diagnosis set at discharge. Of the ICD-10 diagnoses at discharge, 132 children (55%) were diagnosed as concussion, 60 children (25%) as having a contusion, two children (1%) had a skull fracture, six children (2%) had other head injuries (such as trauma capitis, subdural haematoma and epidural haematoma), 19 children (8%) had other diagnoses (medical evaluation, migraine, gastro-enteritis, and viral infection) and 23 children (9%) had no diagnosis documented.

According to the SHIC, 179 children (74%) were classified as a minimal head injury, 39 children as mild head injury (16%) and five children (2%) as a moderate head injury. No child was classified as severe injury. Eight percent of the children had no documentation of unconsciousness and were therefore not possible to classify.

When comparing the ICD-10 discharge diagnoses and the SHIC, the results showed that the ICD-10 diagnosis concussion had been made in 106 children (59%) in the minimal head injury group. Contusion accounted for forty-two (23%) in the minimal head injury group as compared to fifteen (38%) in the mild head injury and three (60%) in the moderate head injury group
Every second child included in the study was observed in the Emergency Department for varying lengths of time, whereas only 31 (13%) were admitted to a ward for further observation. Significantly more children were admitted to the hospital ($p = <0.05$) (10 % in the minimal head injury group, 21 % in mild head injury group and 60 % in the moderate head injury group). There was no relationship between the ICD-10 diagnosis and observation in the hospital.

5.3 POST-CONCUSSION SYMPTOMS (PAPER III)

The results are based on the responses from 96 children (37girls/59 boys) and their parents. The children's mean age was 4.9 years (range: two months to fifteen years). There were 51 children in the age group less than five years of age and 45 children in the age group five years or older.
There were no significant differences between this group of respondents and those who didn't answer the questionnaires (n=146) regarding age, distribution into age groups, gender, diagnosis at discharge from the Emergency Department, duration of unconsciousness or the SHIC. Of the 96 children included in the study, thirty-five percent (n=33) reported changes/symptoms and/or activity problems at the time of the follow-up, in at least one of the questionnaires, the RPQ, KPCQ or the RHFUQ. Of these 33 children, eleven percent reported both symptoms and functional activity problems. If we assume that the children (n=146) who didn't respond had no symptoms the true incidence of changes or symptoms at three months was 13.6 percent from all 242 children.

In the group of children younger than five years of age, ten parents of children (18%) reported changes in the child's KPCQ. The median score was 2.0 (range 1-4, possible maximum score; 28)

In the children five years of age or older twenty-three (50%) parents and/or children reported symptoms in the child's RPQ. The median score was 5.0 (range; 1-27, possible maximum score 60). The most common symptoms were "headache", "dizziness" and "fatigue".
In functional activity problems measured with the RHFUQ, nine parents and/or children out of 96 (9%) reported functional problems in the child. The most common problem was finding schoolwork more tiring. The median score was 20 (range 1-12 points, possible maximum score 40).
When the children who at three months reported changes, symptoms and/or functional activity problems (n=33) were compared with those who did not report any problems (n=63), there were no significant differences found with respect to the age groups, early acute management or the SHIC documented at the time of injury.

When analyzing the documented initial symptoms it was found that these were distributed significantly differently in the two age groups. In the children five years or older, headache ($p<0.001$), blurred vision ($p<0.013$), nausea ($p<0.02$), amnesia ($p<0.006$) and vertigo ($p<0.026$) were significantly more frequently documented, whereas being agitated ($p<0.011$) was significantly more commonly documented in the younger group of children.
In the younger age group (<5 years of age) the initial documented symptoms of altered consciousness in hospital was significantly correlated with changes in behavior at three months ($p<0.002$). In the age group five years of age or older, the documented symptom of disorientation correlated significantly with the prevalence of symptoms in general at three months ($p= 0.053$). However, the odds ratios are wide due to the small amount of children with symptoms at three months (10 children less than five years and 23 children over the age of five).
The initial documented duration of unconsciousness was not related to the outcome of sequele at three months ($p=0.09$).

5.4 FAMILIES PERCEPTION OF RECEIVED INFORMATION (PAPER IV)

The results are based on the responses from 96 children (37girls/59 boys) and their parents. The children's mean age was 4.9 years (range: two months to fifteen years). There were 51 children in the age group less than five years of age and 45 children in the age group five years or older.
As many as 80 out of 96 families (83%) stated that they had in most part understood the information concerning head injury that had been provided during the visit to the Emergency Department.
Sixty-five families (69%) did for the most part get the information they needed about the head injury before discharge from the Emergency Department. There were no differences between the two age groups whether they received the information and whether they understood ($\chi^2 =2.51$, $df=2$, $p=0.283$) or needed it ($\chi^2 =0.80$, $df=1$, $p=0.371$).
There were significant differences between the two age groups in the questions on information received about common symptoms.
In the age group five years or older, twenty-one families (46%) received information about common symptoms after a head injury compared to ten families (20%) in the younger age group ($\chi^2 =20.98$, $df= 2$, $p <.000$ Cramers V .498).

Significant differences were also found between the two age groups whether or not the child received age appropriate head injury information. In the age group five years or older, twenty-six families(58%) reported that they received age appropriate information compared to eight families (16%) in the younger age group (χ^2 = 35,20, *df= 2, p* <.000, Cramers V .606).
Of all families, fifty-seven (59%) received the information from both the attending physician and the registered nurse. Twenty-seven families (28%) received information only from the attending physician and twelve families (13%) received the information only from the registered nurse. We found no differences between the two age groups and from whom they received information (χ^2 = 1,08, *df=2, p* .580).
Sixteen (16%) families had contacted health care services due to questions about the head injury after the visit at the Emergency Department. We found no differences between the two age groups and the ones who needed further health care service (χ^2 = 2,83, *df=2, p* .284)
The severity of head injury according to the SHIC (χ^2 =2.77, *df*=6, *p* .837) or ICD-10 discharge diagnosis (χ^2 =14.71, *df*=10, *p* .143) had no association to any of the questions.

5.6 FAMILIES NEEDS FOR INFORMATION (PAPER V)

The results are based on the response from 57 participating families. Content analysis revealed that the families of children with mild head injuries expressed two different kinds of needs, i.e.,(i) a need for information concerning the injury itself, and (ii) the need for support.
The informational need could be divided into two subcategories, i.e., a need for immediate information regarding the head injury and the need for information concerning the subsequent everyday care of their child. The family expressed the need for health-care staff to treat their child on the basis of their professional observations, as well as to inform the entire family of the results of these observations.
The families expressed a need for information concerning the daily care of their child at home and they also wanted information about the recovery process and possible restrictions on educational and other activities of their child.

The families also expressed the need for reassurance and support in connection with their coping, as well as a need to share the emotional burden during their stay at the Emergency Department. In their efforts to cope with the situation, the families posed questions concerning the recovery of the child and sought reassurance. They also wanted to know about any possible long-lasting consequences of the head injury. In addition, the parents of children less than five years of age asked questions concerning the impact of the head injury on the physical development of the child that were not posed by the parents of the older children.
The families expressed a need to share various aspects of the emotional burden they were experiencing. They described feelings such as fear, anxiety and overall concern about the situation. Furthermore, they sought assurance about possible guilt feelings regarding their own management of their child's injury with questions like "*Should we have come to the hospital by ambulance?*" and "*Should we have come to the hospital sooner?*".

6 DISCUSSION

6.1 THE GENERAL STUDY DESIGN

In this thesis, both quantitative and qualitative methods were adopted. Such a design was chosen as it was considered that the key issues could be satisfactorily addressed only by means of using mixed methods. This approach was considered to be advantageous as it incorporated different paradigms and thereby brought different kinds of knowledge to the area of head injuries in children. Thus, quantitative analysis of questionnaire data was used whenever a large sample of the group was studied, whereas the qualitative approach was used whenever an in-depth elucidation was the aim (94).

An obvious limitation of our study is that there are probably children who hit their head and might not have sought medical attention due to the head injury. However, as our figure for the mean annual incidence 865/100 000 is comparatively high, it speaks to the fact that the proportion of missing cases would be rather low. In addition, Astrid Lindgren Children's hospital is the single paediatric trauma centre in the metropolitan area of Stockholm (population 1.4 million), and is supposed to be the single emergency unit for paediatric surgical trauma including head injury.

In the vast majority of all previous studies in this area, children irrespective of age-group have been analysed as one single sample not taking into account the fact that the ability of very young infants to verbalise their experiences must have an impact on how symptoms are registered. Therefore, we collected and analysed data using different, age-adjusted methods in the different age-groups. The children were divided into two age groups, children less than five years old and children five years of age or older. This subdivision, which is in accordance with Piaget's developmental theory, was used in order to make a distinction between pre-schoolers and older children (95).

<u>The series</u>

Regarding the sample, it was considered that the data-based hospital register of discharge diagnoses could contain erroneous diagnoses.

As there could be a risk that the discharge diagnosis might not always correspond to the true fact about the child's condition because of the difficulties in examining children of young age, we decided to collect our data directly about signs and symptoms recorded in the medical records.

The most crucial potential source of bias would be the records taken by the triage nurse. Her/his account of the parents' report given immediately upon arrival was accepted as such.

In addition, one of our main aims was to evaluate the feasibility of using medical data to assess the management of the child, and the documentation in the medical records was the only way to evaluate what was carried out.

The methods

The use of the documentation of the GCS or the Paediatric Coma Scale has to be seen in the light of the limitations of these scales. Studies have shown that the different scores in the scales are dependent on the clinician's own experiences of how to perform and judge the neurological assessment and how this is valid especially in children (97). Documentation of the results of such measurements therefore, has to be used with caution in order to avoid drawing false conclusions.

Another limitation to our study is the time-period of three months for the follow-up questionnaires. The fact that is that the experience of the head injury and the information given at the Emergency Department could have been forgotten and/or not even been considered as relevant three months post injury. However, it seems reasonable that the impact of a head injury suffered by a child is a stressful event and therefore not easily forgotten.

The questionnaires used in this sample were constructed for the adult population in the UK by the team at the Oxford Head Injury Service, Rivermead Rehabilitation Centre. These questionnaires are used all over the world and used in Sweden in several studies (98-100).

However, an analysis of whether the questionnaires are valid for a Swedish sample has not been investigated at this time. In addition, measuring symptoms in children using an adult questionnaire could result in not recording child specific experiences. In 2005, the construct validity of Rivermead was investigated by Eyres and co-workers (96), and they found that the RPQ did not meet modern psychometric standards. However, when the RPQ is split up into two different scales (RPQ-13 and RPQ-3), each set of the items forms a unidimensional construct for people with head injury at three months post injury. In the testing of these two subscales a good test-retest reliability and adequate external construct validity was shown (96). The translation process of the Rivermead Post-concussion Symptom Questionnaire (RPQ) and the Rivermead Head Injury Follow-up Questionnaire (RHFUQ) was conducted in our study according to scientific rules about the translation of questionnaires (101) and tested in a small pilot study to make sure that the concept was correctly understood by parents of young children. Nevertheless, the original content could even then have been interpreted differently in the original sample.

For children less than five years of age we constructed (using our own clinical experience) a symptom questionnaire, The Karolinska Post-Concussion Questionnaire (KPCQ) that consisted of symptoms usually seen after a head injury in children of this age group. This questionnaire was not validated which means that extra caution should be used in the interpretation of the results. Nevertheless, the result showed that the impact from a head injury can result in recordable symptoms at three months in children less than five years.

In the studies on information we do not know who answered the questionnaires, parent or child. This means that we cannot draw any conclusions about whose questions and needs are being expressed. However, the impact of a child's head injury might be believed to be answered mainly by parents due to the high number of children who were less than five years of age in our study. However, special attention should be made in the future to the specific needs from the children's perspective and using their own words.

<u>The analysis</u>

As most of our data was not normally distributed, the statistical analysis is mostly from non-parametric statistics which could indicate that the statistical power is considered to be low. However, we have tried not to draw too many major conclusions from the statistical results.

The fact that we wanted to try to identify age specific initial symptoms, out of a wide range of variables and possible differences in the management of different age-groups, resulted however, in small sub-samples. The combination of rather small sub-samples and many variables gave some constraint in the statistical analyses. On the other hand, the importance of being able to show age-dependent differences might outweigh the statistical drawbacks. For the same reason, a Poisson regression model was used in the analysis of the monthly distribution of the children, and the external causes of the injuries, ages, weekdays and gender.

In the statistical analysis of the descriptive symptom questionnaires the answers were dichotomised into yes (scoring 2-4) and no (scoring 0-1). This means that the interpretation of the answers was made to make the calculation of the statistical correlations possible. This procedure is in accordance with the recommendations by Eyres and co-workers (96) that combining these responses would improve the scaling properties of the the RPQ.

In the analysis of the qualitative data in our study content analysis was used. In the use of this method the credibility or reliability and validation were considered by using the procedures described by Weber (92) and Lundman & Graneheim (93). Reliability in qualitative work involves consistent coding of the same text in the same manner, which we attempted to optimise by allowing two of the authors to read the text and code it independently and having the third author check and agree with their joint conclusions. Reliability also refers to accuracy, i.e., the extent to which the classification of a text conforms to a standard or norm. In this respect our classifications are in good agreement with reports from authors such as Hopia (85) and Snowdon (101).

All content analysis, even of a manifest text, involves some degree of interpretation by the individual performing this analysis (92). We attempted to minimise any subjectivity which might have been associated with such interpretation by involving an author who was unfamiliar with the circumstances concerning each child with a head injury in the coding process. The validity (according to Weber) was considered by on one hand trying to give a description of the correspondence between the data and method, and the generalization of the findings on the other (92). Our findings must be seen in the light of the 57 respondents; however, the results could probably be applicable to the needs of families from all head injured children.

6.2 RESULTS

The results show that the incidence of head injury (minimal-severe) in the Stockholm Region were 865/100,000 children (0-15.9 years) The most remarkable result was the conspicuous variation of incidence by age-group, with the highest incidence for head injury, 2,379/100,000 in children between 0 to 18 months of age. This figure is of special interest as it was demonstrated by Billmire in 1985 that in 64 percent of all children less than one year of age with a head injury represented a non-accidental head injury (103). The documentation available for our scrutiny of the Karolinska series did not reveal a single case representing such non-accidental head injury aetiology. Contradictory to this well-known Cincinnati study (103), Keenan (104) estimated the incidence of non-accidental traumatic brain injuries (TBI) in children less than two years of age or younger in the United States to be 17/100,000 person-years compared to 15.3/100, 000 person-year for accidental TBI (104). A recent study in the UK reported the overall annual incidence of subdural haemorrhage and effusion to be 12.54/100,000 for children under two years of age of whom 57 percent suffered from non-accidental TBI (105). In the light of these figures it is remarkable that no child in our series had the documented findings of a non-accidental traumatic brain injury. In the Cincinnati study one third of the children with non-accidental head injury also had a child-abuse report. Therefore, it seems possible that there are children in the Stockholm population that have avoided detection for non-accidental head trauma.

The different distributions of initial symptoms, as documented in the medical records in the two-age groups included in our study, probably reflect the age-related ability to verbalise complaints than differences in physiological properties. On the other hand, you cannot be absolutely sure about true difference or not. Another problem could be an inability in the examiner's capability to judge different signals.
One solution to these problems could be the use of age-appropriate and validated symptom scoring sheets. The age-dependent difference could also be applicable in the post-concussion symptoms that were reported. In the children five years of age or older the most commonly reported symptoms at three months were "headache", "dizziness" and "fatigue", while for the children less than five years of age changes in "sleeping patterns" and "mood fluctuations" were the most commonly reported problems.
In the literature (106), which usually has been based on adult populations, the most common post-concussion symptoms reported after a TBI can be grouped into three categories: cognitive (decreased memory, attention and concentration), somatic (headache, fatigue, insomnia, dizziness, tinnitus and sensitivity to noise and light) and affective complaints (depression, irritability and anxiety). It could be speculated that the differences seen between symptoms and age groups is due to normal developmental maturation. Whereas small children have a decreased ability in cognitive performance, older children have developed these skills. Therefore, our results demonstrate that findings from the adult population cannot be applied to children.

Our finding concerning the incidence of post-concussion symptoms in 13.6 percent are well in line with the results from Wittenberg et al. (6), Borgaro et al. (52), Mcallistar et al. (53), Overweg-Plandsoen et al. (108) and Hawley et al. (8). On the other hand, the results from Ponsford et al. (9), Necajauskaite et al. (60) and Donders et al. (61) show

that post-concussion symptom are most likely to resolve within weeks after the head injury.
There are however, differences in the occurrence of sequele in different studies. The studies that demonstrate sequele and those that do not are most likely due to the differences in the populations under study with respect to age distribution and differences in used head injury definitions. Thus, it seems more likely that the debate will continue about the recovery of children with head injury, until the same set of criteria has been used by several research groups who investigate children with head injuries.

In many studies, attempts have been made to link initial symptoms and findings to the development of later sequele (66-72) and no strong predictors have been found. This is especially valid for children due to age group differences. Whether this situation is a consequence of inadequate methods for observation or reflects the observable signs and symptoms remains to be judged. Despite a thorough attempt we were as most other scientists, not able to find any clusters of initial signs and symptoms which could be useful for prediction of development of post-concussion symptoms. Interestingly, altered consciousness in the hospital was significantly correlated with changes in behaviour at three months post head injury for a child less than five years of age, whereas in the older children the documented symptom of disorientation correlated significantly with the prevalence of symptoms in general at three months. This raises the question as to whether these symptoms, disorientation and altered consciousness, are part of the same neural network, not only the formatio reticularis but also other areas representing the neuronal mechanism of conscious awareness (107) representing different levels. It is interesting to speculate that the documentation in fact may reflect the way health care staff is able to observe these symptoms.

The management of head injury is consuming major health care resources. A question arises as to whether the management plans that are used are cost-effective. The fact that so many children seek medical attention due to a head injury should be used when planning health care services for these children and families to meet their special needs.
The documented management showed no correlation between the discharge diagnoses and the documented initial symptoms. For example; the decision to admit a child or to have A CT scan performed after a head injury was not obviously based on the available documentation. Recently, in 2005, af Geijerstam and co-workers (36) showed that an early CT-scan can reduce the need for hospitalisation. This was shown in a Swedish study including individuals six years or older with a mild head injury. Our results seem to show that such an investigation was not included in the current management in the everyday clinical setting, as no correlations were found in the management between the children who had a CT scan performed and of those who had no CT scan performed. In our study the question remains open; is the decision to plan a CT scan based on, parental anxiety, initial symptoms or some kind of non-documented global clinical judgement or impression?

We also found that in 65 percent (n=57) of the 242 children no GCS was documented. This could mean that GCS was not systematically used or not documented. The reasons for this are beyond the scope of this investigation, but the findings raise several questions. Firstly; the incomplete documentation hampers our analysis as it is not absolutely clear that our inability to show a clear relationship between documented findings and management decisions is a consequence of faulty documentation or of a true absence of such a link. Secondly, the finding may be interpreted so that the recommended management is not perceived as meaningful as it apparently is not used for decision making. This would call for a thorough reconstruction of currently used documentation.

The more recently developed SHIC appeared to be a somewhat better predictor of subsequent management than the rather crude ICD-10. However, the SHIC as such might not be used as the only basis in the decision about which individual needs hospitalisation as our results showed that in the youngest children its usefulness was unimpressive. Another evident drawback of SHIC could be that the population for whom it is supposed to be used is not clearly defined in the original report (10).
At the start of our research project the hypothesis was that the SHIC could be a reliable method for identifying the children with head injury who run a higher risk of developing post-concussion symptoms. However, the hypothesis was not supported.

The fact that only 1 percent of all children had documentation of a planned follow-up appointment implies that this was not a part of the regular management plan. Over ten percent of the children in this group according to our study will show neurological sequele, most of them escaped any attention unless they later on underwent a neurological examination. The need for a follow-up visit or contact is also underlined by the findings that specifically the families with very young children had not received satisfactory initial or age-appropriate information regarding common symptoms. We also know that sixteen percent of the children involved in our study had contacted health care services due to questions about head injury after the visit at the Emergency Department. Whether or not information could have prevented the additional health care visits or the influence of social or economic conditions of the families is not within the scope of this research to answer but should be considered when planning health care services for these children.

When it comes to the families' perception of information provided during the emergency care visit, our results shows that fifteen percent of the families said that they only in some part received information that was understood or needed. Of course, it could be speculated if it is possible to reach the goal of optimal information in an acute situation. On the other hand, we know that parents often feel themselves disempowered when dealing with acute illness in their children (74-77). This calls for sensitivity of the staff in the care of the child and family. We also know that doctors and patients differ in their opinions of what they consider to be the most important information during a visit to an out patient clinic (109).
The fact that so many families reported lack of age-appropriate head injury information as well as the information not being directed towards the child has to be highlighted. Children are likely to understand what has happened to them, therefore they need information about what is happening, what to expect and when to talk to an adult about how they feel. Involving children in the decision-making process is one way in which

they can have some control over the situation in the Emergency Department (76). Furthermore, the child needs his or her parents and both need information. The work in a pediatric setting should be family focused so that both the child and parents' needs are met (76, 85).

We cannot be certain whose needs (parents or children) are being expressed in the present investigation. Younger children might be especially interested in questions concerning the present situation, while parents might want to know more about the future. This might explain the particular concern of the families of the younger patients about the possible impact of the head injury on physical development. The families also wanted to know, for example, if they had made the right decision concerning the initial care of their child, which would seem to indicate a lack of knowledge concerning what is normal or not in connection with a head injury. This educational need should be investigated further which might improve the health care services of today.

Two major categories of informational needs were reported from the families of the children. The need for information concerning everyday care expressed by our families has also been described in other studies of children with head injuries [21-23], but none of these other investigations has explored what type of information the patient and/or his/her family desired. Our families all expressed the same needs, despite differences in the severity of the child’s injury and requirement for hospitalisation. This observation, along with the reported needs for emotional support documented here, are major novel aspects of the present study.

7 SUMMARY OF FINDNINGS

To the best of our knowledge the present set of studies is the first attempt to incorporate incidence, initial symptoms, management, early sequele and the families' informational needs in a group of children with head injury on the basis of the same sample in a single research project placing the children into age-groups.

The overall incidence of head injury was 865 per 100,000 children in the Stockholm region and the highest incidence, 2,379 per 100,000 for a head injury was found in the youngest age-group (0 to <18 months of age).

Diverging initial symptoms were documented for the different age-groups showing that there are differences in the observable signs and symptoms in head injured children. The documentation of clinical findings was only to a limited extent related to early management. Management guidelines were not easily discernible in the clinical practice as reflected in documentation.

The usefulness of currently used documentation and classification of head injuries was shown to be questionable. The SHIC offered some advantages over older methods, but was a failure as a method for identifying children with head injury running a high risk for sequele in this sample.

At three months post head injury 13.6 percent reported post-concussion symptoms. In the young children <5 years the most common symptoms were changes in sleeping patterns and mood changes. In the older group headache, dizziness and fatigue were the most common.

Only a small part of the families received age appropriate head injury information during their stay at the Emergency departments or received information that was directed towards to the child.

As for the families own expressed informational needs the same needs, despite differences in the severity of the child's head injury and requirement for hospitalisation, were; basic head injury information concerning the head injury as well as the need for emotional support.

8 CLINICAL IMPLICATIONS AND FUTURE RESEARCH

The data which emanated from the present research project was hoped to elucidate some, but not all, important aspects of the current situation for children with head injury.
On the basis of our findings it is not possible to create new comprehensive management guidelines for this group of children. However, there appear to be some important lessons, which should be taken into account when developing future management plans.

This study demonstrated that the number of children suffering from a head injury is still high. At present, it seems that the incidence of severe head injury in children in Sweden is decreasing. Whether this favourable development can be seen also in mild head injuries is not known. Therefore our study also points to a need for repeated studies of the incidence pattern. This is the only way to monitor the efficacy of preventive measures and newly emerging risk factors for head injury in society.
The high number of children with a head injury in the age group <2 years requires more in depth investigations so that interventions can be planned for the reduction of head injuries in small children. The prevention could take place in the form of information to novice parents as well to paediatric health care staff.
An even more serious concern is the fact that our study raises a suspicion that cases of non-accidental head injury may have escaped attention. Extensive use of modern neuroradiography and fundus photography are tentatively useful methods for an objective diagnosis. Such relatively invasive methods cannot possibly be used for the entire group of infants. Therefore, there is a need for defining high-risk groups and to evaluate the feasibility of such procedures.

Defining high-risk groups of various kinds among children with head injuries is still a rather delicate task. Like all other previous ones, the present study also failed to identify a procedure to pinpoint children at risk of poor outcomes. In the first place it is mandatory to validate the most appropriate currently used symptom questionnaires. Entirely new assessment procedures, appropriate for the developmental age are needed for the very young children, and especially for those representing the preverbal age–group.

Our data seem to indicate that management plans were not applied systematically. The reasons for this were not studied in this project, but do deserve attention. The fact that several management plans have been developed and used during the last few years indicate that the lack of reliable management plans is a universal phenomenon. Introduction of paediatric management guidelines for both the emergency care as well as for the care of admitted head injury children is probably the only way to improve the management and to make it more cost-effective. As validated management plans do not exist today, it is necessary to monitor the effects of possible changes of the management.

At this point the evident lack of knowledge is a major obstacle for creating an evidence based management plan for children with head injury. In line with this, it is not truly known whether all children with a head injury really benefit from visiting or being observed in the Emergency departments. However, at present there is no obvious alternative. It can be speculated that improved, easily accessible guidance over the telephone or internet might reduce the frequency of head injuries and also reduce the number of visits for health care. The follow-up after the immediate phase of the injury is another problem. This huge number of children can not possibly undergo meticulous neurological screening repeatedly during the subsequent months. There are no methods for the identification of high risk groups. A possible solution would be the use of well-trained, highly knowledgeable advisors easily accessible by phone or electronically.

The management plan should also include guidelines for how to deal with the families need for information during the initial phase of care. The health-care staff should regularly provide age appropriate feedback to the families of children under assessment or observation. Both oral and written material is needed and must deal with the diagnosis, the nature and treatment of the child’s head injury. This support should be designed to offer support and to relieve the emotional burden experienced by the families.

9 POPULÄRVETENSKAPLIG SAMMANFATTNING PÅ SVENSKA

Skallskador hos barn är en av de vanligast förekommande olyckorna under barns uppväxtår. Svårigheterna att på ett så tillförlitligt sätt som möjligt neurologiskt undersöka och bedöma barn i samband med en skallskada har beskrivits i flera studier men någon gemensam metodik har inte utarbetats.
Från litteratur som beskriver vuxna som drabbats av skallskador har de flesta riktlinjer och huvuddelen av informationsmaterialet tagits fram och sedan applicerats på barn i olika åldrar. Vår erfarenhet av att arbeta med barn med skallskador, har dock inte alltid varit överensstämmande med gällande riktlinjer och informationsmaterial. Vårt syfte har därför varit att undersöka antalet barn med skallskador, deras initiala och sena symtom, omhändertagande på sjukhus samt även vilket informationsbehov som familjen har.
Vi inkluderade alla barn (0-15.9 år) med skallskador och deras föräldrar samt valde att genomföra studierna vid Astrid Lindgrens barnsjukhus vid Karolinska Universitetssjukhuset i Stockholm, den enda kirurgiska akutkliniken för barn i Stockholms län finns. Detta innebär att upptagningsområdet innehåller över 350 000 barn 0-15.9 år.
Under ett år, september 2002-september 2003 samlade vi in information från alla barn som sökt sjukhusvård via barnakutmottagningen på grund av en skallskada, oavsett svårighetsgrad. Informationen baserades på uppgifter via akutjournal samt barnens egen journal. Under året samlade vi även in information för att belysa förekomst av sena symtom (tre månader efter skadan), information om omhändertagandet samt föräldrars och barns egna upplevda informationsbehov i samband med skallskadan.

Incidens och omhändertagande

Våra resultat visar att antalet barn som sökte för en skallskada under hela året var 3168 vilket resulterar i en incidens av 865 per 100 000 barn/år. Den högsta incidensen fann vi bland barn 0-<18 månader; 2379/100 000. Denna siffra är ovanligt hög och behöver undersökas ytterligare för att ge en djupare förståelse. Orsaken till skallskadan var till största andelen beskriven som fall (68 %) av barn/förälder medan 9 procent var trafikolyckor. De allra flesta av barnen, 57 procent fick diagnosen skallskada, 23 procent fick en diagnos som inkluderar hjärnskada och 2 procent, diagnosen skallfraktur. Hela 18 procent fick en annan diagnos (exempelvis migrän).

Ungefär hälften av barnen observerades en period på akutmottaggningen men endast 396 barn blev inlagda. Under året (2002-2003) var det nio barn (0.3%) som krävde neurokirurgisk vård i samband med sin skallskada. Hos bara en procent (n=41) av barnen fann vi dokumentation om en planerad uppföljning.

Klassifikation av skallskador

Vårt syfte var att undersöka om aktuella klassifikationssystem skulle kunna appliceras på barn med skallskada, för att på så sätt kunna skapa en evidensbaserad vårdkedja. Vi undersökte om den skandinaviska skallskadeklassifikationen kunde appliceras, baserad på uppgifter tagna ur journalen till 242 barn (0-15.9 år) som under en månad (september-oktober år 2002) sökt för en skallskada till Astrid Lindgrens barn-akutmottagning. Vårt resultat visade, att utav 242 barn var 137 flickor och 105 pojkar. Den genomsnittliga åldern bland barnen var 5.3±4.4 år. Av dessa klassificerades 73 procent som minimala skallskador, 17 procent som milda skallskador och två som medelsvåra skallskador. Under denna månad sökte ingen för en allvarlig skallskada.
Resultatet visade även att barn i olika åldrar uppvisade skillnad i vilka symtom som fanns dokumenterade samt även antal symtom. Yngre barn hade mindre antal symtom samt mindre variation i dokumenterade symtom. Resultatet visade också att det kliniska omhändertagandet inte alltid var baserat på dokumenterade kliniska symtom, klassifikation eller utskrivningsdiagnos.

Post-commotio symtom

För att undersöka förekomst av sena symtom (tre månader) hos barn med lätt skallskada använde vi oss av frågeformulär där barn/föräldrar bads fylla i eventuella besvär tre månader efter skadan. Av 242 barn, deltog 96 barn/föräldrar i denna uppföljning, ålder 2 månader–15 år.
Vårt resultat visade att 35 procent (n=33) av barn/föräldrar beskrev sena symtom och/eller funktionella symtom. Bland barn över fem år var det vanligaste symtomet huvudvärk, yrsel och trötthet medan barn under fem år hade förändringar i sovmönster samt humörsvängningar. Om vi förutsätter att de barn/föräldrar som inte svarat inte har haft några symtom skulle det innebära att 13.6 procent av alla 242 barn beskriver symtom upp till tre månader efter en lätt skallskada. Vi fann inga dokumenterade initiala kliniska symtom som kunde förutse vilka barn som beskrev kvarvarande symtom efter en skallskada.

Familjens upplevelse av given information under deras besök på akutmottagningen i relation till en lätt skallskada hos barn.

För att undersöka i vilken grad barn/föräldrar upplever att given information varit nödvändig använde vi oss av ett frågeformulär som de tidigare beskriva 96 barn/föräldrar besvarade. De allra flesta barn och föräldrar (83 procent) förstod informationen som de fått under besöket medan 69 procent fått den information som de ansåg sig behöva. Vi fann skillnader mellan de två åldergrupperna, över och under fem år, där föräldrar till barn under fem år ansåg att de inte fått åldersrelaterad skall-skadeinformation samt att informationen inte heller var riktad till barnen. Sexton barn/föräldrar hade sökt ny kontakt med sjukvården med frågor gällande skallskadan hos deras barn. Vi fann ingen skillnad mellan svårighetsgrad av skallskada och vilken information som barn/föräldrar ansåg sig ha fått.

Informationsbehov bland barn och föräldrar i samband med deras barns skallskada
För att låta barn och föräldrar själva berätta om vilken information de skulle ha önskat sig vid deras besök för en skallskada gjordes en uppföljning av barn (0-15 år) som sökt akutmottagningen vid Astrid Lindgrens Barnsjukhus för sena besvär efter en skallskada och/eller de som varit inlagda på sjukhus på grund av skallskadan.
Femtiosju barn/föräldrar fick själva skriva ned vilka frågor de haft vid deras besök på sjukhuset vilka sedan analyserades. Familjerna beskrev i huvudsak två typer av frågor; information gällande skallskadan, dess natur, omhändertagande, akuta undersökningar och eventuella följder samt behovet av emotionellt stöd. Familjen ville både få stöd men även dela olika emotionella känslor som skuld, oro och ångest med personalen.

Sammanfattningsvis visar resultaten av studierna på en rad områden som kan vidareutvecklas; omhändertagande på sjukhus, aktuell dokumentation samt informationsmaterial, detta för att säkerställa vården för de skallskadade barnen och dess föräldrar.

10 ACKNOWLEDGEMENTS

First of all, I would like to thank all the children and their parents who have been there with all their questions and supporting me by enforcing that I need to speak their mind.

During my work of completing this thesis many people have supported me and I would especially like to wish my gratitude to:

Lennart von Wendt, my main supervisor, for excellent guiding me into research and who always shared research experiences and knowledge with me. Your good advice and encouragement have made this work possible.

Birgitta Klang, my second supervisor, who been there with support and encouragement throughout the work with the thesis. It has been a privilege to work with you.

Juulia Paavonen, co-author and statistician*,* for valuable help and discussions through out the statistical considerations and analyses.

My greatfullness to *Claes Cederfjäll*, supervisor, who is no longer with us but I am sure he would have enjoyed to be part of all the work with laughs and his supportive mind!

Agneta Witalisson and *Birgitta Negussi*, who were there during the data collection, your support and our discussions really made a difference. Without you, it would not have been possible!

The Workgroup *Bengt Gustavsson, Margareta Lannge, Anders Boman, Hans Forssberg* and *Catharina Kumlien* for supporting and giving valuable remarks throughout the work.

A special thanks to *Bo Ericsson* who always supported me and my thoughts concerning children with head injuries. Without your support and encouragement, this work would not have been possible.

To all colleagues at the *Neuropediatric Rehabilitation Team* at Astrid Lindgren children's hospital who shared their knowledge and experiences with me.

All the colleagues and staff in the *Emergency department*, *Neuropediatric out patient clinic* and *Neuropediatric day care unit* and the *Neuropediatric Ward* (Q82) who supported me and were there for valuable discussions.

For the support and inspiring thoughts from my colleagues at my workplace, the *Pediatric ICU* at the Karolinska University hospital

National Health Care Science School, with the remarkable support, encouragement and the ability to get together all the fantastic courses of which I have participated in.

All colleagues in the class of *HK-04*, all the laughs, support and many discussions of any- and everything

To everyone at the *Neuropediatric seminar group team* at level 7, thank you for inviting me and letting me be part of all fruitful and inspiring discussions.

To the Pediatric research and seminar group with Björn Tingberg, Nina Andersson, Leena Jyllie, and Britt-Marie Ygge for all your support and encouragements.

To my family, *Roland*, for all the help with all computer problems and my daughter, *Li*, who have had a hard time to understand why her mother needs to go to school for so many years. Now it is over!
My mother, *Monica,* who always have supported me throughout the years.
And to my friends, especially *Veronica Lindström* and *Agneta Witalisson,* who shares the same interest, head trauma patients, for all our discussions, laughs and for just being there!

These studies have been financially supported by The Cancer and Traffic Injury found (CTRF), Foundation of Samariten, The Jerring Foundation, The Sunnerdahl Foundation, The Foundation of Frimurare-Barnhuset in Stockholm, The Capio Foundation and the National Health Care Science School.

11 REFERENCES

1. Balak N, Elmaci I. Costs of disorders of the brain in Europe. *Eur J Neurol* 2007; 14:e9.

2. Rune V. Acute head injuries in children: a retrospective epidemiologic, child psychiatric and elektroencephalographis study on primary school children in Umeå. *Acta Paediatr Scand* 1970; 209 (suppl):3-12.

3. Kraus, J. *Epidemiological features of brain injury in children*, ed. S. Broman and M. ME.: Oxford: Oxford University press, 1995.

4. Statens Beredning för medicinsk utvärdering. *Hjärnskakning, övervakning på sjukhus eller datortomografi och hemgång.* Mölnlycke, Elanders Infologistics Väst AB, 2000.

5. af Geijerstam J-L, Britton M, Marké L-Å. Mild head injury: observation or computed tomography? Economic aspects by literature review and decision analysis. *Emerg Med J* 2004;21:54-58.

6. Mittenberg W, Wittner MS, Miller LJ. Postconcussion occurs in children. *Neuropsychol* 1997; 11:447-52.

7. Mittenberg W, Strauman S. Diagnosis of mild head injury and the postconcussion syndrome. *J Head Trauma Rehabil* 2000; 15:783-791.

8. Hawley C. Reported problems and their resolution following mild, moderate and severe traumatic brain injury amongst children and adolescents in the UK. *Brain Inj* 2003; 17: 105-129.

9. Ponsford J, Willmott C, Rothwell A, Cameron P, Ayton G, Nelms R, Curran C, Ng K. Cognitive and behavioral outcome following mild traumatic brain injury in children. *J Head Trauma Rehabil* 1999;14:360-72.

10. Romner B, Ingebrigtsen T, Kock-Jensen C. Scandinavian guidelines for initial management of minimal, mild and moderate head injuries. The Scandinavian Neurotrauma Committee. *J Trauma* 2000; 48:760-766.

11. Pediatrics (editorial). The management of minor closed head injury in children. *Pediatrics* 1999; 104:1407-15.

12. Teasdale G, Jennet B. Assessment of coma and impaired consciousness: a practical scale. *Lancet* 1974;ii: 81-84.

13. Emergency nurses Association. *Trauma Nursing Core Course*, provider's manual. Pediatric Coma Scale pp 313, Fourth edition. USA, 1995.

14. Starmark JE, Stålhammar D, Holmgren E. The Reaction Level Scale (RLS 85) *Acta Neurochirurg* 1988;91: 0942-0944.

15. Rosenthal M, Griffin E, Kreutzer J, Pentland B. *Rehabilitation of the adult and child with traumatic brain injury*, third edition. USA: F.A. Davies Company, 1999.

16. American Congress of Rehabilitation medicine. Definition of mild head trauma. *J head trauma Rehabil* 1993; 8: 86-87.

17. Malec J, Brown A, Leibson C, Flaada J, Mandrekar J, Diehl N, Perkins P. The Mayo clinic classifiacation system for traumatic brain injury system. *J Neurotrauma* 2007;24: 1417-1424.

18. Ruijs MB, Keyser A, Gabreels FJ. Assessment of posttraumatic amnesia in young children. *Dev Med Child Neurol* 1992; 34(10):885-892.

19. Hawley C, Ward A, Long J, Owen D, Magnay A. Prevalence of traumatic brain injury amongst children admitted to hospital in one health district: a population based study. *Injury, Int J Care Inj* 2003; 34: 256-260.

20. Guerrero J, Thurman D, Sniezek J. Emergency department visits associated with traumatic brain injury: United States, 1995-1996. *Brain Inj* 2000; 14(2):181-186.

21. Bazarian J**,** McClung J**,** Cheng Y T**,** Flesher W**,** Schneider S M**.** Emergency department management of mild traumatic brain injury in the USA. *Emerg Med J* 2005; 22(7):473-477.

22. Methodological issues and research recommendations for mild traumatic brain injury: The WHO collaborating centre task force on mild traumatic brain injury. *J Rehabil Med* 2004; 43:113-125.

23. Jennet B. Epidemiology of head Injury. *Arch Dis Child* 1998; 78:403-406.

24. Tate R, McDonald S, Lulham J. Incidence of hospital treated traumatic brain injury in an Australian community. *AUS N Z J Public health* 1998; 22:419-423.

25. Andersson E. H, Björklund R, Emanuelson I, Stålhammar D. Epidemiology of traumatic brain injury: a population based study in western Sweden. *Acta Neurol Scand* 2003;107 (4):256–259.

26. World Health Organization. *International Classification of diseases and related health problems- ICD -10*, rev.1992. Geneva: WHO, 1992

27. Borg J, Holm L, Cassidy D, Peloso P, Carroll L, von Holst H, Ericson K. Diagnostic procedures in mild traumatic brain injury: the results of the WHO collaborating centre task force on mild traumatic brain injury. *J Rehabil Med* 2004;43:61-75.

28. Shaneyfelt TM, Mayo-Smith MF, Rothwangl J. Are guidelines following guidelines? The methodological quality of clinical practice guidelines in the peer-reviewed medical literature. *JAMA* 1999; 281:1900-1905.

29. Jagoda A, Cantrill S, Wears R, Valadka A, Gallagher E, Gottesfeld. Clinical policy: Neuroimaging and decision making in adult mild traumatic brain injury in the acute setting. *Ann Emerg Med* 2002; 40:231-249.

30. National Institute for health and clinical excellence. *Head injury, triage, assessment, investigation and early management of head injury infants, children and adults, 2007*. (NICE clinical guidelineNo.56) www.nice.org.uk/CG056

31. Kraus JF, Nourjah P. The epidemiology of mild, uncomplicated brain injury. *J Trauma* 1988; 28(12):1637-1643.

32. Davies C. Mothers anxiety may increase child's distress. *Nurs mirror* 1984; 158:30-31.

33. von Holst H, Cassidy D. Mandate of the who collaborating centre task force on mild traumatic brain injury. *J Rehab Med* 2004; 43:8-10.

34. Peloso P, Carroll L, Cassidy J, Borg J, von Holst H, Holm L. Critical evaluation of the existing guidelines on mild traumatic brain injury. *J Rehabil Med* 2004; 43:106-12.

35. Quayle K, Jaffe D, Kupper mann N, Kaufman B, Lee B, Park T, Mcalister W. Diagnostic testing for acute head injury in children: When are head computed tomography and skull radiographs indicated? *Pediatrics* 1997; 99: 11-22.

36. af Geijerstam J, Oredsson S, Britton M. Medical outcome after immediate computed tomography or admission for observation in patients with mild head injury: randomized controlled trial. *BMJ* 2006; 333:465.

37. Van Eldik L and Wainwraight M. The janus face of glial-derived S100B: beneficial and detrimental functions in the brain. *Restor Neurol Neurosci* 2003; 21: 97-108.

38. Townend W, Ingebrigtsen T. Head injury outcome prediction: a role for protein S100B? *Injury* 2006; 37: 1098-108.

39. Wade DT, King NS, Wenden FJ. Routine follow up after head injury: a second randomized controlled trial. *J Neurol Neurosurg Psychiatry* 1998; 65:177-83.

40. King NS, Crawford S, Wenden FJ. Interventions and service need following mild and moderate head injury: the Oxford Head Injury Service. *Clin Rehabil* 1997; 11:13-27.

41. Ponsford J, Willmott C, Rothwell A, Cameron P, Ayton G, Nelms R, Curran C, Ng K. Impact of early intervention on outcome after mild traumatic brain injury in children. *Pediatrics* 2001; 108:1297-1303.

42. Hawley C, Ward A B, Magnay A R, Long J. Outcomes following childhood head injury: a population study. *J Neuro Neurosurg Psychiatry* 2004; 75:737-742.

43. Bazarian J, Hartman M, Delahunta E. Minor head injury: predicting follow-up after discharge from the emergency department. *Brain Inj* 2000; 14: 285-294.

44. Kraus JF, Fife D, Conroy C. Pediatric brain injuries: the nature, clinical course and early outcomes in a defined United States population. *Pediatrics* 1987;79:501-507.

45. Dunning J, Batchelor J, Stratford-Smith P, Teece S, Browne J, Sharpin C, Mackway-Jones K. A meta-analysis of variables that predict significant intracranial injury in minor head trauma. *Arch Dis Child* 2004; 89: 653-659.

46. Gruskin K, Scutzman S. Head trauma in children younger than 2 years, Are there predictors for complications? *Arch Pediatr Adolec Med* 1999;153:15-20.

47. Hahn YS, McLone DG. Risk factors in the outcome of children with minor head injury. *Pediatr Neurosurg* 1993;19:135-142.

48. Emanuelson I, v Wendt L. Epidemiology of traumatic brain injury in children and adolescents in south-western Sweden. *Acta Paediatr* 1997; 86:730-735.

49. Snoek J, Minderhoud J, Wilmink J. Delayed deterioration following mild head injury in children. *Brain* 1984; 107:15-36.

50. Greenes D, Schutzman S. Clinical indicators of intracranial injury in head-injured infants. *Pediatrics* 1999;104: 861-867.

51. Brown L, Moynihan J, Denmark K. Pediatric head trauma requiring neurosurgery. *Am J Emerg Med* 2003; 21(6): 467-471.

52. Borgaro S, Prigatano G, Kwsnica C, Rexer J. Cognitive and affective sequele in complicated and uncomplicated mild traumatic brain injury. *Brain Inj* 2003; 3:189-198.

53. Mcallistar T, Arciniegas D. Evaluation and treatment of post concussive symptoms. *Neurorehabil* 2002; 17: 265-283.

54. Levin H, Mattis S, Ruff R, Eisenberg H, Marshall L, Tabador K, Hugh W, Frankowski, R. Neurobehavioral outcome following minor head injury: a three center study. *Neurosurg* 1987; 66:234-243.

55. Mittenberg W, Zielinsky R, Fichera S. Recovery from mild head injury: A treatment manual for patients. *Psychotherapy in private practice* 1993; 2:37-51.

56. Casey R, Ludwig S, McCormick M. Morbidity following minor head trauma in children. *Pediatrics* 1986; 78(3): 497-502.

57. Hooper S, Alexander J, Moore D, Sasser H, Laurent S, King J, Bartel S, Callahan B. Caregiver's report of common symptoms in children following a traumatic brain injury. *Neurorehabil* 2004;19:175-189.

58. Yeates K, Luria J, Bartkowski H, Rusin J, Martin L, Bigler E. Postconcussive symptoms in children with mild closed head injuries. Neurobehavioral issues in Pediatric Head trauma. *J Head Trauma Rehab* 1999; 14:337-350

59. Jaffe K, Fay G, Lopissar N, Martin K, Shurtleff H, Rivara J, Winn R. Severity of pediatric traumatic brain injury and early neurobehavioral outcome: A cohort study. *Arch Phys Med Rehabil* 1992; 73: 540-547.

60. Necajauskaite O, Endziniene M, Jureniene K. The prevalence, course and clinical features of post-concussion syndrome in children. *Medicina (Kaunas)*2005; 41:457-464.

61. Donders J, Strom D. Neurobehavioral Recovery after pediatric head trauma: injury, pre-injury and post-injury issues. *J Head Trauma Rehabil* 2000;15: 792-803.

62. Hawley C. Reported problems and their resolution following mild, moderate and severe traumatic brain injury amongst children and adolescents in the UK. *Brain Inj* 2003;17 (2): 105-129.

63. Emanuelson I, v Wendt L, Beckung E, Hagberg I. Late outcome after severe traumatic brain injury in children and adolescents. *Pediatric Rehabil* 1998; 2: 65-70.

64. Stiell IG, Lesiuk H, Wells GA, McKnight RD, Brison R, Clement C, Eisenhauer MA, Greenberg GH, MacPhail I, Reardon M, Worthington J, Verbeek R, Rowe B, Cass D, Dreyer J, Holroyd B, Morrison L, Schull M, Laupacis A; Canadian CT Head and C-Spine Study Group. The Canadian Head CT rule study for patients with minor head injury: rationale, objectives and methodology for phase I. *Ann Emerg Med* 2001;38(2): 160-169.

65. Haydel J, Preston C, Mills T, Luber S, Blaudeau E, DeBlieux P. Indications for computed tomography in patients with minor head injury. *N Engl J Med Overseas Ed* 2000;343(2): 100-5.

66. Teasdale G, Murray G, Andeson E, Mendelow A, Macmillan R, Jennet B, Brooks M. Risks of acute traumatic intracranial hematoma in children and adults: implications for managing head injuries. *Br Med J* 1990;300: 363-367.

67. Palshak M, Holmes J, Vance C, Gelber R, Schauer B, Harrison M, Willis-Shore J, Wootton-Gorges S, Derlet R, Kupperman N. Does an isolated history of loss of consciousness or amnesia predict brain injuries in children after blunt head trauma? *Pediatrics* 2004;113: 507-513.

68. Anderson V, Catroppa C, Haritou F, Morse S, Pentland L, Rosenfeld J, Stargatt R. Predictors of acute child and family outcome following traumatic brain injury in children. *Pediatr Neurosurg* 2001;34: 138-148.

69. Yeates K, Taylor H, Barry C, Drotar D,Wade S, Stancin T. Neurobehavioral symptoms in childhood closed-head injuries: changes in prevalence and correlates during first year post injury. *J Ped Psychol* 2001;2: 79-91.

70. Kruijk J, Leffers P, Menheere P, Meerhoff S, Rutten J, Twinjnstra A. Prediction of posttraumatic complaints after mild traumatic brain injury: early symptoms and biochemical markers. *J Neurol Neurosurg Psychiatry* 2002;73:727-732.

71. Savola O, Hillbom M. Early predictors of post-concussion symptoms in patients with mild head injury. *Eur J Neurol* 2003; 20: 175-181.

72. Korinthenberg R, Schreck J, Weswe J, Lehmkuhl G. Post-traumatic syndrome after minor head injury cannot be predicted by neurological investigations. *Brain Dev* 2004;26: 113-117.

73. Erlanger D, Kaushik T, Cantu R, Barth J, Brochek D, Freeman J, Webbe F. Symptom based assessment of the severity of a concussion. *J Neurosurg* 2003;98: 477-484.

74. Brewster A. Chronically ill hospitalized children's concepts of their illness. *Pediatrics* 1982; 69:355-362.

75. Edwinsson M, Arnbjörnsson E, Ekman R. Psychological preparation for children undergoing acute appendectomy. *Pediatrics*1988; 82:30-36.

76. Bently J. Distress in children attending A&E. *Emerg Nurse* 2004; 4:20-6.

77. Hallström I, Runesson I. Needs of parents of hospitalized children. *Theoria: Journal of nursing theory* 2001; 10:20-27.

78. Kai J. Parents´ difficulties and information needs in coping with acute illness in preschool children: a qualitative study. *Br Med J* 1996; 313:987-990.

79. Taanila A, Järvelinen M-J, Kokkonen J. Parental guidance and counseling by doctors and nursing staff: parents views of initial information and advice for families with disabled children. *J Clin Nurs* 1998; 7:505-511.

80. Kristensson-Hallström I. Strategies for feeling secure influence parent's participation of care. *J Clin Nurs* 1999; 8:586-592.

81. Miles M. Support for parents during their child's hospitalization: a nurse's guide to helping parents cope. *J Adv Nurs* 2003; 103:62-64.

82. Helseth S. Help in times of crying: nurses´ approach to parents with colicky infants. *J Adv Nurs* 2002; 40:267-274.

83. Tomlinson P, Hall E. Expanding knowledge in family health care. *Scand J Caring Sci* 2003; 17:93-95.

84. Homer C, Marino B, Cleary P, Alpert H, Smith B, Crowley Ganser C, Brustowicz R, Goldman D. Quality of care at a children’s hospital, the parents perspective. *Arch Pediatr Adolesc Med* 1999; 153:1123-1129.

85. Hopia H, Paavilainen E, Åseth-Kurki P. Child in hospital: family experiences and expectations of how nurses can promote family health. *J Clin Nurs* 2005; 14:212-222.

86. Aitken M, Mele N, Barret K. Recovery of injured children: Parents perspectives on family needs. *Arch Phys Med Rehabil* 2004; 85:567-573.

87. King N.S, Crawford S, Wenden FJ, Moss N, Wade DT. The Rivermead postconcussion symptoms questionnaire: a measure of symptoms commonly experienced after head injury and its reliability. *J Neurol* 1995; 242:587-592.

88. Rescorla L. Assessment of young children using the Achenbach system of empirically based assessment (ASEBA). *Ment Retard Dev Disabil Res Rev* 2005; 11:226-237.

89. Crawford S, Wenden F J, Wade DT. The Rivermead head injury follow-up questionnaire: a study of a new rating scale and other measurements to evaluate outcome after head injury. *J Neurol, Neurosurg Psychiatry* 1996; 60:510-514.

90. Picker Institute; *Patient satisfaction questionnaire*: available at www.pickereurope.org/index.php, accessed November 5, 2005.

91. Krippendorff, K. *Content Analysis: An Introduction to its Methodology*. Thousand Oaks, California: Sage Publications, 2004.

92. Weber, R. *Basic Content Analysis*. 2nd ed. Newbury Park: Sage Publications, 1990.

93. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurs Educ Today* 2004; 24:105-112.

94: Creswell J. *Qualitative inquiry and research design, choosing among five traditions*. Thousand Oaks, California: Sage publications, 1998.

95. Elkind David. *Barns utveckling och uppfostran ur Piagets perspektiv*. Stockholm: Natur och kultur, 1976.

96. Eyres S, Carey A, Gilworth G, Neurman V, Tennant A. Construct validity and reliability of the Rivermead post-concussion symptoms questionnaire. *Clin Rehabil* 2005; 19:878-887.

97. Cuff S, DiRusso S, Sullivan T, Risucci D, Nealon P, Haider A, Slim M. Validation of a relative head injury severity scale for pediatric trauma. *J Trauma* 2007; 63(1):172-178.

98. Stålnacke BM, Björnstig U, Karlsson K, Sojka P. One-year follow-up of mild traumatic brain injury: post-concussion symptoms, disabilities and life satisfaction in relation to serum levels of S-100B and neurone-specific enolase in acute phase. *J Rehabil Med* 2005; 37 (5):300-305.

99. Dahl E, v Wendt L, Emanuelson I. A prospective, population based, follow-up study of mild traumatic brain injury in children. *Injury* 2006; 37:402-409.

100. Ingebrigtsen T, Waterloo K, Marup-Jensen S, Attner E, Romner B. Quantification of post-concussion symptoms 3 months after minor head injury in 100 consecutive patients. *J Neurol* 1998; 245: 1432-1439.

101. Maneesriwongul W, Dixon J. Instrumental translation process: a method review. *J Adv Nurs* 2007; 58:386-395.

102. Snowdon A, Kane D. Parental needs following discharge of a hospitalized child. *Pediatr Nurs* 1995; 5:425-428.

103. Billmire E, Myers P. Serious head injury in infants: Accident or Abuse? *Pediatrics* 2005; 75:340-342.

104. Keenan HT, Runyan DK, Marshall Sw, Nocera MA, Merten DF, Sinal SH. A population-based study of inflicted traumatic brain injury in young children. *JAMA* 2003; 290:621-626.

105. Hobbs C, Childs AM, Wynne J, Livingstone J, Seal A. Subdural hematoma and effusion in infancy: an epidemiological study. *Arch Dis Child* 2005; 90:952-955.

106. Mcallistar T, Arciniegas D. Evaluation and treatment of post concussive symptoms. *Neurorehabil* 2002; 17: 265-283.

107. Ortinski P, Meador K. Neuronal Mechanism of conscious Awareness. *Arch Neurol* 2004; 61:1017-1020.

108. Overweg-Plandsoen W, Kodde A, van Stratten M, van der Linden E, Neyens L, Aldenkamp A, Vermeulen M. Mild closed head injury in children compared to traumatic fractured bone; neurobehavioral sequel in daily life 2 years after the accident. *Euro J Pediatr* 1999; 158:249-252.

109. Laine C, Davidoff F, Lewis CE, Nelson EC, Nelson E, Kessler RC, Delbanco TL. Important elements of outpatient care: a comparison of patients´ and physicians´ opinions. *Annuals of Internal Medicine* 1996; 8:640-645.

Appendix

RIVERMEAD FRÅGEFORMULÄR SYMTOM EFTER SKALLSKADA,

TILL BARN >5 ÅR

Efter en skallskada eller olycka är det inte ovanligt att en del människor får symtom/besvär som kan leda till oro eller obehag. Med detta frågeformulär vill vi undersöka om Du har några problem eller lider av några besvär eller symtom. Eftersom många av de beskrivna symtom kan förekomma även om man inte har skadat sig, vill vi att du jämför med hur det var innan Din skada/olycka.

Markera för varje fråga den siffra som bäst stämmer.

0= inte alls
1= inte längre
2= är ett litet problem
3= är ett medelmåttligt problem
4= är ett stort problem

Jämfört med före skadan/olyckan besväras jag av (t.ex. det senaste dygnet)….

	Inte alls	**Inte längre**	**Ett litet problem**	**Ett medel-måttligt problem**	**Ett stort problem**
Huvudvärk	0	1	2	3	4
Yrsel	0	1	2	3	4
Illamående eller kräkning	0	1	2	3	4
Överkänslig för ljud, blir lätt störd av högt ljud	0	1	2	3	4
Störd sömn	0	1	2	3	4
Trötthet, blir lättare trött	0	1	2	3	4
Irritation, blir lätt arg	0	1	2	3	4
Känner mig ledsen, vill gråta	0	1	2	3	4
Känner mig frustrerad eller otålig	0	1	2	3	4
Glömmer, dåligt minne	0	1	2	3	4
Dålig koncentration	0	1	2	3	4
Besvär med synen	0	1	2	3	4
Känslig for ljus, blir lätt störd av starkt ljus	0	1	2	3	4
Ser dubbelt	0	1	2	3	4
Otålig	0	1	2	3	4

Om Du upplever några andra besvär/symtom, beskriv och skatta dessa nedan

	Inte alls	**Inte längre**	**Ett litet problem**	**Ett medel-måttligt problem**	**Ett stort problem**
	0	1	2	3	4

Appendix

RIVERMEAD FRÅGEFORMULÄR UPPFÖLJNING TILL BARN

Efter en skallskada är det inte ovanligt att en del människor får symtom som kan leda till oro eller obehag. Med detta frågeformulär vill vi undersöka om ditt barn haft några besvär/problem som ni kan relatera till skallskadan. Vi vill att Du jämför med hur det var innan Din skada/olycka.

Markera för varje fråga den siffra som bäst stämmer.

0 = ingen förändring mot tidigare

1 = ingen förändring, men är lite svårare nu

2 = liten förändring

3 = medelmåttig förändring

4 = stor förändring

Jämfört med före skadan/olyckan har Du upplevt någon förändring i …… ?

	Ingen förändring	**Ingen förändring men lite svårare**	**Liten förändring**	**Medel-måttlig förändring**	**Stor förändring**
Att prata med mer än en person	0	1	2	3	4
Att prata med 2 eller flera personer	0	1	2	3	4
Att som tidigare göra rutinsaker hemma	0	1	2	3	4
Att hänga med som innan skadan	0	1	2	3	4
Att som tidigare kunna deltaga i fritidsaktiviteter	0	1	2	3	4
Att fungera som tidigare i skolan/förskola	0	1	2	3	4
Skol-/ förskolearbetet är mera tröttande	0	1	2	3	4
Att som tidigare vara tillsammans med kamrater	0	1	2	3	4
Att som tidigare vara tillsammans med din familj	0	1	2	3	4
Att hjälpa till hemma som Du brukar	0	1	2	3	4

Appendix

KAROLINSKA FRÅGEFORMULÄR SYMTOM

BARN <5 ÅR

Eter en skallskada är det inte ovanligt att en del barn får besvär som man kan känna sig orolig över. Barn som inte kan berätta hur de känner sig vet vi fortfarande väldigt lite om och vill därför ställa några frågor om hur de mått efter skallskadan. Vi vill att Du jämför med hur det var innan ditt barns skada/olycka.

1. **Har du upplevt att ditt barn är förändrat på något sätt jämfört med innan skallskadan?**

   helt och hållet   till viss del   till liten del   inte alls

2. **Har du upplevt att ditt barn är förändrat gällande sina matvanor?**

   helt och hållet   till viss del   till liten del   inte alls

3. **Har du upplevt att ditt barn är förändrat gällande sina sovrutiner?**

   helt och hållet   till viss del   till liten del   inte alls

4. **Har du upplevt att ditt barn är förändrat gällande sitt rörelsemönster?**

   helt och hållet   till viss del   till liten del   inte alls

5. **Har du upplevt att ditt barn är förändrat till sitt humör?**

   helt och hållet   till viss del   till liten del   inte alls

6. **Har du upplevt att ditt barn är förändrat i sina lekvanor?**

   helt och hållet   till viss del   till liten del   inte alls

Kommentera gärna dina svar på frågorna eller om det finns andra saker som du/ni vill berätta för oss

……………………………………………………………………………………………