UNIVERSITY OF OSLO

PEDIATRIC TRAUMATIC BRAIN INJURY: A PROSPECTIVE COHORT STUDY INVESTIGATING INCIDENCE, OUTCOMES AND UNMET TREATMENT NEEDS

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"Children are a third of the world's population and the entire future"

-Unknown

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PREFACE

I. Acknowledgments

I will start by thanking all patients and caregivers for their participation and time and for sharing their experiences during a vulnerable time (hospitalization and at follow-up). Without their cooperation and understanding, this work would have been impossible. I hope that this study will contribute to improvements in care for children and adolescents with traumatic brain injury.

This Ph.D. project was carried out at the Department of Clinical Neurosciences for Children of Oslo University Hospital, in collaboration with the Department of Research, Sunnaas Rehabilitation Hospital Trust and the Department of Physical Medicine and Rehabilitation, Oslo University Hospital, Oslo, Norway. The study was funded by the South-Eastern Norway Regional Health Authority (project no. 2017019).

The TBI group included was a pediatric extension of the CENTER-TBI study [1] at the Oslo site. I am grateful for the opportunity to use an ongoing study to select patients for my research and for all the positive support from the central, national, and local site leadership by Nada Andelic of the CENTER-TBI study.

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I also thank my co-supervisor, Professor Nada Andelic, Senior Researcher and rehabilitation specialist, for introducing me to the field of TBI research. In our pediatric neurology team at OUH-Ullevål, we have already looked to the exemplary clinical care for adult patients provided by her department during acute and subacute phases, implementing similar care for children with traumatic brain injuries. She saw the possibility to develop a protocol for a pediatric TBI study when including the Department of Clinical Neurosciences for Children in the CENTER-TBI study, ensuring that this pediatric side-study could be conducted. She has advised and supported the development of the protocol for the research and writing of the three papers of this thesis.

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I would also like to thank the Trauma Registry-OUH for supplying me with data crucial for Paper I. Special thanks goes to Morten Hestnes for educating me in AIS and ISS scoring systems and readily supporting me with information, answering all my possibly good and odd questions.
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One of the most challenging aspects of completing this work has been simultaneously prioritizing clinical and research work. This combination has been possible due to an enormous understanding, patience, stand-in, and support from my coworkers Gro Anita, Simone, Linnea, Martin and Gunnthorunn and the head of my department Anette Ramm-Pettersen, the leader of my research group NervOUS I and Associate Professor. I am very grateful for their support.

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Supplement:
I have discovered a mistake regarding Paper II; page 7 is missing. The correct version: DOI: 10.1111/apa.16693.
Paper III is published: DOI: 10.1016/j.ejpn.2024.01.002.

II Abbreviations

AIS	Abbreviated Injury Scale
AIS head	AIS head; covers injuries to the cranium and brain
CENTER-TBI	Collaborative European NeuroTrauma Effectiveness Research in TBI
CT	Computerized tomography
GCS	Glasgow Coma Scale
GOS-E	Glasgow Outcome Scale-Extended
ICF-CY	International Classification of Functioning, Disability, and Health for Children and Youth
ICI	Intracranial injury
ISS	Injury Severity Score
LOC	Loss of consciousness
MRI	Magnetic resonance imaging
OUH	Oslo University Hospital
PedsQL	Pediatric Quality of Life Inventory
RPQ	Rivermead Post-Concussion Symptoms Questionnaire
pTBI	Pediatric traumatic brain injury
TBI	Traumatic brain injury
TR-OUS	Trauma Registry at Oslo University Hospital

III Summary

Background:
There may be long-term symptoms and impairments following pediatric TBI (pTBI) of all severity grades. Depending on the extent and location of the injured area, problems with participation in school and social activities can range from mild to severe. Understanding of the positive effects of rehabilitation services on patient outcomes after pTBI has increased. However, several studies have described unmet needs regarding rehabilitation services for children following brain injury. Even in the publicly funded Norwegian health care system, studies have shown that 31% of adult TBI patients report unmet emotional, vocational, and cognitive needs five years after the injury. Equivalent knowledge of Norwegian pTBI patients is lacking.

Aims:
This thesis aimed to investigate the incidence, symptom burden, and development of symptoms in pediatric patients experiencing TBI. Furthermore, we aimed to explore the unmet health care or educational needs of the population in Norway's southeastern region.
In Paper I, we aimed to investigate the volume and burden of pediatric patients hospitalized after a TBI in the southeastern region of Norway.
In Paper II, we aimed to investigate whether children with TBI had specific unmet health care needs compared with a matched control group hospitalized with other traumatic injuries of similar severity. We examined the accessibility and utilization of health care and educational services for the two groups and assessed whether unmet needs influenced health-related quality of life.
In Paper III, we aimed to evaluate whether TBI symptoms persisted after two years, leading to a need for health care or educational service, and whether unmet needs were associated with reduced health-related quality of life.

Methods:
We started by evaluating the incidence, injury mechanism, and severity grade of pTBI in the southeastern region of Norway by extracting data from the OUH trauma registry on 176 patients aged 0-15 years admitted with a TBI diagnosis verified by an AIS score ≥ 1 in 2015-16. We retrieved information on injury mechanisms, injury severity, and length of hospital stay.
In 2015-16, OUH was a site of a European TBI study, the CENTER-TBI study, including all age groups. As an extension of the CENTER-TBI study, 53 children were included in our study (the TBI group), with data collection, clinical examinations, and structured interviews conducted in the acute phase at six and 24 months. At six months, 49 participated, and at 24 months, 47 completed the follow-up assessment. We included a control group of 58 children with other injuries (matched by age group, sex, and overall injury severity) admitted to the same wards from December 2018 to January 2020; 51 of these patients were followed up six months postinjury.
TBI injury severity was divided into mild, moderate, and severe according to the Glasgow Coma Scale (GCS) and Abbreviated Injury Scale (AIS-Head). Mild TBIs according to GCS scores were further classified as complicated (presence of trauma-related intracranial abnormality) or uncomplicated (absence of trauma-related abnormality). The Injury Severity Score (ISS) was used to compare injury severity between the two groups. To assess impairments, we used the International Classification of Functioning, Disability, and Health for Children and Youth (ICF-CY). Outcomes were evaluated by the Glasgow Outcome Scale-

Extended (GOS-E), Rivermead Post-Concussion Symptoms Questionnaire (RPQ) and Pediatric Quality of Life Inventory (PedsQL).
We classified needs into three categories: no need identified, met need, and unmet need/unrecognized need. We used disability revealed at follow-ups and patient- or parent-reported presence/lack of service to divide the patients into groups according to needs.

Results
The incidence of pTBI requiring hospitalization in Oslo in 2015-16 was 29 per 100,000 per year. Injury characteristics were comparable to those in other European countries, but in contrast to most other studies, there was not a male predominance in the adolescent group. Young adolescent girls and boys appeared to have equivalent TBI risk. The leading causes of injury in the adolescent group were falls during sports or leisure activities, especially alpine accidents. Children under seven years old were injured by falls from heights, and children under four years, were mainly injured at home and indoors. Children aged 5-7 years (more independent and mobile) were mainly injured as roadside pedestrians or passengers in road accidents. The injury mechanisms leading to severe TBI were transport accidents with high energy trauma involving car accidents, horseback riding, skateboarding, and mobility scooter accidents. Fatal accidents occurred during play or by intentional injury in patients under one year of age.
Patients with intracranial injury (ICI) visible on neuroimaging had longer hospital stays, with a median of two days. Children aged seven years or younger seemed to experience more severe ICI from trauma to the head than older groups.

We investigated the symptoms and impairments caused by trauma, including the accessibility and use of health care services. We compared the two groups to examine whether the pTBI patients had specific unmet health care needs.
In total, 47% of the TBI group reported unmet needs six months postinjury, compared to 12% of the control group. The risk of having unmet needs was four times higher in the TBI group. Ninety-four percent of the control group had planned follow-ups after discharge compared to 20% in the TBI group. pTBI patients with unmet needs experienced lasting cognitive and emotional symptoms, affecting their return to school and interactions with peers, associated with reduced quality of life.

After 24 months, 25% of the patients still reported unmet needs due to persistent cognitive and emotional symptoms affecting school functioning and social interaction. These patients lacked necessary support for educational and emotional needs and reported unsatisfactory transmission of information about pTBI. They reported reduced quality of life, with emotional symptoms and school performance under the cutoff value for identifying specialist health care needs. Their parents stated that the children had significantly more problems at school and with participating in activities due to physical symptoms, e.g., fatigue, compared to those with no and met needs.

Conclusion:
The incidence of hospital-treated pTBI in our region was low compared to that in most areas globally. However, researchers should attend to new social trends and focus on the youngest group when tailoring measures to prevent brain injuries in childhood. Over the past ten years, alterations in the boy:girl ratio have suggested that adolescent girls have caught up with boys in terms of TBI risk. Children younger than seven years old seem to experience more severe ICI from trauma to the head.

Furthermore, the duration of symptoms must be considered, along with GCS scores and neuroimaging findings, when identifying which patients need follow-up and rehabilitation.
A systematic follow-up method is needed for children and adolescents with TBIs of all grades of severity. Almost half of the pTBI group reported unmet needs at six months, and one-fourth still reported unmet needs after two years due to long-lasting symptoms. This highlights the need for knowledge of long-term symptoms after TBI for parents, communities, and the health care and educational system. Patients should be followed over several years to ensure that accommodation to care and referrals are initiated and continued as the children face increasing challenges at school and in social interactions.

IV Summary in the Norwegian language

Bakgrunn:
Traumatisk hjerneskade av alle alvorlighetsgrader i barnealder (pTBI) kan føre til langvarige symptomer og utfall. Avhengig av omfanget og lokalisasjonen til hjerneskaden, kan det bli små eller store problemer med å delta i skole og sosiale sammenhenger.
Det har vært økende kunnskap om at tilpasset rehabilitering kan ha positiv effekt på langtidsfølgende etter TBI. Motsatt har det også vært flere rapporter om barn som opplever mangel på tilrettelagt rehabilitering i denne gruppen. Selv i Norge, med offentlige helsevesen, har studier på voksne TBI pasienter avdekket at 31% ikke hadde mottatt hjelp for emosjonelle, yrkesmessige og kognitive vansker 5 år etter sine hodetraumer. Vi har manglet lignende oversikt over dekningen av rehabiliteringsbehovet for barn med TBI.

Mål:
Vi ønsket å finne ut antall, skadetype og alvorlighetsgrad av TBI hos barn i Helse Sør Øst (HSØ), (Artikkel I).
Deretter ønsket vi å finne ut om barn innlagt med TBI hadde spesifikke udekkede rehabiliteringsbehov, sammenlignet med andre barn som var innlagt med andre typer skader av samme alvorlighetsgrad. Vi ønsket også å undersøke om det var ulik tilgang til og utnyttelse av helsehjelp eller pedagogisk hjelp for de to gruppene, og om udekkede behov medførte redusert livskvalitet (Artikkel II).
Vi ville se om symptomer knyttet til hjerneskaden varte i to år etter skaden i en grad som medførte behov for helsehjelp eller pedagogisk hjelp, og finne ut om udekkede behov fortsatt da medførte redusert livskvalitet (Artikkel III).

Metode:
I Artikkel I undersøkte vi epidemiologiske data fra Traumeregisteret på OUS angående barn innlagt med påvist TBI diagnose. Vi innhentet informasjon på 176 pasienter som, i alderen 0-15 år, innlagt i 2015-16 med påvist hjerneskade ved AIS score $\geq$ 1.Vi fikk data om antall, skademekanismer og skadegrad, og vi undersøkte hvilke faktorer som kunne være assosiert med behov for oppføling.
I 2015-16 var OUS var med i en stor Europeisk TBI studie, CENTER-TBI, som inkluderte voksne og barn. Vi inkluderte 53 av disse pasientene som vår studiegruppe (TBI-gruppen) og fulgte dem opp i akuttfasen og etter 6 og 24 måneder. De gjennomgikk klinisk undersøkelse og både barn og foreldre fylte ut spørreskjemaer ved kontrollene. 49 pasienter kom til 6 måneders kontrollen og 47 pasienter kom til 24 måneders kontrollen. Vi sammenlignet TBI gruppen i akuttfasen og ved 6 måneder med en gruppe matchede barn som var innlagt for andre traumeskader med sammenlignbar alvorlighetsgrad. Kontrollgruppen besto av 58

pasienter, og var matchet på kjønn, aldersgruppe og skadegrad. De var innlagt i perioden desember 2018 til januar 2020, og ble fulgt i 6 måneder, 51 pasienter møtte til kontroll. Alvorlighetsgrad av TBI-skaden ble klassifisert til mild, moderat eller alvorlig med Glasgow Coma Scale (GCS) og Abbreviated Injury Score (AIS hode). Mild GCS ble videre delt inn i komplisert mild (funn av traumerelatert hjerneskade på MR eller CT) og ukomplisert mild (ikke funn av traumerelatert hjerneskade).

Vi brukte Injury severity score (ISS) til å sammenligne alvorlighetsgraden av skaden til pasientene i de to gruppene. For å vurdere omfanget av symptomer etter skaden brukte vi The International Classification of Functioning, Disability, and Health for Children and Youth (ICF-CY).

Grad av konsekvenser pasienten hadde etter skaden ble vurdert ved hjelp av Glasgow Outcome Scale-Extended (GOS-E), i kombinasjon med svarene på spørreskjemaene, Rivermead Post Concussion Symptoms Questionnaire (RPQ) og Pediatric Quality of Life Inventory (PedsQL).

Udekkede behov ble inndelt i tre grupper: ingen behov, ivaretatte behov, udekkede/uerkjente behov. For å finne riktig gruppe, vurderte vi symptomer som ble avdekket på kontrollene sammen med rapportene fra pasienter og foreldre på kontrollene angående dekkede og udekkede behov.

Resultater:

Insidensen av TBI var lav sammenlignet med andre områder i verden. Insidensen av barn bosatt i Oslo innlagt med TBI var i 2015/16 29 pr 100 000 pr år. Vi så ikke samme dominans av gutter i tenåringsgruppen som i andre studier, men at tenåringsjentene så ut til å ha tatt igjen guttene angående risiko for TBI. Viktige skadeårsaker i denne aldersgruppen var fall i sport og fritidsaktiviteter, med alpin-skader som viktig bidragsyter. Barn under 7 år skadet seg ved fall fra høyder, og gruppen under 4 år skadet seg hovedsakelig innendørs og hjemme. Gruppen 5-7 år, som er mer selvstendige, fikk skaden som fotgjengere eller passasjerer i trafikkulykker.

Skademekanismer som medførte alvorlig skade var transportulykker med stor energi; bilulykker, rideulykker, skateboard og sparkesykkel-ulykker. Dødelige skader forekom ved lekeulykker og for spebarn ved påført skade. Vi fant at pasienter med skaderelatert synlig hjerneskade på CT eller MR (ICI) hadde lengre sykehusopphold enn de uten. Barn under 7 år så ut til å få mer alvorlig ICI ved hodeskader sammenlignet med eldre barn.

Vi sammenlignet TBI-gruppen med kontrollgruppen for å undersøke symptomer og utfall forårsaket av skader, i tillegg sjekket vi tilgjengelighet og bruk av helsetjenester, for å se om det var spesifikke udekkede behov for TBI-gruppen.

Vi fant at 47 % av TBI-gruppen hadde udekkede behov ved 6 måneder sammenlignet med 12 % for kontrollgruppen. Risikoen for å ha udekkede behov var fire ganger høyere i TBI-gruppen enn i kontrollgruppen. Det var planlagt oppfølging ved utskrivelse hos 94% av kontrollgruppen sammenlignet med 20 % i TBI-gruppen. TBI-pasienter med udekkede behov hadde langvarige kognitive og emosjonelle symptomer som medførte problemer på skolen og i samvær med venner i en grad som påvirket livskvaliteten.

Vi fulgte TBI-gruppen til 24 måneder og fant at 25 % fortsatt rapporterte om vedvarende kognitive og emosjonelle symptomer; konsentrasjonsvansker og fatigue, i en grad som påvirket tilbakeføring til skole og omgang med venner. Disse pasientene rapporterte om mangel på tilrettelegging i skolen og behov for hjelp med emosjonelle vansker, samt problemer med overføring av infomasjon om konsekvenser av hjerneskaden ved skifte av skole/klassetrinn. Disse pasientene scoret for redusert livskvalitet på et nivå som tilsa behov for helsehjelp. Foreldrene deres scoret også at barna hadde signifikant mer skoleproblemer ($p = 0.028$) og for redusert deltagelse i aktiviteter ($p = 0.024$) grunnet blant annet fatigue, sammenlignet med dem som ikke rapporterte behov eller hadde dekkede behov.

Konklusjon:
Insidensen for barn innlagt med TBI diagnose i vår region var lavere enn i andre deler av verden, men allikevel er det noen hodeskader som kan forhindres. Over de siste 10 årene har det skjedd en endring i gutt: jente ratioen som tilsier at tenåringsjenter tar risiko på linje med guttene. Barn under 7 år ser ut til å få mer alvorlig skade på hjernevev ved traumer mot hodet enn eldre barn. Vi må ha oppmerksomhet rundt nye sosiale trender og et søkelys på de yngste barna når vi planlegger forebyggende tiltak for hodeskader hos barn.
Alvorlighet av hjerneskade bør bedømmes, ikke bare med GCS, men også med AIS scoring-dvs. bildediagnostikk. Vi bør også se på varighet på innleggelsen når vi vurderer hvem som trenger oppfølging og tiltak. Vi trenger en plan for systematisk og langvarig oppfølging for barn med TBI av alle alvorlighetsgrader; halvparten av TBI pasientene hadde udekkede behov ved 6 måneder og en fjerdedel ved 24 måneder på grunn av vedvarende symptomer. Kunnskapen om langtidsfølger etter hodeskade må økes hos foreldre, i helsetjenesten og i skole. Oppfølgingen bør kontinueres over flere år for å sikre overføring av informasjon og igangsetting av riktige tiltak i oppveksten, siden barna møter økende krav på skole og sosialt ved økende alder.

V List of papers included in this thesis

Paper I

Epidemiology of traumatic brain injury in children 15 years and younger in South-Eastern Norway in 2015-16. Implications for prevention and follow-up needs.
Hilde Margrete Dahl, Nada Andelic, Marianne Løvstad, Ingvil Laberg Holthe, Morten Hestnes, Trond H. Diseth, Mia Cathrine Myhre
European Journal of Paediatric Neurology 31 (2021) 70e77

Paper II

Almost half of children and adolescents had unmet needs 6 months after their traumatic brain injury
Hilde Margrete Dahl, Ingvil Laberg Holthe, Marianne Løvstad, Cathrine Tverdal, Nada Andelic, Mia Cathrine Myhre.
Acta Paediatrica 2023; 00:1–10.

Paper III

Unmet health care needs over the first two years after pediatric traumatic brain injury
Hilde Margrete Dahl, Ingvil Laberg Holthe, Nada Andelic, Marianne Løvstad, Mia Cathrine Myhre.
European Journal of Paediatric Neurology (2023) - Submitted after major revision.

1. INTRODUCTION

How it all started

Early in my career as a pediatrician, I was introduced to child neurology. Soon after I started working at Oslo University Hospital (OUH), I was introduced to traumatically injured patients since OUH is the trauma referral hospital for the southeastern part of Norway. I observed a difference in the rehabilitative care offered in the subacute phase between children and adult patients with traumatic brain injury (TBI). At the outpatient clinic, I realized that many pediatric patients with TBI needed more planned follow-up and that knowledge of the sequelae of TBI in childhood needed to be improved in the community and schools. Rehabilitation of patients with acquired brain injuries in the acute and subacute phases and their follow-up has been one of my main tasks at work for the last 15 years. Since 2011, I have worked part-time at Sunnaas Rehabilitation Hospital as a consulting pediatrician for pediatric patients.

From 2011 to 2013, I was part of a group preparing and writing a care pathway for pediatric-acquired brain injury (pABI) from hospitalization to rehabilitation at the community level in the southeastern region of Norway. OUH, the Hospital of Southern Norway-Kristiansand, Sunnaas Rehabilitation Hospital, and Nordre Aasen Rehabilitation Unit collaborated to develop the care pathway. This work was revised during 2017-2021 in collaboration with all rehabilitation units in the southeastern region of Norway and Statped, and the revised care pathway is currently implemented and has been published at Metodebok.no [2]. Equivalent care pathways have been established in the other health regions of Norway. The development of the care pathway revealed a need to improve the accessibility of and interaction between services for children and adolescents; the care pathway aims to address these issues.

In 2015, OUH was included as a site in the Collaborative European NeuroTrauma Effectiveness Research in Traumatic Brain Injury (CENTER-TBI) study [1], a multicenter, prospective, longitudinal observational study conducted in Europe and Israel in 2015-16. The Oslo site included both adult and pediatric patients with TBI.
There have been several studies on rehabilitation services and unmet needs of adult TBI patients in Norway[3–5,] but equivalent knowledge of the pediatric TBI population is lacking. I was introduced to the field of TBI research by Nada Andelic, who suggested investigating the pediatric TBI population in collaboration with the research group exploring brain injury rehabilitation at Sunnaas Rehabilitation Hospital. We were allowed to conduct a side-study using data from the CENTER-TBI study; we also expanded the follow-up with additional questionnaires validated for use in pediatric patients and conducted neuropsychological assessments in the pediatric group. We used this opportunity to start a pediatric TBI study and included a control group from the pediatric surgical ward in agreement with the Department of Pediatric Surgery. This offered an opportunity to assess the outcomes of injured pediatric patients and investigate whether the pediatric TBI population has specific unmet needs and whether the pediatric patients faced obstacles regarding the use and accessibility of rehabilitation similar to those of adult TBI patients.

2. BACKGROUND

Epidemiology

Head injuries are the single most common and potentially most severe type of injury sustained by children worldwide [6]. Child injuries represent one of the most immediate public health threats, resulting in the death of nearly 2000 children under the age of 14 every day around the world [7]. Once children reach the age of five years, unintentional injuries are the biggest threat to their survival [6].

Modest public health and environmental efforts addressing child injuries began in the 1940s and 1950s, but it was not until the 1960s that the U.S. and other countries concentrated efforts on collecting and using data, formulating policies, and implementing best practices to reduce childhood injuries [7]. Since then, publications identifying risk factors and suggesting preventive measures have steadily increased.

The Convention on the Rights of the Child by the United Nations in 1989 stressed the responsibilities of societies to protect children (from birth to the age of 18 years) and provide them with appropriate support and services, thereby protecting them from injuries [6].

There has been substantial progress in increasing child survival after injury in the 20th century. From 1960 to 2015, global child mortality rates fell from 18.2% to 4.3% [7.] The reduction was largely the result of improvements in clinical medicine, access to health care and the standard of living, among other factors [7], which also contributed to reduced mortality and morbidity following pediatric TBI (pTBI). A global overview of pTBI patients reported a median age of 6.8 years [8]. The incidence of hospital-admitted pTBI patients shows diversity based on different inclusion of admission criteria and varies from 12 per 100 000 in Sweden to 70-75 per 100 000 in the United States [8] and Australia[9].

In Norway, Heskestad et al.[10] evaluated the incidence of TBI in all age groups in the Stavanger region (the southwestern part of Norway) in 2009. Andelic et al. [5] examined hospitalized patients with TBI in Oslo, the capital of Norway, in 2005-2006. However, few studies have focused on the Norwegian pTBI population. One exception is a study by Olsen et al.[11], which estimated the incidence and mortality rates of moderate and severe pTBI (in 71 patients aged 0-16 years) from 2004-2014 in Central Norway. The incidence estimates were 2.4 and 2.5 per 100 000 inhabitants for moderate and severe pTBI, respectively.

Many studies have reported a male predominance of children with pTBI in all age groups above three years of age and a bimodal distribution of pTBI in different age groups, with the most significant injuries occurring in the very young and in adolescents [8,12] Collins et al. reported to a significant sex difference from infancy, with a male predominance in injury mechanism, mortality rates, and lack of use of protective devices [13].

In a recent European study, road traffic incidents were the main reason for pTBI patient admission to the intensive care unit (ICU). Accidental falls were the most frequent cause of injury in the children admitted to a hospital ward [14]. Thus, there is a need to update the epidemiological data regarding Norwegian pTBI patients.

Definition of traumatic brain injury

Traumatic brain injury (TBI) has been defined as an alteration in brain function or other brain pathology evidence, caused by an external force [15].

Classification of the severity of TBI

The severity of brain injury is classified according to the extent of pathophysiologic or pathologic changes identified during the acute period following an injury [16].
The severity of brain injury is used to determine resource utilization, treatment plans, and rehabilitation[17]. The two most commonly used methods of classifying the severity of brain injury for both pediatric and adult TBI patients are the Glasgow Coma Scale (GCS) and the Abbreviated Injury Scale (AIS) [17].

Traditionally, the severity of TBI has been evaluated with the GCS according to the level of unconsciousness at the time of injury [17]. The Pediatric GCS is used for infants and toddlers, assuring age-appropriate assessments [18]. The GCS score ranges from 3 to 15, classifying TBI severity as mild (scores of 13-15), moderate (scores of 9-12), or severe (scores of 3-8). Mild TBI (mTBI) can be further classified as complicated (presence of trauma-related intracranial abnormality) or uncomplicated (absence of any traumatic intracranial injury)[19]. The GCS has been widely used by prehospital and emergency care personnel to aid in trauma triage [20]. A significant limitation of the GCS score is that it is not possible to evaluate patients who are intubated, sedated, or have substantial periorbital trauma [20]. Another limitation of using the GCS at the time of injury is its limited ability to predict the severity of the injury and the patient's length of stay in the intensive care unit (ICU), functional status, and overall survival [20].

Additional indicators of severity are the duration of loss of consciousness and the duration of posttraumatic amnesia (PTA), a transient state of confusion, disorientation, and memory loss following a TBI, as well as evidence of intracranial pathology obtained from neuroimaging tests [16].

The AIS can be used to estimate brain injury severity according to the anatomic brain injury revealed by neuroimaging and clinical features [17]. The AIS can be applied to assess the severity of injury in six regions: the head, face, neck, thorax, abdomen, spine, upper and lower extremities and external/other [17]. The scores are divided into 6 grades: 1: minor, 2: moderate, 3: serious, 4: severe, 5: critical and 6: maximal (currently untreatable). The scale does not divide severity grades into mild, moderate, and severe, but in the literature, grades 1-2 have been categorized as mTBI, grades 3-4 have been categorized as moderate, and grades 5-6 have been categorized as severe [17]. The AIS head evaluates head injury severity based on a combination of symptoms (headache, amnesia, loss of consciousness (LOC), motor responses and radiological findings (type of fractures and characteristics of hemorrhages) [17]. The AIS-08 categorizes mild concussion without LOC as grade 1 and concussion with brief LOC as grade 2. All intracranial injuries are categorized as grade 3 or over, except brain contusions, lacerations, and intracranial extracerebral hemorrhage, which are classified as grade 2.[21] However, the AIS cannot be used as a field triage system [20]. When comparing these scoring systems, AIS and GCS scores are closely correlated for severe TBI, but the AIS is less predictive in cases with moderate and mild injury [17].

The AIS scores are also the basis for the Injury Severity Score (ISS). The ISS is calculated by taking the highest AIS score from the three most severely injured body regions, squaring each, and adding these numbers. The ISS estimates total overall injury severity on a scale of 0-75. An ISS ≥16 defines major trauma [17,18].

Mechanisms of injury to the brain

An injury to the brain can affect the brain tissue and lead to intracranial or extracranial bleeding and fractures to the skull. In the acute and subacute phases, secondary events can occur, such as increased intracranial pressure (ICP), alterations in blood pressure, infections, or epileptic seizures. The treatment of both primary and secondary events is essential for the overall outcome.

Injury to the brain tissue may cause focal or multifocal damage.
Trauma to the brain can result in traumatic axonal injury (TAI), formerly called diffuse axonal injury (DAI). TAI results from shearing forces that stretch neurons, disrupt ion balance, and impact action-potential propagation [22]. According to the Adam classification system [23], grade I includes damage to the hemispheres in the interface between the cortex and the white matter. Grade II includes brainstem lesions, and grade III includes lesions in the dorsolateral rostral brainstem[24].
In CT, detection of TAI is limited to microhemorrhages in the white matter and/or traumatic brain edema. MRI is a more sensitive method and the modality of choice to detect both hemorrhagic and nonhemorrhagic TAI-associated lesions [24].
Prognostic methods to assess long-term outcomes after TAI are not reliable. Hemorrhagic and nonhemorrhagic TAI-associated lesions seem to diminish over time, but residual microhemorrhagic lesions may persist for months to years. Therefore, TAI grading may be facilitated by conducting MRI within the first week after injury [24]. A Swedish study found that lesions were commonly located in the frontal and temporal lobes but that hemorrhagic lesions in the mesencephalon, dorsal pons, thalamus, basal ganglia, and internal capsule were associated with poorer long-term outcomes. [24].
Hersgjovitz et al. [25] found that pediatric patients were more likely to sustain TAI from falls than adult TBI patients. Otherwise, the associated intracranial injury types and rates were mainly comparable to those in adult patients with TBI. However, they found that pediatric patients had a lower total Injury Severity Score (ISS) (i.e., overall trauma severity) than adults and thereby had shorter lengths of total hospital stays and were less likely to die after injury.

In addition to TAI, head injury may cause contusion of the brain tissue [26]. Exacerbation of the contusions may occur within the first 24 hours postinjury, with very few progressing after 3-4 days. A contusion is considered to be caused by continued bleeding from fractured microvessels, exacerbated by coagulopathy. In addition, a "traumatic penumbra" surrounding the contusion core is proposed to reduce cerebral blood flow and precede contusion expansion. On MRI scans performed in the first 72 hours after the injury, one can observe a cytotoxic rim of edema that may be subsumed by vasogenic edema as the lesion progresses. The impact on patient outcomes is unclear, as contusion progression can represent severe TBI. On the other hand, the outcomes of severe TBI are partially mediated by contusion progression. Nevertheless, contusion progression may provide valuable information on the patient's clinical course. Both the presence and volume of progression were significantly associated with unfavorable outcomes at six months postinjury [26].

Head injuries can cause intracranial hemorrhages both extra- and intracranially.
Subarachnoid hemorrhage (SAH) is mainly caused by trauma to the head (i.e., traumatic SAH; tSAH) and is common in all severity grades of TBI. Related events include vasospasms, dyselectrolytemia, pituitary dysfunction, hypoxia, intracranial hypertension, and hydrocephalus, usually in combination with severe TBI [27]. Children with isolated tSAH without midline shift and mTBI rarely need neurosurgical intervention and can generally be

safely discharged after a short observation period [28]. Ore et al. [28] found that 16% of pTBI patients with tSAH had isolated tSAH without a midline shift. These patients are usually admitted to the ICU, although many have a low risk of neurological worsening [28].
Epidural hemorrhage (EDH) occurs in 2-3% of all TBI cases in childhood [29]. The source of the bleeding differs from that of adults; it more often has a venous origin in pTBI and usually occurs in conjunction with a skull fracture. Venous bleeds have low pressure and low flow and give less rise to intracranial pressure (ICP); therefore, they may not need surgical intervention. The size of the EDH is the main factor determining surgical intervention, but GCS scores at admission can be taken into consideration; if GCS scores are over 14, conservative treatment and control CT scan may be the choice of action if observed in a hospital equipped to intervene surgically [29].

In children, 10-30% of head injuries result in a skull fracture, many with associated brain injury. Surgical intervention is mainly performed in cases of skull fracture depression, frontal sinus involvement, or underlying mass lesions. Pediatric skull fractures differ from those in adults due to their greater capacity to heal and remodel as the brain and craniofacial skeleton develop in childhood. The growth of the upper face and aeration of the frontal sinus starts at 4-5 years and progresses until puberty. Thus, frontal bone fractures may be treated conservatively in the youngest patients. On the other hand, the development of the skull in childhood may give rise to complications such as growing skull fractures. Falls, traffic accidents, and getting hit in the skull by an object are the predominant modes of injuries causing skull fractures in need of surgery [30].

Children have less robust autoregulation of blood flow to the brain and a greater tendency to exhibit irregular respiration, breathlessness, and convulsions after head injuries, which renders them more susceptible to secondary injuries [18]. Elsamadicy et al. [31] found that epileptic seizures following pTBI, i.e., posttraumatic seizures (PTSs), seldom occurred; however, they affected the youngest age group (0-5 years) of pTBI patients significantly more than the older age group (1.58% in the 0-5-year group vs. 0.6% in the 6-10-year group and 0.57% in the 11-15-year group) [31]. The immediate seizures (within 24 hours postinjury) may be from neuronal hypoxia and ischemia, while late-onset seizures result from hyperexcitatory states from axonal formations. PSTs are associated with prolonged LOC and intracranial hemorrhage, especially subdural hemorrhage (SDH). Laceration or contusion of brain tissue may lead to PTS. Younger age, trauma caused by abuse/assault, and SDH are all significant predictors of PTS. Closed-head injuries are known to have higher risks of seizures than open-head injuries, but shaken baby syndrome is by far the leading cause of PTS.
Secondary complications may lead to PTS, mainly including supplementary neurological symptoms, respiratory problems, septicemia, and SDH [31].

Outcomes

Depending on the damaged area, impairments and limitations to participation in school and social activities may vary in severity from mild to severe [32]. Focal injuries may have better outcomes in early childhood than in adulthood, but multifocal, bilateral brain injuries may result in poorer outcomes in children with TBI [33].
There may be long-term symptoms and impairments following pediatric TBI (pTBI) of all severity grades. A global overview of pTBI reported that mild pTBI constituted >80% of cases, and severe pTBI accounted for 3-7%. The mortality rate ranged from 1-7% [8]. Children

are less likely to die after head injury than adults [25] and will survive with potential sequelae, necessitating rehabilitation.
Unsurprisingly, children with severe pTBI have the poorest outcomes, with the most significant deficits in cognition and adaptive skills [34,35], and they have an elevated risk of social dysfunction [36]. These patients often have apparent needs for both health care and educational services. Furthermore, patients with moderate and severe pTBI may have impaired social cognition, resulting in reduced empathy, problems recognizing emotions in others, and reduced behavioral inhibition [37]. Social dysfunction is one of the most debilitating symptoms after a brain injury, resulting in reduced social training, rejection by peers, and social isolation [36]. In 2007, Donders et al. reported that participants with early-onset TBI (6-12 years) were less satisfied with their social integration and less likely to be their own legal guardian or to possess a valid driver's license than participants with late-onset TBI (16-20 years) [38].

Some patients with mild pTBI may also be at risk of developing behavioral and social problems [19]; behavioral deficits can be a problem regardless of the severity grade of the pTBI [35]. Patients with a complicated mild pTBI seem to have a symptom load resembling that of patients with a moderate pTBI [39–41]. Other studies have found that even some patients with uncomplicated mild pTBI may have persistent symptoms [39] and thereby need follow-up and access to health care or educational services. Less visible emotional and cognitive symptoms of patients with TBI in childhood may go undetected if not assessed.

The outcome of pTBI is influenced by biological factors, such as the extent of the injury, and psychological factors comprising the child's or adolescent's subjective experiences. Furthermore, social factors such as life events, interpersonal experiences, parenting style, and sociocultural influences may affect the outcome. Engel et al.[42] addressed this interplay of factors, proposing a biopsychosocial model of these complex relationships and thereby providing a theoretical framework for understanding the factors that need to be assessed during rehabilitation after a TBI in childhood.
Injury severity does not explain all the variance in outcomes after pTBI. Pre-injury familial and environmental factors not only account for individual differences pre-injury [43,44]; for a child, the social environment and family functioning are important predictors of function over time after pTBI [45,46]. Furthermore, the school environment is an essential arena for rehabilitation of children and adolescents [47,48], and cooperation between health care and educational services over time with tailored information and education for both families and schools to improve outcomes after pTBI is essential [48].
This implies that there is a need for a holistic approach to the rehabilitation of pediatric patients with a TBI that considers the interactions among the biological, psychological, and social factors influencing the long-term outcome [46].

There is a growing body of research on the use of the International Classification of Functioning and Disability (ICF) to identify people's health care, rehabilitative, and support needs, as well as the effects of the disease and physical, social and policy environments [49]. The ICF framework represents a shift from a medical model to a biopsychosocial model of disability [50]
A pediatric version, the International Classification of Functioning and Disability for Children and Youth (ICF-CY) has been developed. The ICF-CY provides a system for classifying health-related functioning and disability that serves as a valuable framework for understanding the relationship between factors associated with functioning and disability [50]

and provides an adequate way of conceptualizing information on outcomes and rehabilitation needs from early childhood [50].

The developing brain

Plasticity versus vulnerability

The "plasticity" versus "early vulnerability" debate is a dispute of whether the immature brain has a greater capacity for recovery than the mature or adult brain or whether a brain insult would have different consequences at different times throughout development because cognitive development is critically dependent on the integrity of specific cerebral structures at certain stages of development [51]. Previously, TBI in childhood was commonly thought to have more favorable outcomes than in adulthood; the so-called early plasticity theory [52]. This has since been refuted by studies showing that the pediatric brain seems to be particularly vulnerable to injury, threatening future developmental trajectories. Andersen and colleagues investigated age at insult as a predictor of early pTBI outcomes in 2009 [51]. They found that children with early pTBI were at risk for impairments in all domains (intelligence, academic ability, everyday executive function, and behavior) [51]. Children with early pTBI (before two years old) had more global and significant cognitive deficits than older children [34]. In 2019, Resch and colleagues indicated that the developing brain seems to be the most vulnerable in cerebral maturational spurts, especially in early childhood but also in adolescence [53]. Infants and toddlers might have the most plasticity but also have some of the worst developmental outcomes of severe pTBI [33].

Normal development

Brain development differs from infancy to later childhood. In the first year of life, the brain develops through dendritic growth, and the volume of the brain rapidly increases until two years of age. Dendritic growth is followed by synaptogenesis from approximately one year of age to 5-6 years old. The function and structure of the brain mature together from birth to adolescence [54].

The overproduction of neurons in the newborn brain is balanced by subsequent apoptosis, a form of programmed cell death. Cell numbers decrease to adult levels during childhood and adolescence, entirely under genetic control. Synaptogenesis and parallel pruning by synapse reduction is highly dependent on experience and serves as the basis of learning during the early years of life. The different areas of the brain reach the peak of synapse production at different time points. The later the peak of synapse production is, the longer the regions remain plastic [55].

The parts of the cortex involved in visual and auditory perception have a completion of pruning between the 4th and 6th years of life. However, areas involved in higher cognitive functions, such as inhibitory control and emotion regulation, continue through adolescence. The process of pruning excess synapses is essential for the adaptive capacities of the brain during normal development [55]. The myelination of the brain increases during childhood, allowing axons to transmit electric signals faster. Certain sensory and motor areas are myelinated during preschool age, but the prefrontal cortex, involved in higher cognitive abilities, is not completed until early adulthood [55].

Injury to the developing brain

By examining brain function at the molecular and anatomic levels after brain injury in childhood, Giza et al.[33] found that with cell loss or localized cellular dysfunction (or both), the remaining neuronal circuits may be altered and potentially interfere with normal cerebral maturation. Changes in neuronal circuitry are a critical part of normal development, and disruption of this connectivity has been implicated in pTBI-induced learning disabilities and psychiatric disorders.

While the elevated neuroplasticity of the developing brain is generally regarded as beneficial, abnormal neural connectivity can also result in worsened functioning [33]. If the injury alters the developmental trajectory, some impairments will become more evident at a later stage [54]. After a developmental injury, although functional recovery may return performance to baseline, the baseline function of healthy peers has already increased. Therefore, recovery to the preinjury baseline is an inadequate endpoint for pediatric patients [33].

On the other hand, the ability of the brain to benefit from environmental stimulation appears most robust during its maturation, and an enriched environment can improve outcomes [33]. This advocates for increased effort regarding rehabilitation accommodations for pediatric patients with TBI, with family-centered services and cooperation between health care and educational services.

Rehabilitation and accessibility of health care and educational services

Rehabilitation

Rehabilitation may be defined as the multi- and interdisciplinary management of a person's functioning and health. Its goals are to minimize symptoms, disability, and possible health care costs, benefitting the individual and society [56]. Rehabilitation is a process that enables patients to reach and maintain their optimal physical, sensory, intellectual, psychological, and social functioning levels [57]. Rehabilitation services may include physical therapy, educational specialists, speech and language therapy, cognitive therapy, and mental health rehabilitation services [58]. The rehabilitation approaches may include family-centered practice [59], treatment and compensatory approaches, and behavioral and cognitive-communication interventions [60].

Research on pTBI rehabilitation is scarce despite knowledge about the potentially severe consequences of pTBI. There are methodological challenges due to the heterogeneity caused by the interplay between developmental stages in childhood and the variability of symptoms after pTBI [59]. Children with TBI often receive intensive treatment/rehabilitation during the acute and subacute stages but do not systematically receive rehabilitation services in the postacute stages, resulting in unmet rehabilitation needs. In the continuum of care, acute medical care (from the trauma center to inpatient rehabilitation) occurs in a relatively short timeframe (measured in months), compared with the years of recovery managed in home and school environments [59].

Perceived needs

The disruption of an individual’s development by a pTBI may lead to profoundly altered dynamics in their families. Unresolved stress in families has a negative impact on child outcomes [61]. Challenging stages are points of transition, such as discharge from primary rehabilitation in a hospital setting and return to kindergarten/school and previous activities, changes in grades in the school system and developmental stages (e.g., reaching adolescence), resulting in new individual and family needs [62].

Several papers have suggested that interventions aiming to establish compensatory strategies and environmental adaptations may improve the child’s functional level, preferably in a family- or peer-supported context [61–63]. An indirect, family-supported intervention, guiding and empowering parents in therapeutic ways of handling their child, can improve long-term outcomes and reduce perceived family stress following pTBI [61].

Furthermore, knowledge of the positive effects of rehabilitation services on patient outcomes after TBI in childhood is increasing [48,64]. The school environment is essential for rehabilitation, and cooperation between health care and educational services over time is recommended to improve outcomes after pTBI [48].

Unmet needs

Conversely, several studies have described unmet needs regarding rehabilitation services for patients hospitalized with pTBI [65,66]. Fuentes et al.[65] found a higher likelihood of unmet needs in patients with complicated mild pTBI, mainly due to a lack of mental health and educational and physiatrist services. Children with a severe pTBI tended to have more apparent functional impairments, leading to the identification of needs, and usually made more regular use of health care services; however, some of these children experienced unmet needs due to discontinued services with increasing time after injury. Likewise, Brenner et al. [67] recently found similar unmet needs regarding postacute rehabilitation services for moderate and severe pTBI. Medical-based therapy was often identified and met as a need, but psychosocial, educational, and community-based support were often unmet needs. The needs seemed to shift over time, from physical impairment needs to psychological and emotional needs [67].

Gaps between services judged necessary and services received

Several papers have addressed treatment gaps, i.e., the percentage of individuals who require treatment in a society but do not receive it for various reasons [68–70].

The assessment of the health needs of individual patients by health care workers may not reflect the full extent of health needs of the community; health needs can benefit from health care in terms of broader social and environmental changes. Health needs incorporate the wider social and environmental determinants of health, such as housing, education, and employment. A health needs assessment is an objective and valid method of tailoring health services—and an evidence-based approach to commissioning and planning health services—thus, hospitals and primary care teams should both aim to develop services to match the needs of their local populations [70].

Studies addressing service gaps after pTBI have noted equivalent problems with current systems in many parts of the world [48,58,59]. Most children with TBI are discharged and return home following initial injury care at the ED, and only a small percentage receive outpatient services [44]. Slomine et al. found that a substantial portion of children with moderate or severe TBI had unmet (~20%) or unrecognized (~10%) health care needs, most frequently in terms of cognitive services. Reasons for unmet needs include lack of physician recommendation or referral, services not provided in school settings, lack of parent follow-up, and cost [58]. There may be a failure to identify and utilize TBI-related educational services due to a lack of initial transmission of information from health care to school services. Academic achievement can become progressively more difficult as the child ages (with increased demands on cognitive and social skills and expectations of independence), and the evolving problems may not be attributed to the TBI and thereby inappropriately managed [59].

Many studies addressing unmet needs have been conducted in the USA and have reported that family factors predict unmet health care services after pTBI [58,65,71]. These factors include socioeconomic status, ethnicity, insurance status, low income, and family functioning. These

studies have reported that families with commercial insurance coverage are most likely to receive outpatient follow-up and educational adjustment following a pTBI.
In Norway, where the present study was carried out, the health care system is publicly financed and aims to provide universally accessible health care, including rehabilitation and psychiatric and educational services for children. We have publicly funded hospitals. There are services in every municipality responsible for rehabilitation in the home setting, allocating resources regarding adjustments for cognitive, behavioral, and physical impairments in childhood and serving families, kindergartens, and schools. In the southeastern region of Norway, we have one inpatient rehabilitation ward for children after acquired brain injury, including pTBI [2]. Differences in accessibility and use are expected between countries with privately and publicly financed health care systems.

More studies have been conducted on the adult TBI population in Norway [3,4,72]. Even in our public health care system, 31% of patients reported unmet needs in emotional, vocational, and cognitive domains five years after the injury [3]. Equivalent knowledge regarding Norwegian pediatric patients experiencing TBI is lacking. There is more adequately adjusted neurorehabilitation service for adults than for children with TBI. In addition, there might be less attention to the need for follow-up and rehabilitation for children with TBI, especially for the youngest age group.
In the Care Pathway for pABI for the southeastern region [2], we have emphasized the involvement of all services included, ensuring a corresponding understanding of the biopsychosocial needs of patients experiencing a brain injury in childhood and their parents. Studies are needed to map unmet rehabilitation needs and accessibility of the different services for the pTBI group so that our health care and educational services can be adapted accordingly, securing adequate and long-lasting follow-up and covering the challenging stages in childhood and adolescence.
Thurman et al. concluded: "The large public health burden of traumatic brain injury in children clearly justifies greater investment in research on effective methods for their prevention as well as more effective methods for their acute treatment and rehabilitation" [16]. This study may reveal factors related to the identification of patients who may need follow-up and steps in the rehabilitation trajectory in need of improvement.

3. AIMS

This thesis aimed to investigate the incidence, symptom burden, and development of symptoms of TBI in pediatric patients. Furthermore, the aim was to explore the level of unmet health care or educational needs in the pTBI population in the southeastern region of Norway. The specific aims for each paper were as follows:

Paper I

To describe the epidemiological patterns of pTBI in the southeastern region of Norway in terms of the following variables:

- the volume and burden of pediatric patients hospitalized after TBI
- TBI incidence, injury mechanisms, and severity grades
- factors associated with a likely need for follow-up

Paper II

To evaluate symptoms and impairments following TBI in childhood and investigate whether pediatric patients with TBI had specific unmet health care needs by

- comparing symptoms and impairments of TBI patients with matched controls hospitalized with other traumatic injuries of similar overall severity.
- investigating the accessibility and utilization of health care and educational services for the two groups
- assessing whether unmet needs influenced health-related quality of life.

Paper III

To investigate whether symptoms of head injury persist after two years, causing a need for health care or educational services after TBI of different severity grades in childhood by

- examining factors associated with unmet needs two years after the TBI
- assessing whether unmet needs were associated with reduced health-related quality of life.

4. METHODS

Study design, populations, and methods:

Paper I

In Paper I, we used a **register-based design,** retrieving epidemiological and medical data from the trauma registry at Oslo University Hospital [73]. The trauma registry includes all patients who trigger trauma team activation or have an Injury Severity Score (ISS) of 9 or higher (moderate to severe injuries). The TBI group was selected by the AIS 2008; with an AIS-Head score ≥1, and ages of 0-15 years, admitted to Oslo University Hospital (OUH) after a traumatic brain injury from January 2015 throughout December 2016. The dataset comprised 176 patients.
To ensure that the extraction of data from the trauma registry comprised patients with a confirmed head injury, we used AIS-Head score ≥ 1 as the inclusion criterion rather than GCS scores, as this scoring system is based solely on clinical assessment.

Data collection procedures:
We retrieved information on the age at injury, sex, municipality, date and time of the accident and discharge, location of the injury, injury mechanism, and severity according to GCS scores, AIS scores, and ISSs as well as all diagnosis and procedure codes (ICD-10) during the hospital stay, level of hospital treatment and transition of care, length of hospital stay and destination at discharge.

Methods
We estimated the main injury mechanisms and the boy:girl ratio in each age group. The demographic characteristics, injury characteristics, and proportion of pathology on neuroimaging were compared among the mild, moderate, and severe TBI groups (severity level according to the GCS score at admission). Furthermore, we compared two age groups (0-7 years and 8-15 years) in terms of injury characteristics, neuroimaging data, and destination at discharge.

Papers II and III

In Paper II, we used a **case–control design**.

The TBI group

The TBI group was the pediatric clinical cohort of the CENTER-TBI study at the Oslo site (OUH). The CENTER-TBI study [1] was a multicenter, prospective, longitudinal observation study conducted in 59 centers in Europe and Israel, including patients with TBI of all severity grades and all ages to improve the characterization and classification of TBI and identify the best clinical care [1]. The core study covered all spectra of TBI severity, including mild, moderate, and severe, and comprised 4506 patients of all ages. The inclusion criteria were a clinical diagnosis of TBI, patient admitted to the hospital within 24 hours after injury, an indication for CT scanning, and informed consent. Pediatric patients were enrolled at 33 of 59 participating centers [14]. The core of the CENTER-TBI study included 144 pTBI patients aged 1-15 years; we included 53 (37%) of these patients at the Oslo site.

This pediatric TBI cohort was recruited in the same period as that in Paper I, January 2015 to December 2016. Eligible patients were admitted to the ICU or the pediatric surgical ward. The first author invited them and their caregivers to participate in this study in collaboration with study nurses allocated to the CENTER-TBI study. The exclusion criteria were preexisting neurological, psychiatric, or neurodevelopmental disorders that might have affected the outcome assessments and insurmountable language barriers. The follow-up period was two years. The data from the acute phase and six-month follow-up are reported in Paper II.

The control group

The control group (i.e., patients with surgical injuries, SI) was selected and enrolled with equivalent procedures from the same ICU unit and pediatric surgical ward, matched in terms of sex, age group (1-7 years and 8-15 years), and overall Injury Severity Score (ISS). The inclusion criteria were as follows: residing in the southeastern region of Norway, aged 1-15 years, and admitted to OUH with traumatic orthopedic and abdominal injuries (without head injuries). The exclusion criteria for this group were the same as those above: preexisting neurological, psychiatric, or neurodevelopmental disorders that might have affected the outcome assessments and insurmountable language barriers. Enrolment started on December 2018 and ended in January 2020. The patients were evaluated in the acute phase and six months after the injury.

Matching of the groups

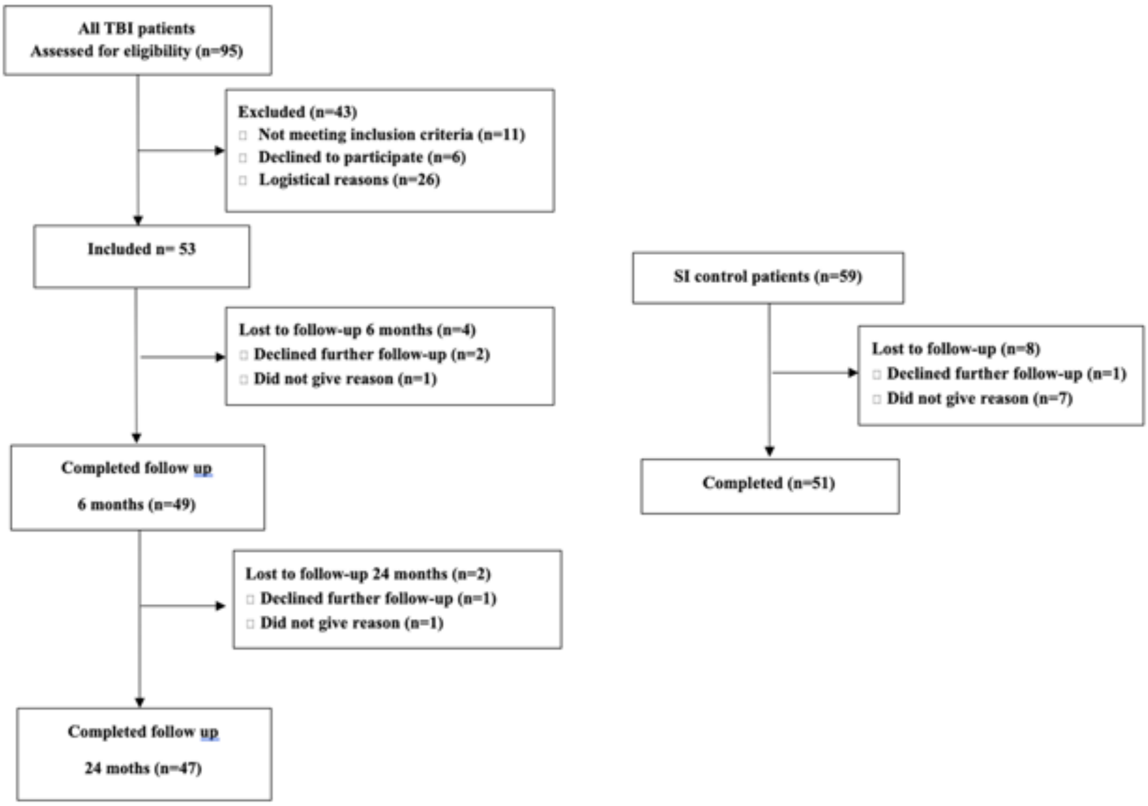
We used the ISS to compare the injury severity of the TBI and control groups. We used the ISS from OUH's Trauma Registry data for the TBI group. To ensure an equivalent evaluation of all study patients, M. Hestnes at the trauma registry verified an equivalent evaluation of AIS scores and ISSs of three patients included in the CENTER-TBI study but not listed in the trauma registry and supervised the evaluation of AIS scores and ISSs for the control group.

Level of treatment

An element of the assessment of injury severity, in addition to GCS scores, AIS scores, and ISSs, is the level of treatment from admission to discharge. The length of stay is another factor affecting the severity assessment. We categorized the level of treatment in the acute phase in line with the CENTER-TBI study [1] as follows: 0 = no injury, 1 = no treatment needed, 2 = outpatient treatment, 3 = admitted to a ward, 4 = observation/basic treatment in the ICU, 5 = intubation, mechanical ventilation, or vasopressor treatment in the ICU, and 6 = nonsurvivable.

In Paper III, we used a **longitudinal cohort design.**
The TBI group described in Paper II was followed up 24 months after the TBI.
We reported data from the acute phase, at six and 24 months, in Paper III.

Figure 1 Study populations in Papers II and III



Data collection procedures

In P**apers II and III**, the patients were neurologically examined and interviewed in the acute phase and at follow-up. Both patients and parents filled out questionnaires separately; children aged 5-7 years completed questions by having them read aloud to them, with a visual aid that contained pictures of happy, neutral, and sad faces provided when needed to support their answers. We retrieved information regarding injury severity, level of impairment, and treatment from the medical records.
In Paper II, 49 of the TBI patients completed assessments at the hospital. Twenty-six patients in the SI group visited the hospital for an assessment, and the other 25 patients were assessed by a combination of self-reports and parental reports by mail and telephone interviews. All control patients under eight years old completed assessments at the hospital.
In Paper III, 47 of the study patients completed the 24-month follow-up, one declined the last follow-up, and one was lost to follow-up (Figure 1).

Measures

Injury severity

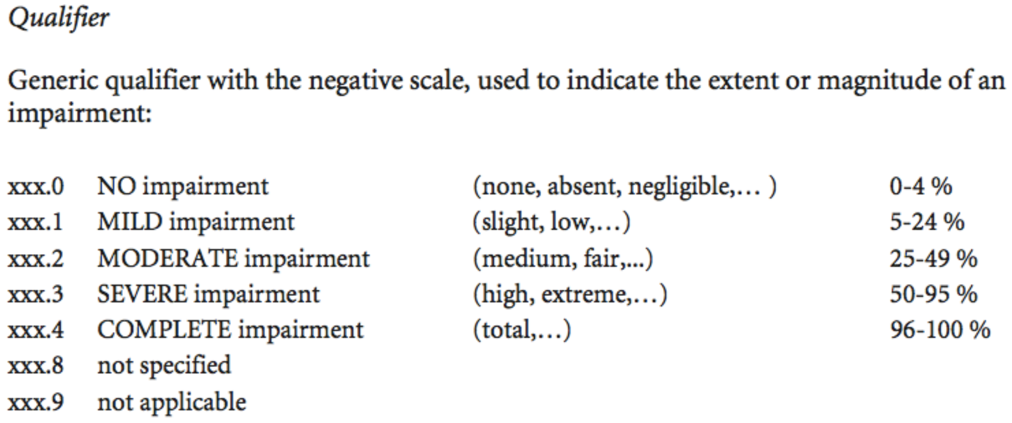
We used the Glasgow Coma Scale (GCS) for to assess patients over three years and the pediatric version to assess patients under three years[17,18] to classify TBI severity at admission. We further categorized mild TBI (GCS scores of 13-15) as complicated (presence of trauma-related intracranial abnormality) or uncomplicated (absence of trauma-related abnormality) by evaluating CT and MRI scans [19]. All patients had a CT scan within 24 hours after injury. Twenty-four of the patients with TBI underwent cerebral MRI scans. A neuroradiological trauma specialist at OUH assessed the CT data according to the Rotterdam score [74] and described the MRI scans. Furthermore, the AIS score and ISS were used to assess the severity of injuries throughout the body [75], as described above.

Assessment of impairment

To categorize the clinical and neurological evaluations in the acute phase and at follow-up, we used a modified version of the International Classification of Functioning, Disability, and Health for Children and Youth (ICF-CY)[49]. The ICF-CY classifies function and disabilities associated with health conditions for children and adolescents.

Impairments in physical, cognitive, and emotional functions were assessed using the clinical examinations reported in the medical records in the acute phase and by assessments performed by the pediatric neurologist in the acute phase and at the 6-month follow-up. Clinical examination was structured by ICF-CY categories. We assessed 17 body functions: physical functions (movement, vision, hearing, olfaction, touch, pain, sleep, muscle power, and motor reflexes), cognitive functions (consciousness, orientation, memory, attention, energy, and drive), and socioemotional functions (emotional function, management of behavior). We scored the symptoms and impairments in the acute phase and at the six-month follow-up for both study groups. We used the first generic qualifier (i.e., quantify the extent of a problem experienced by a person) from the ICF-CY. We recorded a score of 0 for no impairment (0-4%), 1 for mild impairment (2-24%), 2 for moderate impairment (25-49%), 3 for severe impairment (50-95%), and 4 for complete impairment (95-100%). We summarized the scores per patient at each time point. Scoring was performed in collaboration between the pediatric neurologist and rehabilitation specialist. This way of using ICF has been described in adult TBI studies [76], but this study is one of the first to use an analytic approach in pediatric patients with TBI. Therefore, the findings should be interpreted carefully and validated in future studies.

Table 1 ICF-CY impairment scale



Qualifier

Generic qualifier with the negative scale, used to indicate the extent or magnitude of an impairment:

xxx.0	NO impairment	(none, absent, negligible,…)	0-4 %
xxx.1	MILD impairment	(slight, low,…)	5-24 %
xxx.2	MODERATE impairment	(medium, fair,...)	25-49 %
xxx.3	SEVERE impairment	(high, extreme,…)	50-95 %
xxx.4	COMPLETE impairment	(total,…)	96-100 %
xxx.8	not specified		
xxx.9	not applicable		

Outcome measures used in Papers II and III

Table 2 Measures used in Papers II and III

	Acute phase cases and control	6 m cases	6 m controls	24 m cases
Clinical examination	✓	✓	✓	✓
ICF-CY	✓	✓	✓	✓
Level of treatment	✓			
GOS-E		✓	✓	✓
RPQ	✓	✓	✓	✓
PedsQL	✓	✓	✓	✓
CT/MRI	✓			
Met and unmet needs		✓	✓	✓

Global outcome

The Glasgow Outcome Scale-Extended (GOS-E) [77] is considered the gold standard for measuring TBI outcomes and is sensitive to changes in functional status over time [77]. Therefore, we used the GOS-E to assess global outcomes in all participants at all follow-ups. Our study was an extension of the CENTER-TBI study, and we extracted GOS-E data for the TBI group from the center database. We used a manual from the CENTER-TBI study detailing an age-appropriate assessment for children under 12 years old instead of using the GOS-E Peds, a pediatric version of the GOS-E. The GOS-E scoring for the control group was performed by HMD in agreement with NA.

Post-concussion symptoms

We chose the Rivermead Post-Concussion Symptoms Questionnaire (RPQ)[78,79] to assess the load of symptoms. The RPQ is a self-report questionnaire assessing post-concussion symptoms. It is widely used to assess changes in symptoms over time [80–82], as the questionnaire addresses common long-term symptoms after TBI of all severities, such as fatigue, memory complaints, emotional problems, headache, and dizziness. The RPQ has high construct validity, and the Cronbach alpha for internal consistency was 0.93 in a Dutch CENTER-TBI-related study [83]. We used the RPQ in the acute phase and at all follow-ups. The RPQ has been validated for use in children 6 years and older [84]. In our study, patients aged five years and older responded (n=44).

Health-related quality of life

When investigating symptoms in children and adolescents, proxy reports from parents are frequently used, especially for the youngest age groups. The Pediatric Quality of Life Inventory, version 4.0 [85,86], has patient and parent report versions. It allowed us to assess health-related emotional and behavioral problems according to patients at a very young age and their parents separately. A parent version was used for patients aged 2-4 years, and a self-report version was used for patients aged five years and older. The simplified version for children aged 5-7 years has a visual aid containing pictures of happy, neutral, and sad faces. It allowed us to systematically interview the children 5 years of age and older about their

symptoms. The internal consistency of the Norwegian version of the PedsQL was satisfactory, with Cronbach's alpha >0.70 for all subscales in a study on Norwegian adolescents [87].
In the literature, the cutoff scores for identifying special health care needs in children with mild to severe injuries have been set at 82-77 for children under 8 years old and 78-70 for children $\geq$ 8 years of age [88].

Utilization of health care and educational and unmet needs

To group the need levels, we used the categorization by Slomine et al.[58]: no need identified, met need, unmet need, and unrecognized needs. Due to the low number in our study, we collapsed the group reporting unrecognized needs into the group with unmet needs.
We defined "met need" as an impairment or symptom affecting daily life that was addressed and resolved, and "unmet need" as an impairment or symptom raising the need for renewed information regarding necessary adjustments, or referral to a health care or educational service.
We used disability identified at the follow-up, combined with the patient- or parent-reported covered or lacking service, to divide the patients into groups according to needs.
The "no need identified" and "met need" groups were assessed in line with Slomine et al.[58] and Greenspan/MacKenzie [89].
We divided health care and educational services into the same overarching categories as Slomine et al.[58]: cognitive, physical, and socioemotional services. The domains were adapted to Norwegian health care and educational services.

Table 3 Health care services

Domain	**Health care service**
Cognitive need	Speech therapy Special education needs services Pediatric habilitation unit Inpatient rehabilitation unit
Physical need	Hospital follow-up Family doctor Physiotherapy
Socioemotional need	Social services Psychiatric services for children and adolescents Public health nurse at school

Socioeconomic status

Insurance status classification is not relevant since we have a publicly funded health care system with universal access in Norway. The highest educational achievement by a parent was used to indicate socioeconomic status [90].

Statistical analyses

Statistical analyses were performed with SPSS Statistics version 26.0 (IBM Corp., New York USA), and linear mixed model analyses were performed using Stata (StataCorp LP, College Station, TX).

Sample:

We estimated the number of patients eligible for inclusion to be 75 over the inclusion period, based on a former study conducted by Andelic and coworkers [3]. At the Oslo site of the CENTER-TBI study, we expected to include approximately 80% of these patients, i.e., 60. A statistical power analysis beyond study start (DSS Research) showed that a change in function of 0.5 standard deviation in the patient group would result in a statistical power of 98%. However, we finally included 53 patients (71% of 75); we regard this as an acceptable percentage of the expected estimate [91].

We planned to include a control group of 50-60 patients [91]. We succeeded in including 59 control patients but lost eight patients to follow-up before the six-month follow-up. Nevertheless, the final number of patients (51) was within the estimated range (Figure 1).

All results are presented with $p < 0.05$ as the significance level.

Paper I: Statistical analysis

Data are presented either as numbers or percentages for the continuous variables. Medians and interquartile ranges (IQRs) are used to describe continuous variables with skewed distributions.

We chose to calculate the incidence of hospitalized pTBI patients in Oslo due to the lack of complete knowledge of hospital-admitted pTBI patients in the whole southeastern health region. The Pearson chi-squared test was used to compare nominal variables between groups. The groups were not normally distributed; therefore, we performed nonparametric statistics (Mann-Whiney U tests) for ordinal variables.

Papers II and III: Statistical analysis

Data are presented as numbers and percentages for nominal variables and means with standard deviations (SDs) for continuous and ordinal variables (Papers II and III).

Due to the small sample size, the Mann–Whitney U test was used to compare ordinal variables and continuous variables between groups. Missing values for single items were imputed according to the manual for each questionnaire (Papers II and III).

Paired-sample t tests were used to compare changes in RPQ scores at different time points for each groups (Paper II). Furthermore, to compare the differences in RPQ scores across groups (table 4), independent-samples to sided t tests were used.

We used the crosstabs risk estimate to compare unmet needs between the TBI and control groups. The results are reported as odds ratios (ORs) with 95% confidence intervals (CIs) (Paper II).

Binary logistic regression was used to assess symptoms reported on the RPQ at 24 months, and the results are reported as odds ratios (ORs) with 95% confidence intervals (CIs) (Paper III).

We used Linear mixed models' analyses to compare longitudinal data (Paper III)

The results are presented with a significance level of $p < 0.05$.

Erratum:

Paper II contains an error:
"The results are presented with a significance level of $p>0.5$." It should be significance level of $p < 0.05$.

Ethics

The study was approved by the Regional Committee for Medical and Health Research Ethics (REC: 2014/1454 and 2017/1493). The first approval involved pediatric participation in the CENTER-TBI study, and the second approval involved the inclusion of the control group in Paper II. The study was conducted in accordance with the Declaration of Helsinki [92] (World Medical Association, 2013) and the Vancouver Rules (International Committee of Medical Journal Editors, 2018). We obtained informed consent according to local and national ethical and legal requirements. Children aged seven years and older provided their assent to participate in the study, and informed written consent was provided by the legal guardians of children of all ages.

5. RESULTS

Paper I

In Paper I, we investigated the epidemiological patterns of traumatic brain injury in the pediatric population aged 1-15 years in the southeastern part of Norway who were hospitalized at OUH in 2015-16 (N= 176).

The injury characteristics of the hospitalized pTBI patients aligned with those of hospitalized pTBI patients in other European countries. The incidence rate of hospitalization for pTBI among individuals residing in Oslo in 2015-16 was 29 per 100,000 per year.

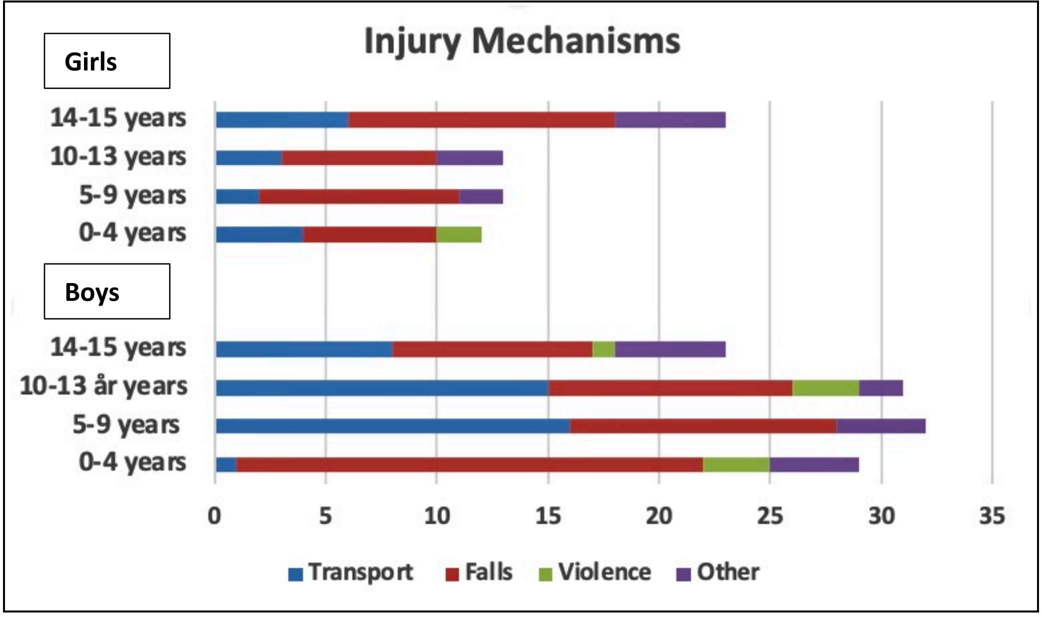
The main cause of TBIs was falls. Many of the falls occurred from a height of over 2 meters or a lower height with an impact on hard surfaces. We found that the accidents mainly occurred at home and indoors in children under four years. At school age, children mainly fell outdoors. Among adolescents, accidents with falls on alpine slopes significantly contributed to TBI.

The second most common injury mechanism was transport accidents. Children who were independent and mobile (5-9 years) were mainly injured as roadside pedestrians or passengers in road accidents. The injury mechanisms leading to severe TBI were transport accidents with high energy trauma involving car accidents (as a passenger or hit by a car), horseback riding, skateboarding, and mobility scooter accidents. Fatal accidents occurred during play or by intentional injury to babies.

We found that the frequency was not bimodally distributed (with modes among preschool children and adolescents), as in other studies [5]. Instead, this sample exhibited a steady increase in TBI rates from the age of two years to adolescence, due to falls and traffic accidents. Furthermore, the boy:girl ratio also differed from that in other studies, lacking a male predominance in the adolescent group above 14 years of age. Young adolescent girls had similar TBI risk as boys. Fatal accidents occurred during play or by intentional injury in patients under one year of age.

Patients with intracranial injury (ICI) on neuroimaging had longer hospital stays of two days or more. Children seven years old or younger seemed to have more severe intracranial injury due to trauma to the head than older children.

Figure 2 Injury Mechanisms



Number of patients according to injury mechanism, categorized by age and sex.

Paper II

In Paper II, we investigated the symptoms and impairments associated with childhood TBI, including the accessibility and use of health care services six months postinjury. We compared the patients hospitalized with TBI to a matched group of children hospitalized with other types of trauma to investigate whether the patients with TBI had specific unmet health care needs.

At six months after injury, there were more severe injury-related impairments in the cognitive, physical, and socioemotional domains in the TBI group compared to the control group. We found that 22 patients (47%) of the TBI group reported unmet needs, compared to 6 patients (12%) of the control group. The risk of unmet needs was four times higher in the TBI group (OR: 3.99, 95% CI: 1.78-8.96).

The planned follow-up after discharge significantly differed between the TBI and control groups; 94% of the control group received a scheduled follow-up at discharge compared to 20% of the TBI group.

The unmet needs of patients with TBI were due to unaddressed cognitive and socioemotional symptoms. There were unmet needs in patients with all severity levels of TBI:

- 30% of patients with mild TBI (mTBI)
- 64% of patients with complicated mild TBI (cmTBI)
- 54% of patients with moderate/severe TBI

These patients with unmet needs experienced long-lasting cognitive and emotional symptoms, such as fatigue, forgetfulness, and concentration problems, affecting their return to school and social interactions with peers. They needed interventions such as reduced environmental stimuli and workloads, extra breaks during the schooldays, and guidance in social interaction with peers and adults. Eight patients with TBI were referred to the Special educational needs service. Furthermore, referrals to psychiatric services were made for 32% of the TBI patients vs. 8% of the control group at six months. These impairments were associated with reduced quality of life.

Paper III

In Paper III, the TBI group from Paper II was followed until 24 months after injury to describe the course and duration of brain-related symptoms and investigate whether the symptoms implied a need for health care or special education services and whether these needs were met.

We found that 12 patients (25%) still reported unmet needs due to persistent cognitive and emotional symptoms affecting school functioning and social interaction. Of these 12 patients, 10 had unmet needs also at six months. The ongoing needs were partly due to discontinued accommodations. These patients expressed a need for help mediating information regarding symptoms and dysfunction following the TBI to their schools. The patients lacked necessary accommodations and support for educational and emotional needs and reported unsatisfactory transmission of information and implementation of recommended measures.

The risk of ongoing concentration problems and fatigue was three times higher in the unmet needs group than in the groups with no needs and met needs (OR: 3.219, 95% CI: 1.495-6.929) and (OR: 3,125, 95% CI: 1.382-7.066), respectively. The risk of being depressed or having headaches were approximately two times higher (OR: 2.040, 95% CI; 1.083-3.842) and (OR: 1.896, 95% C: 1.062-3.387), respectively.

Patients with cmTBI showed minor improvement from 6 to 24 months postinjury compared to the other severity groups.

Among patients who reported ongoing unmet needs, quality of life was reduced at 24 months, with a significant difference in total scores (p= 0.050) and psychosocial health scores (p= 0.036) from those with no or met needs. In this group, children reported problems regarding emotional symptoms and school performance, with scores on emotional and school items defining a need for specialist health care needs [88]. The parents also reported that their children had significantly more problems at school (p= 0.028) and with participating in activities due to physical symptoms compared to those with no and met needs (p= 0.024) (e.g., fatigue).

Of the 22 having unmet needs at six months, ten still reported unmet needs at 24 months, consisting of two with mTBI, five with cmTBI, and three with moderate/severe TBI. Furthermore, two patients had unmet needs uncovered at the 24-month control.
At the 24-month follow-up, the unmet needs were addressed. Six patients reported a need for more or renewed information about brain injury and advice on necessary accommodations after changing schools, four patients were referred to special education needs services and two patients were referred to psychiatric services for children and adolescents (Table 4).

Table 4 Unmet needs

Time Domain	**6 months** **N=22**	**24 months** **N=12**
Cognitive		
Special education needs services	8	4
School adjustments	5	6
Physical	1	0
Socioemotional	8	2

6. GENERAL DISCUSSION

Discussion of main findings

The first paper indicated that the population of hospitalized pediatric patients with TBI in our region had injury characteristics corresponding to those in reports from Europe, Australia, and the USA [8]. The incidence was lower than that in other parts of the world but comparable to that in other Scandinavian studies [8,11,93]. The incidence of pTBI hospitalizations in this study was not bimodally distributed as in other studies [5] that reported a preschool group and an adolescent group. Instead, this sample exhibited a steady increase in risk from the age of two years to adolescence, due to falls and traffic accidents.

In the study population, we found a change in the TBI risk of adolescent girls starting at 14 years of age, as they caught up with the boys (e.g., 1:1 ratio of incident TBI). This is a different pattern than that found in a comparable sample ten years earlier [5] and exemplifies the importance of monitoring changes in risk-taking behavior and tailore prevention measures accordingly. For example, new means of transportation, such as mobility scooters, providing new ways of causing severe intracranial injuries, including in adolescents [94].

The main reason for TBI was falls. Children under four years of age mainly had accidents at home and indoors, substantially contributing to head injuries in this age group. For children under one year, severe and fatal injuries occurred by intentional injuries.

For mobile and more independent children aged 5 to 13 years, transport accidents (with the children as pedestrians or passengers/users of different means of transport) largely contributed to TBI, mainly those in boys. Falls on alpine slopes were also a common injury mechanism in adolescents.

Home safety is important when counseling parents of small, newly ambulatory children, and prevention of child abuse and neglect is essential and needs to be implemented in health care and educational services when handling these children.

Collins et al. [13] found a significant male predominance starting in infancy of injury mechanisms, mortality rates, and lack of use of protective devices. This seemed to be the cause among more independent children over five years of age in our society, even though there is a significant focus on road safety and the use of safety equipment [8].

The contribution of alpine sports is difficult to address, as this is an important leisure activity for many children and adolescents, but given the injury mechanism, some prevention might be warranted.

Furthermore, we found that children aged seven years or younger seem to have more severe intracranial injury (ICI) (i.e., complicated mild, moderate, or severe TBI, assessed by GCS scores and neuroimaging data) from trauma to the head than the older group. Increased vulnerability resulting in pathology on CT/MRI scans and impairments after TBI has also been shown in other studies in the youngest age group [51,95]. This may imply a need for a particular focus on preventive measures and continuation of follow-up for the youngest group, as impairments may be more evident with older age [54].

Furthermore, patients with ICI had longer hospital stays than those without ICI. Our clinic has not focused on this subject, but this might give us a reason to develop a method for selecting patients with TBI who need plans for follow-up.

Our findings indicate that if the hospital stay is longer than two days, it might be necessary to reassess injury severity at admission according to the AIS/neuroimaging and rather than only the GCS. The call for neuroimaging findings preferably by MRI, is especially relevant for the youngest patient group, as they seem to be prone to more severe ICI due to head injury than older children/adolescents.

In Paper II, we found clear differences in plans for follow-up at discharge and experience of unmet needs between the TBI group and the control group, favoring the control group in both aspects. The patients with TBI who experienced unmet needs reported reduced quality of life, with cognitive and emotional symptoms affecting school performance and peer interactions. At the 24 month follow-up in the TBI group in Paper III, we found that 25% had persistent cognitive and emotional symptoms that still affected school functioning and social interaction. Other studies have found that patients with cmTBI may have a symptom load resembling those with moderate TBI after the acute phase [39,40]. In this study, patients with cmTBI exhibited only minor improvement in the global outcome from 6 to 24 months and nonsignificant changes in symptom load (evaluated by the RPQ) between the acute phase and 24 month follow-up.

Holthe et al. reported similar results with neurophysiological testing of the TBI group at six months postinjury [41]. Neuropsychological assessment revealed reduced cognitive performance and abnormally high intraindividual variability in 45.5% of the study sample; the parents of these children reported that they experienced problems with concentration and fatigue. Brain injury symptom load was not linked to TBI severity, but brain injury symptoms were strongly associated with reduced quality of life [41].

Regarding quality of life, the TBI group scored lower on emotional and school functioning than the control group at six months. At 24 months, those with unmet needs scored a symptom load at the level of specialist health care needs [88]. These patients reported a failure to transmit information on TBI sequelae to their schools or discontinuation of appropriate accommodations when changing schools. Furthermore, they reported emotional and cognitive symptoms leading to referral to local special needs education or psychiatric services for children and adolescents. We interpreted these findings as corresponding with those of other studies on a lack of mental health, educational, and physiatrist services for patients with pTBI and that patients with pTBI experience unmet needs due to discontinued services with increasing time after injury [48,59,65].

Studies from other countries [48,59] have described difficulties in identifying patients who will need rehabilitation after hospitalization for pTBI. In this study, 80% of the pTBI group did not have a scheduled follow-up at discharge and might have had undetected cognitive and emotional symptoms affecting school functioning and peer interactions if not assessed. The difference in planned follow-up may be caused by difficulties in identifying patients who need follow-up after TBI due to a lack of knowledge on TBI sequelae in pediatric patients in the health care system, which is similar to findings of other authors [59,65].

Methodological considerations

The clinical and epidemiological approaches used in this thesis represent different research designs; hence, they have different limitations and strengths.

The different designs have different implications for hypothesis testing. The small sample in Papers II and III, especially Paper III, increases the likelihood of type II errors, i.e., wrongly concluding that there is no difference when there is a difference [96].

Outliers or missing data in a small sample may result in type II and type I errors; a type I error is the wrong conclusion that there is a difference when there is no difference [96].

Including a slightly smaller number of patients than estimated can result in type II errors.
We had a heterogeneous sample for Papers II and III but did not contain outliers. We chose to use the measures with the least amount of missing data.
We handled the missing values according to the manual of each measurement tool.

Measurements: Choice of variables

Injury severity assessment

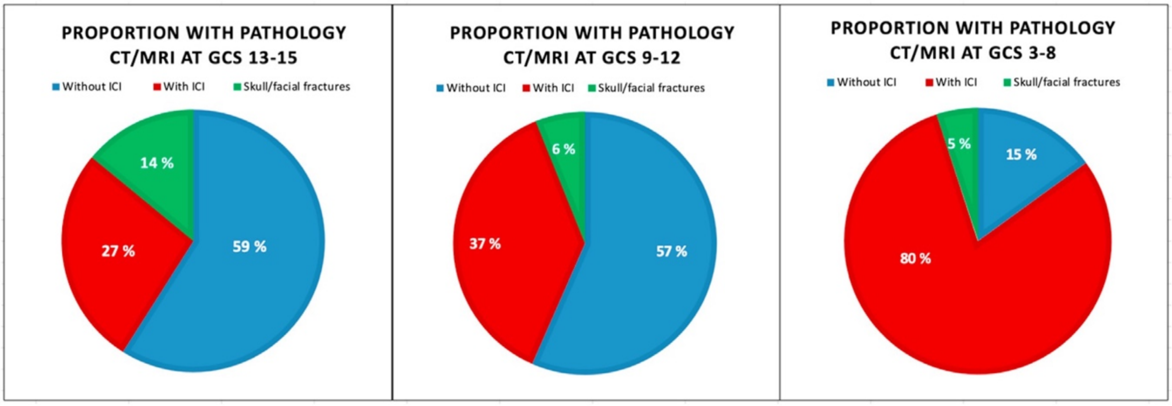
The GCS is based solely on clinical examination and is widely used at admission and in the acute phase to inform decision-making regarding treatment level.
The AIS head score is based on a combination of symptoms described in the patient's medical chart, CT/MRI findings or findings during operation. This score, by necessity, is provided at a later stage than admission. A comparison of the use of AIS head and GCS scores to indicate brain injury severity using retrospective data showed that AIS and GCS scores are highly correlated for severe brain injury. However, AIS scores are less strongly correlated with GCS scores in mild and moderate brain injury cases [17]. This applies to our findings: in Paper I, we found that severe GCS scores corresponded to a high frequency of ICI, while moderate and mild GCS scores included 37% and 27% of patients with ICI, respectively (Figure 3).
Considering sequelae, in Papers II and III, we found that cmTBI had a symptom load similar to that of moderate TBI. This was supported by the neuropsychologic assessments of the TBI group at six months postinjury [41]. Brown et al. found that the AIS head score is the most important for predicting severe outcomes and mortality in children [97].

Table 5 Severity scoring system

	Mild	Moderate	Severe	critical/nonsurvivable
GCS	13-15	9-12	3-8	
AIS$_{\text{head}}$ [17]	1-2	3-4	5	6
ISS	<9	9-15	16-24	25-75
Outcome: GOS-E	7-8	5-6	3-4	2-1

GCS; Glasgow Coma Scale, AIS; Abbreviated Injury Scale, ISS: Injury Severity Score, GOS-E: Glasgow Outcome Scale-Extended

Figure 3 CT/MRI findings for all TBI severity levels.



The proportion of neuroradiological findings of ICI vs. skull/facial fractures vs. no intracranial pathology at three severity levels according to GCS scores. (ICI = intracranial injury, CT = computerized tomography, MRI = magnetic resonance imaging)

To compare injury severity in the TBI and control groups, we used the Injury Severity Score (ISS). The ISS is based on the AIS scores of six body regions and, therefore, can assess injury severity similarly across all trauma patients. We found that including severely injured control patients without head trauma was somewhat challenging. Moksnes et al. found that 46% of patients of all ages admitted to OUH in 2020 with moderate and severe trauma had head injuries among their injuries [98].

Assessment of impairment

We chose the International Classification of Functioning, Disability, and Health for Children and Youth (ICF-CY) to describe the clinical impairments observed in the acute phase and in later assessments. The ICF-CY has been used to describe functional profiles of patients with different health conditions, including both health status and activities of daily living and participation in society [99]; it has been used to assess patients with TBI and was found to be helpful in rehabilitating patients with TBI [32,76].

Level of treatment

The level of treatment of the TBI group in the acute phase after injury was assessed with a scale used in the CENTER-TBI study. We found it helpful to apply this scale to the control group to compare injury severity between the two groups.

Questionnaires:

To assess the symptom load and quality of life by the patients and their parents, we used questionnaires validated for use in pediatric patients, supplemented with interviews of both the parents and patients. Low to moderate concordance between reports from parents and children has been reported [100,101], which highlights the importance of considering the perspectives of both parents and children down to the lowest possible age.

We observed a lack of concordance in PedsQL scores between parents and patients, especially regarding the emotional and physical symptom load at 24 months, but greater concordance in opinions regarding school performance at six and 24 months.

The GOS-E score as measurement for global outcome

GOS-E has sufficient responsiveness (i.e., the ability to detect change) and a low ceiling effect (ability to discriminate higher functional levels) [102]. The interrater agreement between trained interviewers has been reported to be very good and acceptable for use within trauma populations. It is widely used to evaluate the outcomes of brain-injury patients [102].

In our study, GOS-E scores were retrieved from the CENTER-TBI database for the TBI group. Patients in the TBI group with missing information and the control group had outcomes scored according to the reports in the medical chart and interviews with patients and their parents. Scores were assessed by HMD and validated and confirmed by Dr. Andelic, a rehabilitation physician.

Psychometric properties of the Rivermead Post-Concussion Symptoms Questionnaire (RPQ)

We used the RPQ in this study to assess the symptom load at the acute phase and at follow-up. The RPQ is a questionnaire used in both adults and children, validated for use with children six years of age and older. The Health and Behavioral Inventory (HBI) also addresses post-concussion symptoms and is used in children aged seven years and upwards. It is referenced in the paper addressing the neuropsychological assessment of the TBI group at six months postinjury [41]. We chose to use the RPQ in Papers II and III since this questionnaire was also used in the acute phase, providing three measurement points for Paper III.

In Paper II, we also administered the RPQ to the control group to estimate the symptom load in hospitalized patients in the acute phase and at follow-up six months later. Comparison of the TBI and control groups revealed a significant difference in only the somatic subscale in the acute phase but significant differences in the total score and all subscales at six months postinjury. This points to lower construct validity in the acute phase regarding strict measurements of PCS symptoms shortly after injury. Generic symptoms due to injury, surgery, and hospitalization were difficult to disentangle from brain injury-specific symptoms. Hospitalized pediatric patients with new injuries or who have recently undergone surgery may also experience nausea, fatigue, and sensitivity to stimuli.

Psychometric properties of the PedsQL

Health-related quality of life (HRQoL) was assessed by the Pediatric Quality of Life Inventory 4.0 (PedsQL) in this study.

The PedsQL can be used to measure the QoL of children with different diseases[103,104]. A study of the psychometric properties of the PedsQL^{TM} 4.0 when evaluating pediatric patients at an outpatient mental health clinic (compared to children from the general population [105]), found that the PedsQL was a valid instrument for measuring the quality of life of pediatric patients, with consistent reliability of both child self-reports and parent proxy reports.

We considered the PedsQL suitable for use in our study since it allowed the assessment of symptoms of children as young as two years old with parent reports; children's own opinions could be recorded starting at five years old. The disease-specific measure Quality of Life after Brain Injury in Children and Adolescents (QOLIBRI-KID/ADO) was unavailable at the start of the study [106]. This instrument may be used in future studies, as it can measure disease-specific HRQoL across the lifespan.

Unmet needs

In this thesis, we aimed to identify factors associated with a likely need for follow-up, investigate whether pediatric patients with TBI had specific unmet health care needs, and examine factors associated with unmet needs two years after TBI.

To investigate the perceived or identified unmet needs of all included participants, we used a semistructured interview based on the classification used in other studies assessing unmet needs in the pediatric TBI population [58,89]. Health care and educational services were likewise divided into the same overarching categories as Slomine et al.[58] but adapted for those provided in Norway.

We acknowledge the limitation that we did not use a validated measure for assessing unmet needs. However, Fuentes et al.[65] evaluated unmet needs in a similar way, systematically asking participants about access and utilization of relevant rehabilitation services.

Estimated rehabilitation capacity in Norway

The southeastern region of Norway contains 57% of the population of Norway. We found that 80-90 pediatric patients were hospitalized with TBI each year, which suggests that there might be 140-160 pTBI patients in Norway annually. Of these patients, approximately 80% had mild TBI. Nearly half of them had complicated mild TBI. Furthermore, approximately 10% had moderate TBI and 10% had severe TBI.

Based on our results, in the southeastern region of Norway, approximately 60 patients would have unmet needs at six months postinjury, and 30 would have unmet needs at 24 months postinjury.

According to our results, approximately 100 pediatric TBI patients each year in Norway (across the four health regions) would need planned follow-up.

Validity and bias

Validity

Validity, precision, and reliability are essential psychometric properties of questionnaires. Validity refers to the ability of the tool to measure what it is designed to measure. Content validity refers to the extent to which the questions cover all dimensions of the phenomenon meant to be measured. Construct validity expresses whether the questionnaire measures what it is intended to measure. Criterion validity describes how well the measure correlates with or predicts another valid and observable variable. To address these factors, we used internationally validated and widely used questionnaires in research. Internal validity reflects whether the results are correct and valid for the study sample.

The accuracy of the results is determined by the degree of systematic variation in the actual value (validity) and the degree of absence of random variation (precision). The risk of random errors increases with decreasing sample size, and the sample size is often a problem in pediatric studies investigating diseases with rare occurrences, as in this study, increasing the risk of lower precision. However, using questionnaires that have been validated in more extensive studies enhances the generalizability of our results.

External validity

External validity concerns generalizability, i.e., it indicates the extent to which the results are valid under other conditions and for other samples.
The study population in Papers II and III seems to be representative of pediatric patients hospitalized with TBI in our region since the boy:girl ratio, age at injury, and injury mechanisms corresponded to those in Paper I, which investigated the epidemiological patterns of TBI hospitalizations in the pediatric population in the southeastern region of Norway. Therefore, our findings may apply to the pediatric trauma population in our region. The southeastern region contains 57% of the population of Norway [107]; additionally, there might be reason to assume that the findings apply to urban areas in our country.
The socioeconomic status and the publicly funded and universally accessible health care system in this Scandinavian society may reduce the generalizability of this study to countries without free services. However, our findings regarding factors leading to unmet needs correspond with those in studies from other parts of Europe and the USA.

Bias

Bias is a result of trends in the process of selecting study participants or data collection that may lead to conclusions that are systematically different from the true conclusions. [108]

Paper I: A register-based study [109]

Limitations:

The limitations of register-based epidemiology research include the potential lack of availability of necessary information and potentially inaccurate or misclassified information. With the use of a publicly assessable quality register such as the Trauma Registry, data collection is not performed or selected by the researcher. The researcher, therefore, is limited to the variables and level of detail used in the register. Data may be missing due to lack of coverage due to lack of information (e.g., education level of immigrants or children). The aim of data collection is not necessarily that of research. When including data from a selected number of years in register-based studies, the error term may be the year-to-year variation by introducing year as a random term in the model.

Strength:

The strengths of a register-based dataset are its relatively large sample size and that the data were collected prospectively and independently of the research question. The register may have information on exposures and outcomes of interest and ensure completeness, with less missing data, participants lost to follow-up, and selection bias due to nonresponse than self-reported data [109]. The data, therefore, have higher validity than self-reported data. Statistical interference, the process of drawing conclusions regarding the population level of a study based on the study sample, is appropriate in a register-based study. The large sample size enables research on rare exposures and outcomes [109].

For Paper I, we used data from the Trauma Registry at OUH (TR-OUH) since this is considered the most systematic, complete, and consistent source of information on patients with TBI admitted to OUH, the trauma referral hospital for the southeastern region of Norway and the local hospital for the pediatric population of Oslo. We may have excluded some mildly injured patients by including only patients triggering activation of the trauma team or with an ISS of 9 or over. Furthermore, patients with mild TBI residing outside Oslo are maynly admitted to their local hospital. Therefore, the data did not represent a fully representative cohort of patients with mTBI in the southeastern region of Norway. However, we included 140 pediatric patients (79,5%) diagnosed with mild TBI.
We extracted data covering the two years included in the CENTER-TBI database. On the other hand, the admission criteria and treatment level for trauma patients admitted to OUH have remained unchanged since the early 2000s, and the percentage of TBI in the total pediatric trauma population has been relatively stable for the last ten years (M. Hestnes, TR-OUS, email dated February 23rd, 2023). Therefore, generalizations from 2015-16 may be valid.

Papers II and III: Case–control and longitudinal studies [109]

The recruitment of hospitalized pediatric patients involves asking parents and patients in a vulnerable situation to participate, and participating in a study may be perceived as an extra burden that might lead to a lack of willingness to participate or pursue follow-up for some families (according to reported reasons from some of the families), possibly leading to self-selection bias; this might lead to the selection of resourceful families or families with high symptom burden.

Paper II: A case–control study[110]

Selection bias:

Selection bias may occur if the sample is not randomly selected from the population of interest. This can make the study sample less representative and reduce the validity of generalizations. There was selection bias in this paper due to the process by which participants were included in a busy hospital setting. Regarding logistics, we observed that nonincluded patients had short hospital stays (i.e., less than 24 hours) or were admitted during weekends and holidays.

Both cases and controls had parents with high educational levels (i.e., a mean of 17 years of education in the SI group and 16 years in the TBI group) [111]. The study sample reflects the characteristics of the southeastern region of Norway, which has primary urban areas. The exclusion of patients with language barriers also indicates selection bias, as this excludes immigrants and families that may have problems navigating the health and education system in Norway and, therefore, are at higher risk of experiencing unmet needs.

The modest size of our TBI group and its recruitment from a single center are clear limitations and threaten the generalizability of the findings. However, the sample seems to be representative of pediatric patients hospitalized with TBI in our region, as the boy:girl ratio, age range, and injury mechanisms corresponded with the results of Paper I.
We did not have a completely representative proportion of patients admitted to OUH with mild pTBI because it was easier to recruit patients with hospital stays longer than 24 hours. Furthermore, the inclusion criterion of a performed CT scan may have excluded some mildly injured patients. Compared to the nonincluded children hospitalized with TBI, the study patients were similar in age and sex distributions. However, the nonincluded patients had milder injuries, which resulted in early discharge.
The study had restrictions on the age range due to the CENTER-TBI study's definition of adult age, preventing us from including adolescents aged 16-18 years. This resulted in a narrower age span, with a smaller and narrower sample in terms of age than desired.

Controls should be selected to ensure that they represent the exposure distribution in the general population. We selected patients for the control group that matched the TBI group in terms of sex, age, and overall Injury Severity Score. Furthermore, they received a similar level of treatment at the same pediatric intensive care unit and pediatric surgical ward and resided in the same region of Norway. Both the TBI group and control group were hospitalized due to trauma. This may represent a form of Berkson's bias[112], i.e., selecting two groups affected by a disease, regarding the representability for the general pediatric population of the southeastern region of Norway. We believe that the selection of patients exposed to as similar conditions as possible in terms of severity grade and treatment level is a strength of this study, as this made it possible to control for the effect of experiencing hospitalization. Furthermore, we believe that it is logical to assume that both groups represent children with similar risky behaviors since they matched in terms of overall injury severity and treatment levels and trauma to the head or body is relatively random.

Paper III: Longitudinal study design [110]

There can be structural bias if the disease severity or treatment side effects prevent patients from continuing with follow-up visits. One patient from the TBI group and two patients from the SI group withdrew from follow-up due to the total burden on the family due to the injury's severity. In a small dataset, missing data are an important problem and represent bias by restricting the analyses to subjects with complete data.
The patients lost to follow-up in the TBI and control groups were relatively comparable in terms of severity, but there were more boys lost to follow-up in the control group.

Recall bias and use of questionnaires:

The recall period is essential, which is an increasing problem the younger the child is, with shorter recall periods in the youngest patients. Coombes et al. [113]. found that children under

eight years had problems understanding the concept of a week and that short recall periods led to better correlation of their own daily diary reports. Children under five years old cannot validly and reliably self-report health outcomes. Five- to seven-year-olds need dichotomous options for answers, and children over eight years can use a Likert scale [113].
Furthermore, recall bias depends on the characteristics of the disease (acute or chronic) and the duration of the study. In case–control studies, the cases are often more likely to recall exposure to risk factors than the controls [113]. We cannot rule out the possibility that this bias affected our study- and control groups.

Response bias/self-report bias and interviewer bias:
We used questionnaires and interviews where patients and parents responded separately. In studies, the interviewers′ expectations or opinions may interfere with their objectivity, and hints from the interviewers may influence the answers. To address this problem, we interviewed patients aged 5-7 years face to face, supported with a visual aid (emotional faces; happy, neutral, and sad) to secure the interpretation of the questions, accepting answers without interfering. Proxy reports from parents were used for children under five years old. Furthermore, self-report data can be influenced by the subjects' perspectives, views, and opinions; these might have influenced the self-reports of children and parents.
Interviewer training is important, and restricting the number of interviewers may minimize interrater diversity. In our study, the same pediatric neurologist conducted all interviews at all time points.

Social desirability:
Participants may select answers that they think are socially desirable. It is important to use age-validated questionnaires and, if possible, information from several informants (patients, caregivers, teachers). We used age-validated questionnaires and collected data from patients and caregivers separately when possible.

Confounding bias:
In longitudinal studies with children, they mature during the follow-up period. Emotional, cognitive, and physical problems are more common in adolescence and could interfere with the reporting of symptoms at follow-up. However, an age-related increase in reported symptoms would likely affect both groups, and we observed a systematic difference between the TBI and control groups at six months postinjury, which indicates that the control group had a better recovery than the TBI patients.

Ethical considerations

This study followed the principles for medical research involving human subjects defined by the Declaration of Helsinki [92]. Furthermore, it adhered to the restrictions on research on pediatric patients by the Regional Committee for Medical and Health Research. I will discuss ethical aspects considering these principles and restrictions.

We included pediatric patients. This implies considerations regarding the consent competence of the participants and age-appropriate information. The benefits, relevance and burden for the participants must also be considered.

The Declaration of Helsinki (HD) states principles for research on pediatric participants:

Principle 28 in the HD: *"When a potential research subject who is deemed incompetent is able to give assent to decisions about participation in research, the physician must seek that assent in addition to the consent of the legally authorized representative. The potential subject's dissent should be respected."*

The research subjects' own opinions and wishes should be taken into consideration. When the research subject is a child, his or her opinion should be given increasing weight with age.

Informed consent implies four elements:
1. Information elements:
    - Full information given
    - Full information understood
2. Consent elements:
    - Consent competence (legally and actual)
    - Voluntarily

Consent competence (legally and actual) and volunteering:
If a patient is under seven years of age, critically ill, or cognitively impaired, the caregivers may consent on the child's behalf without the correction of the child's opinion. Several of these elements may be present in the TBI population. If the TBI is severe, the impairment may be present for a short or long period (or even permanent). The patient was included through the consent provided by their caregivers. We obtained assent from the patients as soon as possible if the impairment was temporary. We excluded the patient if he or she dissented (n=6). We had the approval of the ethics committee to conduct study enrollment in this manner. We obtained consent according to local and national ethical and legal requirements. We presented written information to the caregivers and age-appropriate information to adolescents and children down to seven years of age. Children aged seven years and older provided their assent to participate in the study, and informed written consent was provided by the legal guardians of children of all ages. Under the age of seven, the children were provided age-appropriate information about the study.

Respect for participants:
Principle 23 in the HD: *"Every precaution must be taken to protect the privacy of research subjects and the confidentiality of their personal information and to minimize the impact of the study on their physical, mental, and social integrity."*
We followed national standards for data storage and secured privacy and confidentiality.

Vulnerable population research:
Principle 17 in the HD: "*Medical research involving a disadvantaged or vulnerable population or community is only justified if the research is responsive to the health needs and priorities of this population or community and if there is a reasonable likelihood that this population or community stands to benefit from the results of the research."*

We believe that this research was responsive to the health needs and priorities of this group of patients and that the pediatric TBI group stands to benefit from the results of our research.

There were limitations on child assessments by the Regional Committee for Medical and Health Research, as procedures requiring sedation were not advised if not indicated medically, leading to less use of neuroimaging than desired for scientific reasons among children under six years of age.

Clinical implications and suggestions for future research

There is insufficient knowledge of the epidemiological characteristics of the severity spectrum of pTBI in the southeastern region of Norway and the actual experience of patients in terms of planned follow-up and met vs. unmet needs. Studies are needed to map the unmet needs and rehabilitation needs of the pediatric TBI group so that health care services can be adapted accordingly.

Identifying patients in need of follow-up:

This study suggests factors that may identify patients with pTBI who need follow-up, such as an extended length of hospital stay due to continued symptom load after pTBI. This is especially relevant for the youngest patient group, as they seem to be prone to more severe ICI due to head injury than older children/adolescents. Awareness about these factors needs to be improved in clinical practice in wards treating these patients. After discharge, patients with persistent symptoms after TBI of any severity grade may need follow-up.

Follow-up and needs for improvement:

We also have identified steps in the rehabilitation trajectory that need improvement, namely, securing planned and continued follow-ups after pTBI and increasing knowledge of parents and the health care and educational systems about the long-term effects of pTBI. In the care pathway for pTBI for the southeastern region of Norway, we have seen these obstacles, such as services not provided in school settings due to a lack of information about brain injuries in childhood, problems with the continuation of accommodations in the long run, and scarcity of service for emotional/behavioral problems that may follow pTBI.

Planning follow-ups with neurological pediatricians seems beneficial, preferably in an interdisciplinary rehabilitation setting. Furthermore, it is essential to ensure follow-up over several years to ensure adequate accommodations and necessary referrals to health care and educational services. It is equally important to ensure the continuation of accommodations, as children face increasing challenges at school and in social interactions.

To facilitate the rehabilitation of pTBI patients, intervention studies and qualitative research are needed involving families experiencing long-term effects of childhood TBI; research should also explore ways to increase the interaction between the health care and educational systems, as kindergartens and schools are essential for rehabilitation.

In our health region, our research group is currently conducting a randomized controlled trial testing the efficacy of a goal-oriented rehabilitation program in the chronic phase of pediatric acquired brain injury. The study involves families and schools and includes qualitative research regarding acquired brain injury in childhood, the Child in Context Intervention (CICI) [114,115].

7. CONCLUSIONS

We need to pay attention to new social trends and focus on the youngest group when tailoring preventive measures against brain injuries in childhood. An improved plan is needed to identify pediatric patients with pTBI who need follow-up. We should increase knowledge of long-term symptoms after pTBI among parents, communities, and the health care and educational system. Follow-up should continue over several years for patients with lasting symptoms to ensure that accommodation to care and referrals are initiated and continued as the children face increasing challenges at school and in social interactions.

1. The incidence of hospitalization for pTBI in the southeastern region of Norway was low compared to that in most regions globally. Over the past ten years, the boy:girl ratio has changed in the southeastern region of Norway, suggesting that young adolescent girls might have a similar risk of pTBI as boys. This novel finding highlights the need to monitor changes in incidence rates and risk-taking behavior to tailor preventive measures to new social trends. Children aged seven years or younger seem to experience more severe ICI from trauma to the head. Emphasis on preventative measures for the youngest group may be needed. Home safety should be discussed when counseling parents of small, newly ambulating children, and the prevention of child abuse and neglect is important and should be implemented in health care and educational services for these children.

2. The severity of the injury, assessed by GCS scores and AIS scores/neuroimaging findings, combined with the duration of symptoms, must be considered when identifying which patients need follow-up and rehabilitation.
It is necessary to develop a systematic follow-up method for children and adolescents with TBIs of all grades of severity. Patients with cmTBI may be considered to have a good prognosis at discharge but experience symptoms that remain undetected if follow-up visits are not planned.

3. Many children in the TBI group experienced persistent cognitive and emotional symptoms that affected their return to school and subsequent social interaction. Nearly half reported unmet needs at six months. At 24 months, a quarter of the TBI group still reported unmet needs due to long-lasting problems with concentration, fatigue, and emotional symptoms. Thus, it is necessary to increase knowledge of long-term consequences among parents, communities, the health care, and educational system and continue follow-up over several years.

4. The long-lasting symptoms that led to unmet needs were associated with reduced quality of life. Interventions targeting the unmet needs of pTBI patients should be developed to improve functioning and health-related quality of life outcomes in this vulnerable population.

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9. PAPERS

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Epidemiology of traumatic brain injury in children 15 years and younger in South-Eastern Norway in 2015–16. Implications for prevention and follow-up needs

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ABSTRACT

Objective: This retrospective study aimed to describe the volume, severity, and injury mechanism of all hospital-admitted pediatric traumatic brain injury (pTBI) at Oslo University Hospital (OUH), emphasizing consequences for prevention and factors indicating a need for follow-up programs.
Method: Data were extracted from the OUH Trauma registry on 176 children, 0–15 years old, admitted to OUH in 2015 and 2016 with a pTBI diagnosis. The dataset contains demographic data, injury mechanism, type, and severity (Glasgow coma scale, GCS; abbreviated injury scale, AIS; injury severity score, ISS), ICD-10 diagnosis codes, level of treatment, and destination of discharge.
Results: 79.5% had mild, 9% moderate, and 11.4% severe TBI. The incidence of hospital-treated pTBI in Oslo was 29 per 100,000 per year. The boy: girl ratio was 1.9:1, but in the young teenage group (14–15 years), the ratio was 1:1. Intracranial injury (ICI) identified on CT/MRI was associated with extended hospital stays, with a median of 6 days compared to 1 day for patients without ICI. 27% of the patients assessed as mild TBI at admission had ICI. Children below eight years of age had a higher incidence of moderate and severe ICI from trauma (53% v.s. 28% in children $\geq$ eight years).
Conclusion: The injury characteristics of hospital-treated pTBI are in line with other European countries, but we find the boy-girl ratio different as young teenage girls seem to be catching up with the boys. ICI and length of stay should be considered when deciding which patients need follow-up and rehabilitation.

1. Introduction

Head injuries are the single most common and potentially most severe type of injury sustained by children worldwide [1], and traumatic brain injury (TBI) affects more than three million children every year [2]. Improvement in road and car-safety, mainly in high-income countries, has contributed to a decrease in hospitalized pediatric TBI (pTBI) patients. Still, falling remains the main

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reason for TBI for the youngest children, while sports accidents and motor vehicle accidents are predominant reasons for injury in older children and adolescents. TBI in children thus causes potentially preventable neurological disabilities [3].

TBI has been defined as an alteration in brain function or other brain pathology evidence, caused by an external force [4]. Traditionally, the severity of TBI is evaluated by the level of unconsciousness at injury time by the Glasgow coma scale (GCS). Mild TBI can be further classified as a complicated (presence of trauma-related intracranial abnormality) or uncomplicated (absence of any traumatic intracranial injury) [5]. The abbreviated injury scale (AIS) can estimate brain injury severity by the grade of anatomic brain injury based on neuroimaging and clinical features [6]. However, the AIS is only occasionally used for the severity designation in epidemiological pTBI studies.

TBI represents a substantial challenge for the health care system due to the heterogeneity in the causes of injury, severity, and prognosis. There is great diversity regarding the outcome, and long-term treatment needs [7,8]. Compared to their adult counterparts, children with TBI warrant particular concern given the developmental consequences of early brain damage [2]. Previous studies have shown that younger age is associated with more severe outcomes following TBI, which is most pronounced for severe injuries [9].

Many studies report a male predominance for children in all age groups above three years of age and a bimodal distribution of pTBI in different age groups, with the most significant injury occurring in the very young and the teenage group [2,10]. Collin et al. refer to a significant gender difference existing from infancy, with male predominance regarding injury mechanism, mortality rates, and lack of use of protective devices [11].

A global overview of pTBI reported a median age of 6.8 years. Mild TBI constituted >80% of the cases, and severe TBI accounted for 3–7%. The mortality rate ranged from 1-7% [2]. The incidence of hospital admitted pTBI patients showed diversity, based on different inclusion of admission criteria. The incidences vary from 12 per 100 000 in Sweden to 70–75 per 100 000 in the United States [2] and in Australia [12]. In a recent European study, the main reason for pTBI admission in the intensive care unit (ICU) was road traffic incidents. Accidental falls were the most frequent cause of injury in the children admitted to a hospital ward [13].

Many studies over the past decade have provided valuable information about the epidemiology, outcome, and health care needs following adult TBI in Norway and formed the basis for improved clinical management and rehabilitation services for adults with TBI [14–16]. Studies by Heskestadet al. and Andelic et al. looked at the TBI incidence for all ages in the Stavanger region (the South-Western part of Norway) in 2009 [17], and hospitalized TBI patients from the capital of Norway, Oslo in 2005/2006, respectively [14]. Few studies have, however, addressed the Norwegian pTBI population. One exception is a study by Olsen et al. [18], which estimated the incidence and mortality of moderate and severe pTBI (71 patients 0–16 years of age) from 2004-2014 for Mid-Norway. The incidence estimates were 2.4 and 2.5 per 100 000 inhabitants for moderate and severe pTBI, respectively.

None of these studies have focused on pTBI of all severity levels. It would be helpful to have updated knowledge about all pTBI related hospitalization to understand the extent of brain injury of all severity levels and identifying the high-risk groups in the child population. Studies from Norway may be of international interest because of a well-organized public trauma system with a highly developed infrastructure enabling pTBI patients to be transferred to the trauma centers for definitive treatment and a publicly funded welfare and -healthcare system. Still, there are deficiencies in the follow-up after hospital care since neurorehabilitation healthcare for children is less developed than the offer for the adult population nationwide. More detailed knowledge of all severity levels of pTBI would help provide an essential indicator of the impact of injuries on hospital resources, thereby enable improved plans for acute and post-acute pTBI care systems.

1.1. Objectives

This study's main objective was to investigate the volume and burden of hospital-admitted pediatric TBI by describing incidence and injury characteristics, including injury mechanism and distribution of all severity levels of pediatric TBI in the South East region of Norway. Based on previous studies stating that younger age is associated with worse cognitive outcomes following TBI [9,19]' we also explored age effects on injury mechanism and level of intracranial injury (ICI). An additional aim was to assess which factors are associated with the hospitalization duration and a likely need for follow-up programs and rehabilitation.

2. Methods

2.1. Study region

Oslo University Hospital (OUH) is the primary hospital for Oslo's pediatric population and a Trauma Referral Hospital for the South East region of Norway. This region comprises 57 % (2,9 million of the population of Norway [20], and approximately 570 000 children 0–15 years of age [21]. All children residing in Oslo that suffer from a TBI, including those presenting with signs of concussion and clinical indication for computerized tomography (CT) scan or short -time (6–24 h) observation, are referred to OUH. Also, patients with TBI in need of neurosurgical evaluation or treatment from the South-Eastern region residing outside of Oslo are referred directly to OUH. Patients with mild TBI residing outside of Oslo are usually admitted to their local hospital for observation. We had oversight over pTBI of all severity grades for Oslo residents, and the incidence is therefore estimated separately for Oslo.

2.2. Data source

Data were extracted from the Trauma registry at OUH (TR-OUS) from January 2015 through December 2016. TR-OUS includes all patients admitted with all traumas that trigger the trauma team activation or have an Injury Severity Score (ISS) of 9 or higher (moderate to severe injuries). A certified AIS specialist with access to medical records has manually coded the AIS-08 scores.

2.2.1. Inclusion

The dataset included hospital-admitted pTBI at OUH from 1 January 2015 to 31 December 2016, selected by AIS 2008: AIS head ≥1 and age group 0 years up to and including 15 years of age. AIS head ≥1 extracts all patients registered with a head injury, regardless of GCS and ICD-10 diagnosis codes.

The extracted data set contains age, sex, municipality, date and time of accident and discharge, location of the injury, injury mechanism and severity (GCS [6], AIS [6], ISS [6]), all diagnosis codes and procedure codes (ICD-10) during the hospital stay, level of hospital treatment and transition of care (admission to ICU or ward), length of hospital stay and destination of discharge. GCS is based on clinical examination bedside: assessing best eye, verbal, and motor response. GCS is scaled by the following classification: mild (GCS 13–15), moderate (GCS 9–12), and severe TBI (GCS 3–8) [6]. The GCS value was recorded at arrival time in the hospital, mostly at triage in the emergency department. Pediatric GCS was used for infants and toddlers [22].

AIS head is an anatomic brain injury severity score based on CT or magnetic resonance imaging (MRI), operative, and autopsy findings. The score can not be calculated at the scene of trauma and requires a manual review of the patient's medical record. AIS code is by description divided in 1:minor, 2: moderate, 3: serious, 4: severe, 5: critical, 6: maximal (currently untreatable) [23]. In the literature, grade 1–2 has been categorized as mild TBI, 3–4 as moderate, and 5–6 as severe TBI [6].The AIS-08 scores define cerebral concussion grade 1 as mild concussion, no loss of consciousness (LOC), and grade 2 concussion with brief (observed) LOC. All intracranial injury is categorized in grade 3 and above, except tiny brain contusions and lacerations and intracranial extracerebral hemorrhage (grade 2). Overall injury severity was assessed ISS. The ISS severity is categorized as <9 (minor), 9–15 (serious), 16–24 (severe), 25–75 (critical). ISS is calculated by taking the highest AIS from the three most severely injured body regions, square each, and add these numbers [6]. There are six body regions in all (head, face, thorax, abdomen, extremities, and external/other). There is one exception: If AIS is 6, the number is not squared but gives ISS 75 points directly.

Traditionally the GCS [6] defines the injury severity evaluated by the level of unconsciousness at injury time or later. Mild TBI has been classified as a complicated mild TBI (presence of trauma-related intracranial abnormality) or uncomplicated (absence of any traumatic intracranial injury) [5]. AIS head is a consensus-derived, global severity scoring system for assessing TBI severity, based on medical records and radiology. AIS head can be used to approximate the definition of brain injury severity [3]. ISS is an internationally recognized anatomical scoring system for overall trauma severity [24]. Brown et al. found that the ISS is less predictive of mortality in children than in adults, and that level of AIS head is most important regarding predicting severe outcomes and mortality in children [24]. A comparison of AIS head and GCS scores as indicators of brain injury severity in retrospective data has shown that AIS and GCS are more highly inter-correlated when a brain injury is severe, but in mild and moderate cases of brain injury, AIS is less predictive of the GCS value [6].

2.2.2. Statistical analysis

The incidence of hospitalized pTBI patients residing in Oslo was calculated based on information from Statistic Norway [25] on the pediatric population of Oslo in 2015/2016: 234.471 people aged 0–15 years as the denominator, and new cases of pTBI registered in TR-OUS, as the numerator. The chi-squared test was used to compare the boy: girl ratio in each of the other age groups to the oldest group. Medians and interquartile range (IQR) were used in Table 1 to describe mild, moderate, and severe pTBI by age at injury, and describe GCS, AIS head, ISS, and hospital stay in Table 2. When comparing GCS and AIS head scores combined in the youngest (0–7 years of age) to the eldest (8–15 years of age) group, we used the Mann-Whitney U test (Table 3). We used the Chi-Square test when analyzing combined values for the site of injury, CT at admission, and CT/MRI findings for the youngest and eldest group. The Mann-Whitney U test was used to compare the length of hospital stay for mild TBI with or without CT/MRI pathology.

All statistical analyses were performed with IBM SPSS Statistics, version 26 (IBM Corp.Armonk, N.Y., USA, 2019).

3. Results

The Trauma Registry recorded 306 patients aged 0–15 years in 2015 and 2016. Approximately one-third of these, i.e., 90 (29%) and 86 (28%), respectively, were admitted with a head injury had a head injury (AIS head ≥ 1). Of these 176 children, two patients had AIS = 1 with scalp injury only.

The 176 children were classified by GCS at admission, and 140 (79.5%) had a mild TBI (GCS 13–15). Of the mild TBI group, 27% had complicated mild TBI (ICI on MRI), and 14% had skull fractures (Fig. 1). 16 (9%) had a moderate TBI (GCS 9–12) and 20 (11.4%) had severe TBI (GCS 3–8). Three patients (1.7%) died within 24 h after admission. When classified by AIS head, 108 (61%) had mild TBI (AIS head ≤ 2), and 68 patients (39%), i.e., 19% more than bases on GCS), had moderate and severe TBI (AIS head ≥ 3). The median age was 10 years (CI ± 0.73).

3.1. Incidence

Of the 176 patients, 68 (38.6%) were residents of Oslo. 93 patients (52.8%) were admitted from other parts of the South-Eastern health region of Norway, and 15 patients (8.5%) were either from elsewhere in Norway or from other countries.

The incidence of hospitalized patients with pTBI residing in Oslo 2015/16 was 29 per 100 000 per year. For mild pTBI, the incidence assessed by GCS 13–15 (n = 60) was 25.6 pr 100 000 per year, and by AIS head < 3 (n = 51) was 21.8 per100 000 per year. For moderate and severe pTBI evaluated by GCS ≤12 (n = 8), the incidence was 3.4 per 100 000 per year, while assessed by AIS head ≥ 3 (n = 17), the incidence was 7.3 per 100 000 per year.

3.2. Boy: girl ratio

The overall boy: girl ratio in this sample was 1.9:1. The ratio was approximately 2.4:1 in all age groups other than the oldest group (14–15 years), where the ratio was 1:1. The lack of male predominance in the teenage group (14–15 years of age) was specific for this age group, as the ratio differed significantly from all other groups (Table 1).

3.3. Injury characteristics

3.3.1. GCS and AIS

When divided into severity levels by GCS evaluation at admission, all groups had a proportion of patients with ICI and patients without any neuroradiological findings. Even in the severe TBI group, 20% of patients were without ICI. In the group defined as mild TBI at admission, 27% had ICI on MRI, and 14% had isolated fractures in the skull or the facial bones (Fig. 1)

Twenty-eight of the patients had no CT scan at arrival. Of these, 25 patients had an MRI performed later during their hospitalization. Twenty-one of these had mild TBI assessed by GCS (13–15), of which MRI scans showed pathology corresponding to moderate TBI as categorized by AIS head (score 3 or 4) in 16 patients, and severe TBI in two patients (AIS head 5) (Table 3). Among these were four of five toddlers exposed to intentional injury (Table 2).

3.3.2. Mechanism of injury

The leading cause of TBI among children admitted to OUH was falls (49%).Transportation accidents contributed to 31% of pTBI, mainly due to falling off a bike or being hit by a car or bicycle as a

Table 1
Boy:girl ratio by age groups.

Age (years)	Total number (boys/girls)	Boy: Girl ratio	p value
0–4	41 (29/12)	2.4:1	0.049
5–9	45 (32/13)	2.5:1	0.039
10–13	44 (31/13)	2.4:1	0.048
14–15	46 (23/23)	1:1 (ref)	

The p-value for chi-square tests comparing the boy: girl ratio of each of the younger groups to the 14–15 year group (ref = reference group).

Table 2
Demographic and injury characteristics in the sample according to injury severity estimated at admission.

Assessed by GCS:	Mild TBI	Moderate TBI	Severe TBI
	n = 140	n = 16	n = 20
	Median [IQR]	Median [IQR]	Median [IQR]
Age at injury (years)	10 [5.0, 14.0]	10 [5.0, 13.5]	8 [4.25, 13.25]
Gender (boy / girl)	93 / 47	10 / 6	12 / 8
GCS	15 [14.0, 15.0]	11.5 [10.0, 12.0]	6 [4.25, 7.0]
AIS head	2.0 [1.0, 3.0]	2.5 [1.0, 3.0]	5 [3.0, 5.0]
ISS	5 [2.0, 10.0]	7 [1.25, 21.25]	25 [9.0, 26.0]
Hospital stay (days)	1 [1.0, 4.0]	3 [1.0, 15.75]	10 [2.0, 30.75]
Site of injury (n)			
Domestic	29	2	4
Indoors	9	0	2
Outdoors	102	14	14
Mechanism of injury (n)			
Traffic accident	43	8	4
Fall	68	7	12
Violence	8	0	1
Other	21	1	3
Discharge (n)			
Home	131	13	11
Rehab unit	1	3	5
Other care	8	0	1
Dead	0	0	3

GCS = Glasgow coma scale, AIS = abbreviated injury scalerehab unit = rehabilitation other care = primary hospital, alternative care, dead other mechanisms = accidents in sports, a massive object falling over the child, sledding accidents.

pedestrian. The violence group consisted of children 0–2 years old exposed to intentional injury and boys between 9 and 15 years of age assaulted by peers (Table 3).

3.3.3. Mechanism causing the most severe TBIs

Of the total patients, 174 had blunt head traumas, while only two had penetrating head trauma. Fall was a leading contributor to severe injuries (Table 2).

To estimate the mechanisms leading to the most severe injuries, we looked at the 17 patients with brain injury classified to 5–6 (critical, maximal) as assessed by AIS head (Table 3). The group had GCS ranking from 3-15, including 11 patients with GCS 3–8 (severe). ISS scores varied from 25-75 (severe, mainly multi-trauma patients), with a mean of 32,5. Transport accidents ($n = 5$) leading to severe TBI were high energy trauma involving car accidents (passenger or hit by a car), horseback riding, skateboard, and electric bicycle accidents. Falls ($n = 9$) were divided into being caused by fall from over 2 m or lower falls with an impact on hard surfaces in the age group 2–8 years, and accidents with falls in alpine slopes for the teenagers. Other reasons ($n = 3$) were fatal accidents during play and intentional injury (Table 3).

3.3.4. Length of stay and discharge

Of the 176 TBI patients, three died within 24 h after admission. Length of stay (LOS) varied from 0 – 84 days, with 103 patients (59%) were discharged within the second day. LOS was over 7 days for 18 % of the patients. The mean LOS for all 176 patients was 5,8 days (SD 10,7), with a median of 2 days (CI ± 1.6).

Patients with ICI, as demonstrated by CT or MRI-scans, had a median LOS of 6 days, regardless of injury severity. Even children with mild TBI, estimated by GCS at admission, but with confirmed ICI (complicated mild TBI), had more prolonged hospital stays compared to those with mild TBI with normal neuroimaging (uncomplicated mild TBI) ($p < 0.001$). The median LOS was 4 days (IQR 2.5–7.5) for the patients with pathology and 1 day (IQR 1.0–1.0) for the ones without pathology (Fig. 2).

The majority of the patients, 155 (89%), were discharged to their homes. Nine patients (5%) were transferred to a specialized rehabilitation unit with services for children. Due to additional orthopedic injuries or familial considerations, seven patients (4%) were transferred to their local hospital. (Table 3).

3.4. Difference between the youngest and eldest group

The proportion of moderate and severe TBI (AIS ≥ 3) in the youngest group was 53% compared to 28% in the oldest group (Table 3). In all age groups, up to 13 years, boys were more exposed to head injuries regardless of injury mechanisms. However, in the adolescent group (14–15 years of age), there was no difference between the genders (Table 1).

4. Discussion

4.1. Incidence

The incidence of pTBI in Oslo was comparable with other Scandinavian studies [2,18,26] . Our results may reflect that the Scandinavian focus on road safety and the use of safety equipment has resulted in lower incidences than other parts of the world [2]. Still, known preventable mechanism of injury contributed to severe pTBI.

4.2. Boy: girl ratio

A large body of studies has described a male predominance for pTBI. The European study of TBI patients 0–18 years old included patients from Norway, found a boy: girl ratio of 1,7:1 [13]. Finland reported a male predomination of 1.5:1 in 2012 in patients under 18 years of age [26]. We found that the boy-girl ratio in our sample was 1.9:1. In 2005–2006, male predomination was 1.2:1 among children residing in Oslo, and the difference between the genders was most prominent in the young teenage group (10–14 years of age) [14].

In our sample 10 years later, the pattern is different and indicates that young teenage girls might be catching up with the boys in exposure to TBI. The injury mechanisms may suggest that young adolescent girls were engaged in high energy activities more in line with teenage boys in our study. The teenage girls had more falls and got more head injuries in a contact sport, the latter in line with a recently published review by Arambra et al. [10]. However, they were less involved in transport accidents (notably bicycle) than adolescent boys. Only girls acquired their head injury by horseback riding, and only teenage boys were involved in violent episodes. This gender difference in injury mechanism resembles Collin et al.'s findings, but the changes in risk-taking behavior in young teenaged girls indicate that we need to change focus on adolescent groups at risk of TBI [11].

Our study had a slightly higher male predominance for the children under 13 years of age than reported in other European studies. Many studies report a bimodal distribution of pTBI in different age groups, with the most significant injury occurring in the very young and teenage groups [2,10]. In our study, the distribution is steadily increasing in frequency of pTBI from 2 years old to the teenagers, mainly contributed to boys with TBI from falls and traffic accidents.

4.3. Severity grades

Our results are in line with existing literature, with 80% mild TBI assessed by GCS [2]. The occurrence of complicated mild TBI and skull fractures was slightly higher than referred by Hansen et al. [5].

Table 3
Injury characteristics of the youngest versus the oldest groups.

	0–7 years (n = 74)	8–15 years (n = 102)	p value
GCS 13-15	57 (77%)	83 (81.4%)	0.282
GCS 9-12	8 (11%)	8 (7.8%)	
GCS 3-8	9 (12%)	11(10.8%)	
AIS head 1-2	35 (47%)	73 (72%)	0.002
AIS head 3-4	30 (41%)	21 (20.5%)	
AIS head 5-6	9 (12%)	8 (7.8%)	
CT at admission			
Normal	31 (42%)	65 (64%)	0.059
Intracranial injury	25 (34%)	27 (26%)	
CT at admission not performed	18 (24%)	10 (10%)	0.009
CT/MRI findings			
Normal	27 (36%)	65 (63%)	<0.001
Intracranial injury	47 (63%)	34 (33%)	
Neuroimaging not performed	0	3 (3%)	–
Site of injury			
Domestic	27 (36.5%)	8 (7.8%)	<0.001
Indoors	2 (3%)	9 (8.8%)	
Outdoors	45(60.8%)	85 (83.3%)	
Mechanism of injury			
Traffic accident, n = 55 (31%)	17 (23%)	38 (37%)	
Pedestrian hit by car/bike/bus	6	8	
Biker* hit by car/bus	1	5	
Riding a bike*	4	21	
Passenger	6	4	
Fall, n = 87 (49%)	42 (57%)	44 (43%)	
Sport/leisure	0	22	
Domestic	15	5	
Outdoors	12	9	
>2 m	15	8	
Violence, n = 9 (5%)	5 (7%)	4 (4%)	
Other mechanism, n = 26 (15%)	10 (14%)	16 (16%)	
Accidents sport	1	6	
Object falling over	2	4	
Blunt trauma during sport/play	1	4	
Sledding accidents	4	2	
Penetrating injury	2	0	
Discharged to			
Home	67 (91%)	88 (86%)	
Other hospitals	3	4	
Rehab	1	8	
Other care	2	0	
Dead	1	2	

GCS = Glasgow coma scale, AIS = abbreviated injury scale; p-value for 0–7 v.s. 8–15 from the Mann-Whitney U test (combined analyzes of GCS and AIS head) and the chi-square test (combined analyzes for the site of injury, CT at admission, and CT/MR findings).

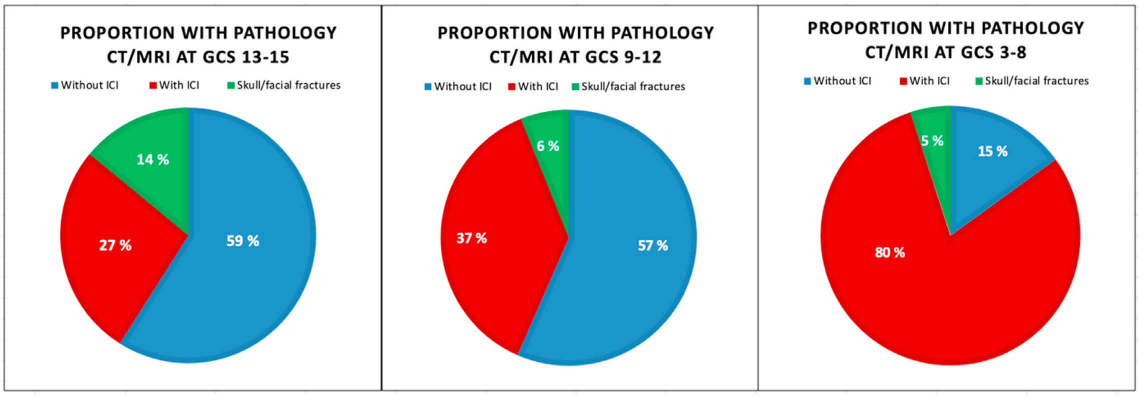

Fig. 1. Neuroradiology in all TBI severity levels in CT and MRI.
The proportion of neuroradiological findings of ICI v.s. skull/facial fractures v.s. no intracranial pathology at three severity levels according to GCS.
(ICI = intracranial injury, CT = computerized tomography, MRI = magnetic resonance imaging)

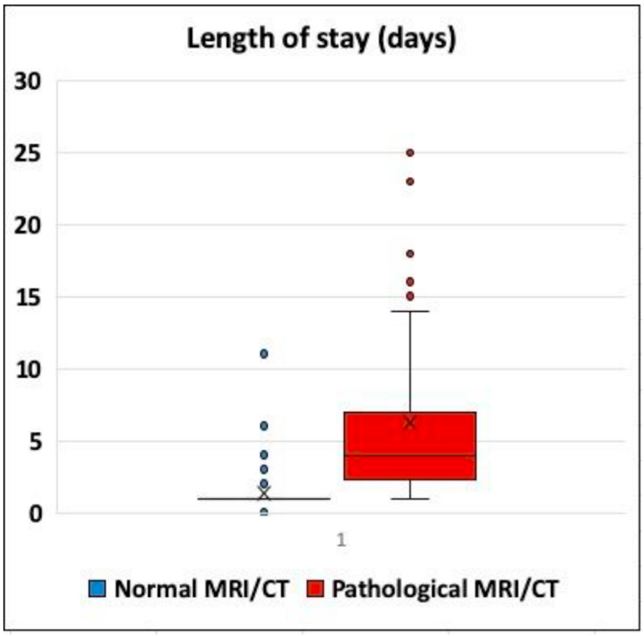

Fig. 2. Length of stay by intracranial injury in mild pTBI.
Mann-Whitney U test was used to compare the length of hospital stay in days for mild pTBI with or without MRI/CT pathology. A horizontal line represents the Median. The Mean is represented by x. MRI = magnetic resonance imaging, CT = computerized tomography.

The proportion of severe injuries was slightly higher since OUH is a trauma referral center; thus, more severe TBI patients were transferred to OUH from other hospitals in the region.

Severity distribution was somewhat different if assessed by AIS head, characterizing 61% as mild TBI (AIS head 1-2). The severe TBI assessment was similar using GCS and AIS head (11.4% v.s. 10%), confirming that these instruments provide more similar results for severe brain injuries [6].

Thirty-three (19%) of the patients had multi-trauma injuries (ISS $\geq$ 16), probably impacting the length of hospital stay, especially on the most extensive admissions. The proportion of multi-trauma is relatively lower than stated in other studies [24,27].

4.4. *Differences between the youngest and eldest group*

The severity grade estimated by the AIS head in the current sample was significantly different between the youngest group (0–7 years) and the oldest group (8–15 years), with a higher rate of moderate and severe ICI in the youngest group. These findings indicate that younger children are prone to more severe structural injuries by trauma to the head. This result points to a particular need for radiological follow-up for this group.

The children under 7 years of age were injured primarily by falls from heights, the group under four years, mainly at home and indoors. The more independent mobile group (5–7 years) were roadside pedestrians or passengers in road accidents, coinciding with findings in other studies [3,13,28]. Fall in sport or leisure activities is only occurring in the older group (Table 3), with alpine accidents being a significant contributor.

4.5. *Which TBI patients require admission, and who need follow-up?*

Pediatric patients with severe TBI are all admitted for observation and treatment, but only some of them have established rehabilitation plans at discharge. One-fifth (20%) of our sample was classified as moderate and severe TBI at admission. Of these, only a minority were transferred to a rehabilitation unit for children. Of the group of mild TBI classified by GCS at admission, 27% had ICI confirmed during admission, for some changing the severity grade assessment. One in this group was considered to need specialized neurorehabilitation.

In Norway, neurorehabilitation in health care for children is less developed than in the adult population, especially for children under 6 years of age, which is probably a contributing factor in the current discharge practices. Besides, there might be less attention to a possible need for follow-up or rehabilitation for pediatric patients, especially for the youngest age group. There is a need for future studies surveying uncovered rehabilitation needs for the pediatric TBI group so that the healthcare services can be adjusted accordingly.

The Scandinavian guidelines for mild and moderate pTBI [29] recommend that children with mild TBI, but high-risk trauma, should be admitted for observation regardless of a normal head CT. Children under 1 year of age should be admitted after head injury regardless of symptoms [29]. A large number of pTBI patients observed in the hospital will, therefore, have mild and moderate TBIs. The challenge is to decide, based on the right criteria, which patients would benefit from follow-up after discharge.

4.5.1. *Assessment of need for follow-up*

There has been a discussion regarding the use of CT scans for the age group 0–4 years, as they are more sensitive to radiation-induced malignancies [30]. As a result, there has been a focus on limiting CT scans for the youngest patients. Instead, we are observing them as an in-patient [29]. In this sample, a group of patients with no CT scan at admission had later findings of moderate to severe ICI on MRI, including 30% of the patients in the 1–4 year age group, compared to 7% for the children >9 years old. This probably indicates a more restrictive approach in the use of CT scans for the toddlers in line with the Scandinavian guidelines. Consequently, this may lead to overlooking intracranial injuries of significance. Of note, among the toddlers exposed to child abuse, the majority had high GCS scores at admission but moderate and severe ICI on neuroradiology.

This study's results indicate that GCS at admission alone does not point to which patient requires prolonged observation or follow-up. The course and duration of head injury-related symptoms, such as headaches, fatigue, light and sound sensitivity, or post-traumatic amnesia symptoms during the hospital stay, should also be considered. pTBI of all severity grades with pathology on MRI stayed for 2 days or more. This may suggest that patients categorized with GCS 13–15 at admission with symptoms lasting more than 48 h may need neuroimaging to assess a potential ICI.

The findings also suggest that the youngest age group was more prone to more severe ICI by head trauma. Several studies show that a proportion of patients with mild TBI do not recover without long-term problems [8] and may benefit from follow-up and plans for a stepwise return to school and sports. Furthermore, a recent study showed that early psychoeducation might be beneficial for children with mTBI [31]

Therefore, it might be advisable to have a continuous rehabilitation pathway for pediatric patients with TBI adjusted to provide individualized treatment and follow-up for all pediatric patients with ICI or prolonged symptoms following TBI of all severity grades.

4.6. *Strengths and limitations*

We consider using the Trauma Registry (TR-OUS) data to be a strength of this study. TR-OUS is the most systematic and consistent source of information on patients with TBI, systematizing information from medical records, and neuroimaging prospectively. We chose AIS head as selection criteria since ICD10 codes, in clinical care and especially emergency departments, is considered to be an inaccurate way of defining TBI severity [3]. This inclusion strategy, including AIS head ≥1, has made it likely that almost all pTBI admitted to the hospital were included. Thus, we believe we have a representative sample regarding all severity levels of pTBI from Oslo. OUS is the only trauma referral hospital with neurosurgical services in the region for over 50 % of the Norwegian population, and our findings of severe injuries may, therefore, be representative of the most populated part of Norway.

Moreover, at OUH, the admission criteria, triage, and treatment level for pTBI had remained unchanged since the early 2000s, before Andelic et al. conducted their study on a comparable population in 2005–2006 at the OUH. We, therefore, had the opportunity to compare the incidence of pTBI and the male: female ratio with historical data.

A limitation is that we did not have access to information regarding patients age 16–18 years.This made a comparison with other studies for the oldest teenagers difficult. We did not have a register including all patients with mild and possibly also moderate TBI who were admitted at other hospitals in the South-Eastern region of Norway and, therefore, could not indicate the incidence for the whole region. A retrospective design is a limitation, but we find that the Trauma Registry's stringent and unchanged inclusion criteria limit these disadvantages.

5. Conclusion

The incidence of hospital-treated pTBI was low compared to most regions globally, but still, many of the TBIs in childhood may be preventable. We found that the boy: girl ratio has been altered over the past ten years in the South-Eastern region of Norway, suggesting that young teenage girls might be catching up with the boys in TBI exposure. This novel finding highlights that we need to monitor changes in incidences and risk-taking behavior to tailor preventive measures to new social trends.

Children aged seven years old or younger seem to get more severe ICI from trauma to the head and might need a particular focus regarding prevention measures and follow-up.

There may also be a reason to maintain and emphasize the discussion on prevention measures for the youngest group. Counseling parents on fall accidents in the newly ambulating small toddlers and road safety may increase awareness of this problem. The severe consequences of abusive head injuries in the youngest also emphasize the importance of preventing child abuse and neglect [32]. The severity of the injury, assessed by GCS and AIS/neuroimaging, combined with the duration of symptoms, must be considered when evaluating which patients need follow-up and rehabilitation. It might be advisable to provide individualized treatment and follow-up for all pediatric patients with ICI or prolonged symptoms following TBI of all severity grades. However, neurorehabilitation healthcare for children is less developed than for the adult population, and sequelae may be overlooked. There is a need for future studies surveying uncovered rehabilitation needs for the pTBI group to adjust the health services as needed.

Declaration of competing interest

none.

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NURTURING THE CHILD

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ORIGINAL ARTICLE

Almost half of children and adolescents had unmet need 6 months after their traumatic brain injury

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Abstract

Aim: Very few studies have focused on how children with traumatic brain injuries (TBI) access and use publicly funded healthcare and educational services. We aimed to compare the symptoms, recovery and service use of children with TBIs and a control group with other traumatic injuries.

Methods: This case–control study was conducted at Oslo University Hospital, Norway, from 2015 to 2020. It focused on 49 patients aged 1–15 years who were hospitalised with TBIs and compared them with 51 matched patients with other traumatic injuries. Unmet needs were based on reports from parents, patients and clinicians 6 months after the injury.

Results: Many children hospitalised after TBIs experienced persistent cognitive and emotional symptoms that effected their return to school and subsequent social interactions. These were associated with reduced quality of life. Nearly half (47%) of the children in the TBI group had unmet needs after 6 months, compared to 12% of the controls. Patients with TBIs also had more symptoms and showed less favourable recoveries than the controls.

Conclusion: Paediatric patients with TBIs had long-term cognitive and emotional symptoms that affected their return to school and social functioning. Almost half of them had unmet needs 6 months after their acute injury.

KEYWORDS
healthcare use, post-concussion symptoms, quality of life, recovery, traumatic brain injury

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Abbreviations: GCS, Glasgow Coma Scale; GOS-E, The Glasgow Outcome Scale Extended.

1 | INTRODUCTION

A traumatic brain injury (TBI) in childhood and adolescence may cause persistent functional, cognitive, behavioural and psychosocial impairments.[1,2] These can affect mental health, school performance, social participation and health-related quality of life.[3] An early TBI may cause developmental consequences and entail vulnerability to long-term sequelae.[1,4] Knowledge about the positive effects of rehabilitation services on patient outcomes is increasing.[1,5] However, studies have also recently described unmet needs regarding rehabilitation services for paediatric patients hospitalised with a TBI.[6,7]

Like adult TBIs, paediatric TBI are primarily mild in approximately 80% of the cases, while severe cases account for 3–7% of TBIs when they are classified using the Glasgow Coma Scale (GCS).[4] Research from Hansen et al.[8] reported that there were two types of mild TBI. Uncomplicated TBI was the absence of any traumatic intracranial injury on neuroimaging. Complicated mild TBI was the presence of a traumatic intracranial injury: depressed skull fracture, haemorrhage, contusion or oedema.[8] Studies have found similar symptom load in patients with moderate TBIs and complicated mild TBIs.[2,9] One study found that 27% of children hospitalised with mild TBIs had complicated mild TBIs.[10] The complicated mild rate was 41% in another study of hospitalised children with mild TBIs who required a head computer tomography scan after their injury.[11]

Fuentes et al.[6] found a higher likelihood of unmet needs in patients with complicated mild TBIs, mainly due to a lack of mental health and educational and physiatry services. In contrast, children with a severe TBI usually made more regular use of healthcare services. Even patients with a mild TBI risk developing behavioural and social problems.[12]

Other studies have described family factors that predicted unmet health care services after a paediatric TBI. These included socioeconomic status, ethnicity, insurance status, and low-income and family functioning.[3,6,13] These studies were mainly conducted in the USA and reported that families with commercial insurance coverage were most likely to receive outpatient follow-ups and educational adjustments following a TBI in childhood.[12] In Norway, where this study was carried out, the healthcare system is publicly financed and aims to provide universally accessible healthcare. This includes rehabilitation and psychiatric and educational services for children. As far as we know, Norway and the USA share similar goals for the multidisciplinary rehabilitation practices offered by healthcare- and special education services.[12] However, their accessibility and use may differ in countries with privately and publicly financed healthcare systems. In Norway, healthcare is divided into hospital-based specialist care and outpatient clinics, rehabilitation units and community care. Educational services are organised independently of the healthcare system. Although the overall aim is to provide equal and adequate care for all, the transition between different services is not seamless and children and adolescents may still have unmet needs.

One Norwegian study on the adults with TBIs showed that nearly a third (31%) had unmet emotional, vocational and cognitive needs 5 years after their acute hospitalisation.[14] There is a lack of knowledge about how paediatric patients with TBIs, and their families, access and use healthcare and educational services in a publicly funded healthcare system.

The aim of this study was to compare the symptoms and impairment caused by paediatric TBIs, including recovery and the effect that they had on health-related quality of life and the use of healthcare services. We compared children and adolescents aged 1–15 years with a TBI to matched controls 6 months after hospitalisation. The controls were children hospitalised with other traumatic injuries of a similar overall severity. This comparison enabled us to investigate whether paediatric patients with TBIs had specific unmet healthcare needs.

Key Notes

- We compared the symptoms, recovery and service use of 49 children aged 1–15 years with traumatic brain injuries (TBIs) and 51 matched controls with other traumatic injuries.
- TBI patients had long-term cognitive and emotional symptoms that affected their return to school, social functioning, quality of life and recovery.
- Almost half (47%) had unmet needs 6 months after their acute injury, which was considerably higher than the controls (12%).

2 | METHODS

2.1 | Study site

This study was conducted at Oslo University Hospital, which is the main hospital for Oslo's paediatric population and a level 1 trauma referral hospital for the Southeast region of Norway. The region covers 57% of the Norwegian population[15] and serves approximately 570 000 children aged 0–15 years.[16]

2.2 | Study participants

The TBI group was a paediatric extension of the CENTER-TBI study carried out at the Oslo site. The CENTER-TBI study was a multicentre, prospective, longitudinal observational study conducted in Europe and Israel. The core study covered all spectrums of TBI severity, namely, mild, moderate and severe, and comprised 4506 patients of all ages who attended 65 centres.[17] Patients were included from January 2015 to December 2016. The inclusion criteria for the paediatric extension at the Oslo site were children aged 1–15 years with a clinical diagnosis of a TBI who were admitted to a local medical facility within 24 h of a TBI. Computed tomography scanning was performed. We obtained informed consent from the parents and assent from the patients, in line with local and national ethical and legal requirements. The exclusion criteria were preexisting neurological, psychiatric or neurodevelopmental disorders that might have affected the outcome assessments and insurmountable language barriers. Patients living outside the Southeast region of Norway were also excluded.[18] This article reports data from the acute phase and the 6-month follow-up.

We identified and assessed 95 patients with a TBI for inclusion, 52 agreed to participate, and 49 of these patients completed the 6-month follow-up, as two patients withdrew and one did not attend the control visits. The 43 patients who were not included were had premorbid conditions, were tourists and/or were patients who were lost to inclusion due to logistical reasons (Figure 1). The 49 included patients (61% male) ranged from 1 to 15 years of age, with a mean age of 9.6 years (Table 1).

A second group was recruited to control for being injured and hospitalised in childhood. The group comprised 51 children and adolescents hospitalised with other traumatic injuries of a similar overall severity. These were mainly traumatic orthopaedic and abdominal injuries without a head injury. The controls were recruited from the paediatric intensive care unit and the paediatric surgical ward from December 2018 to January 2020.

The control group was matched with the TBI group by sex, age and overall injury severity score.[19] We followed up 26 controls when they visited the hospital for an assessment 6 months after their injury. The other 25 patients were assessed through a combination of self-reports and parental reports by post and telephone interviews. Patients under 8 years of age were all interviewed face-to-face. The 51 included patients (male 65%) ranged from 1 to 15 years of age, with a mean age of 10.3 years (Table 1).

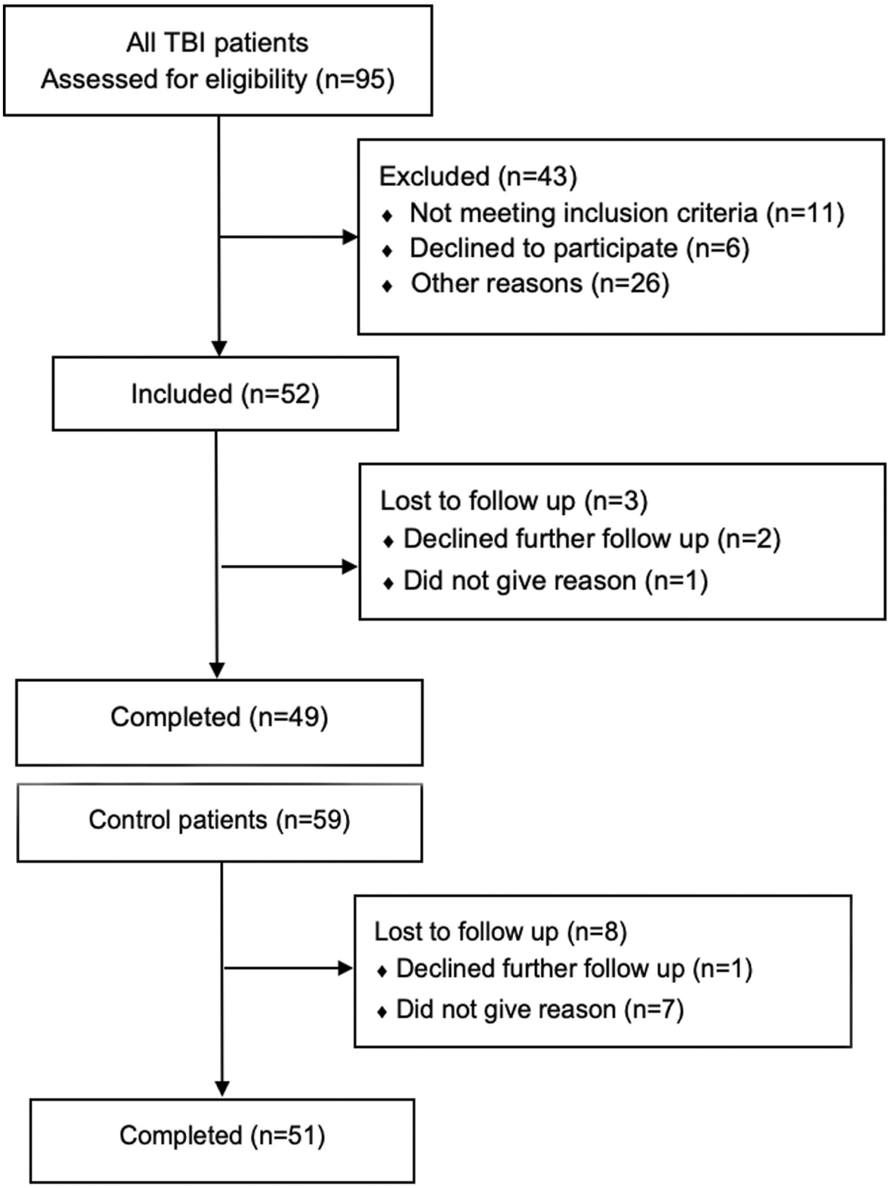

FIGURE 1 Flowchart of the study group and the control group.

TABLE 1 Demographics and injury characteristics in the TBI patients and controls.

Demographics and injury characteristics	**Controls ($n = 51$)**	**TBI patients ($n = 49$)**	***p* values**
Age at injury (years), mean (SD)	10.3 (4.13)	9.6 (4.08)	0.395
Sex (% male)	61	65	0.641
Caregiver education (years), mean (SD)	17 (2.74)	16 (2.53)	0.413
Mechanism of injury (% of cases)			
1. Transportation	15.7	36.7	
2. Fall	29.4	34.7	
3. Sport	45.1	20.4	
4. Other	9.8	8.2	
GCS[a] at arrival (3–15), mean (SD) by severity group:	15.0 (0.14)	12.3 (3.684)	<0.001
Mild TBI		14.43 (0.712)	
Complicated mild TBI		14.17 (0.937)	
Moderate/severe TBI		8.0 (3.633)	
Injury severity (ISS[b]), mean (SD)	9.75 (7.58)	11.8 (13.26)	0.884
Days hospitalised, mean (SD)	7.57 (9.23)	7.76 (10.90)	0.150
Level of treatment (0–6) mean (SD)	3.47 (0.67)	3.49 (0.77)	0.878

aGCS: The Glasgow Coma Scale.

bISS: The injury severity score.

The same paediatrician (HMD) performed all the assessments in both groups, during the acute phase and 6 months after the injuries.

2.3 | Injury severity

The Glasgow Coma Scale (GCS)[19] was used to classify the TBI severity of all participants on admission, using the following scores: severe (3–8), moderate (9–12) and mild (13–15).[19]

The injury severity score[20] was based on the abbreviated injury scale of 1–6,[19] which assesses six body regions: head, face, thorax, abdomen, extremities and external or other. It is calculated by taking the highest abbreviated injury scale score from the 3 most severely injured body regions, squaring each value and adding these numbers together.

The level of treatment was classified according to the treatment level in the acute phase after the injury: zero was no injury, one was no treatment needed, two was outpatient treatment, three was being admitted to a ward, four was observation in the intensive care unit, five was intubation and vasopressor treatment in the intensive care unit, and six was nonsurvivable. These scores were consistent with the CENTER-TBI assessment of treatment level.[17]

The levels of impairments in the acute phase and at 6 months were categorised using a modified version of The International Classification of Functioning, Disability, and Health for Children and Youth.[21] The scale of 0–4 related to no, mild, moderate, severe and complete impairment, respectively.

The first author (HMD) scored all the participants' impairment levels based on a clinical examination and observations recorded by physicians, physiotherapists and nurses in the patient's medical chart. The scoring was validated by another author, who is a rehabilitation physician (NA).

The body function areas were categorised into three groups. Cognitive function covered consciousness, attention, memory, interaction, activity level, communication and orientation. Physical functions covered speech, seeing, smell, sensibility, pain, sleep, mobility, muscle power, motoric abilities and reflexes. Socioemotional functioning covered emotions and cooperation.

Nine patients with a TBI were intubated more than 24 h after admission and were assigned a value of four for the nine cognitive and socioemotional variables in the acute phase, which totalled 36 points. The total and subscale scores are reported in the acute phase and at 6 months.

The Glasgow Outcome Scale Extended (GOS-E)[22] was used to assess global outcomes in all participants 6 months after their injuries. A manual detailing an age-appropriate assessment was used for children under 12 years of age.[17] This scale is considered to be the gold standard for measuring TBI outcomes and is sensitive to changes in functional status over time.[22] The scores of 1–8 indicate: dead, vegetative state, lower severe disability, upper severe disability, lower moderate disability, upper moderate disability, lower good recovery and upper good recovery, respectively. The scores were retrieved from the CENTER-TBI study database for the patients with a TBI. The first author (HMD) assessed the control group using the GOS-E and the scores were confirmed by the rehabilitation specialist (NA).

2.4 | Outcomes reported by patients and parents

The Rivermead Post Concussion Symptoms Questionnaire[23,24] is a self-reported assessment of post-concussion symptoms. The questionnaire consists of 16 items that measure somatic symptoms (nine items), emotional symptoms (four items) and cognitive symptoms (three items). It has been validated in Scandinavia for children aged 5 years and older.[25] Symptoms are reported based on a 5-point Likert scale that ranges from zero for not experienced to four for severe problems. Only patients aged 5–15 years were asked to report total and subscale scores during the acute phase and after 6 months. Responses were provided by 35 TBI patients and 42 controls during the acute phase and by 42 and 44, respectively, after 6 months.

The Paediatric Quality of Life Inventory[26,27] covers core health dimensions, including daily living and health-related emotional and behavioural problems. The parent version is used for patients aged 2–4 years and the self-report version is used for patients aged 5 years and older. There is a simplified version, with 21 items for the youngest children aged 5–7 years. Responses are provided on a 3-point Likert scale of zero for not at all, two for sometimes and four for a lot. The scale is supported by a visual aid that contains pictures of happy, neutral and sad faces.

The instrument used by the parents and children aged 8–15 years in our study consisted of 23 items divided into four subscales: physical (eight items), emotional (five items), social (five items) and school functioning (five items). The items are scored on a Likert scale of 0–4, from never a problem to almost always a problem. The scores were transformed as follows, according to the manual: zero became 100, one became 75, two became 50, three became 25, and four became zero. A higher total score indicated a better quality of life.

Responses to the Paediatric Quality of Life questionnaire were provided at the 6-month follow-up by 37 parents and 36 TBI patients: 12 children aged 5–7 and 24 children aged 8–15. They were also provided by 48 control parents and 44 control children: 8 children aged 5–7 and 36 children aged 8–15.

2.5 | Healthcare needs at 6 months after the acute injury

A semi-structured interview was used to assess the patients' and parent's perceptions of met and unmet needs at the 6-month follow-up visit. This was modelled on the studies by Slomine et al.[13] and Greenspan and MacKenzie[28] of unmet healthcare needs after a paediatric TBI.

The parents of all participants were asked if their child had received services from a medical or surgical specialist at the hospital, their family doctor, a public health nurse at their school, a physiotherapist or a speech therapist. They were also asked about whether they had received social care, care from a community-based paediatric habilitation unit, special needs education, psychiatric services or a stay at a rehabilitation unit after the acute phase. The answers to these questions were categorised into the three overarching health domains according to Slomine et al.[13] cognitive, physical and socioemotional (Table 2).

TABLE 2 Healthcare utilisation domains.

Domain	Healthcare service
Cognitive need	Speech therapy
	Special educational needs services
	Paediatric habilitation unit
	Inpatient rehabilitation unit
Physical need	Hospital follow up
	Family doctor
	Physiotherapy
Socioemotional need	Social services
	Psychiatric services for children and adolescents
	Public health nurse at school

Needs were categorised into no need identified, need met and need unmet, in line with the studies by Slomine et al.[13] and Greenspan and MacKenzie.[28] We based those classifications on any cognitive, physical and socioemotional impairments identified by the paediatric neurologist and the parent and patient reports on healthcare services that were or were not received by the follow-up visit.

No need was if the patient or parent did not report receiving any healthcare services and exhibited normal function in all domains. Need was categorised as met if the patient had made follow-up visits or received treatment before the 6-month follow-up visit. Unmet needs were based on reports from parents or patients, regardless of the level of function or impairment. The paediatric neurologist (HMD) allocated the patients to the need groups after reaching a consensus with the rehabilitation specialist (NA).

2.6 | Socioeconomic status

We recorded the number of years the parents were in education, and the highest achieved education was used as an indicator of socioeconomic status.

2.7 | Ethics

The study was approved by the Regional Committee for Medical and Health Research Ethics (REC: 2014/1454 and 2014/1454). It was conducted in accordance with the Declaration of Helsinki and the Vancouver Rules (International Committee of Medical Journal Editors, 2018). Children aged 7 years and older provided their assent to participate in the study, and written informed consent was provided by the parents of children of all ages.

2.8 | Statistics

All the statistical analyses were performed with SPSS Statistics version 26.0 software (IBM Corp., New York).

Sample demographics, injury characteristics and hospital treatment are presented descriptively. The Mann–Whitney U-test was used to compare the GCS score, the injury severity score, days of hospital stay, Rivermead Post Concussion

Symptoms Questionnaire and the Paediatric Quality of Life Inventory between the TBI and control groups. Missing values on single items were imputed according to the manual for each questionnaire. T-tests were used to compare changes in the Rivermead scores from the acute phase to 6 months after the injury. We used the crosstabs risk estimate to analyse unmet needs for the TBI and control groups, and the results are reported as odds ratios (OR) with 95% confidence intervals (CI). The results are presented with a significance level of $p > 0.5$.

3 | RESULTS

Table 1 shows that the TBI and control groups were comparable with regard to the age at injury, sex and socioeconomic status. All the patients underwent similar levels of treatment and had comparable overall injury levels and lengths of hospital stays. Of the 49 TBI patients, 38 were diagnosed with mild TBI, which was complicated mild in 18 (47%) cases, four had moderate TBI, and seven had severe TBI.

The two groups differed in terms of the injury mechanisms, as the control group had more sports accidents, while falls and transport accidents were more common in the TBI group. Patients with TBIs had a lower GCS score on arrival at the hospital, which was related to the severity of the TBI (Table 1).

3.1 | Impairments and symptoms at 6 months after the acute injury

A significant difference in injury-related impairment levels was observed between the two groups in the acute phase and at 6 months after their injuries (Table 3). There were more severe impairments in the cognitive, physical and socioemotional domains identified in the TBI group. This group also showed a lower level of function, as assessed by global outcome (Table 3). Almost half (47%) of the patients with a TBI reported various symptomatic symptoms 6 months after their injury, compared to 12% of the control children with other injuries.

The subjects in the TBI and the control groups showed more prominent emotional and cognitive symptoms in the acute phase than before injury, as measured by the Rivermead Post Concussion Symptoms Questionnaire. Six months after their injury, the TBI group reported higher symptom levels in all domains, as they were still experiencing emotional symptoms, prolonged fatigue, forgetfulness and concentration problems. In contrast, the control group reported significantly fewer symptoms (Table 3).

The children with a TBI reported lower health-related quality of life than the control group 6 months after their injury. This was because they reported emotional and cognitive problems and difficulties at school, which were assessed by the Paediatric Quality of Life Inventory. No differences in the physical symptoms were observed between the groups. The parents of patients with a TBI tended to report that their children had more problems functioning at school than the parents of the control group. However, the difference was not statistically significant (Table 3).

Both groups showed improved scores in the total and subscores of the Rivermead questionnaire between the acute injury and the first 6 months after the injury (Table 4). However, the patients with a TBI had a high symptom load at both evaluation points, but the patients with surgical injuries reported a lower symptom burden 6 months after injury (Table 3).

3.2 | Unmet needs

The reported unmet needs differed between the TBI and control groups. Figure 2 shows that the control group included more patients with no identified needs (59%) and met needs (29%) than the TBI group, at 31% and 22%, respectively. The risk of having unmet needs was four times higher in the TBI group (OR 3.99, 95% CI, 1.78–8.96). There were unmet needs in groups with all severity levels of TBI: 30% of patients with a mild TBI, 64% in the subcategory with a complicated mild TBI and 54% with a moderate or severe TBI.

The unmet needs of patients with a TBI were cognitive and socio-emotional symptoms that had not been addressed. At the 6-month follow-up, we found that it was necessary to refer some patients to local special needs education or psychiatric services for children and adolescents. These referrals were made for 16 patients (32%) with a TBI and four controls with surgical injuries (8%). In addition, six (12%) patients with a TBI needed a new medical or neuropsychological evaluation to ensure that necessary school adjustments were made, such as reducing environmental stimuli, pauses during the school day and guidance relating to social activities. Nine of the patients with a TBI were referred to more than one healthcare service. One patient with a surgical injury and seven patients with a TBI were discharged to a rehabilitation hospital.

A distinct difference in planned hospital follow-up visits after discharge from the acute hospital was observed between the control and TBI groups ($p = < 0.001$). At discharge, 48/51 (94%) patients in the control group had been given a scheduled follow-up visit to the hospital, but only 10/49 (20%) patients in the TBI group had a similar visit scheduled.

4 | DISCUSSION

Patients with a TBI had more prolonged symptoms and impairment than those in the control group, who had other traumatic injuries. The symptoms were evaluated by reports from the children, adolescents and their parents, together with clinical assessments of their impairments. Approximately 50% of the children with a TBI reported various somatic symptoms, such as fatigue,

TABLE 3 Impairment, post-concussion symptoms and quality of life in the acute phase and at 6 months after injury in patients with TBI compared to patients with other traumatic injuries.

	Controls	TBI patients	
	mean (SD) *n* = 51	mean (SD) *n* = 49	*p* values
Impairment[a] in the acute phase	4.96 (3.94)	17.33 (13.13)	<0.001
Impairment[a] at 6 months	1.35 (3.04)	6.81 (5.62)	<0.001
ICF -CY $_{\text{COG 6 M}}$	0.29 (0.58)	3.70 (2.73)	<0.001
ICF-CY $_{\text{PHYS 6 M}}$	0.96 (2.55)	1.94 (2.30)	0.012
ICF CY $_{\text{SOCIOEM 6 M}}$	0.10 (0.41)	1.17 (1.19)	<0.001
GOS-E 6 months (Scale 0–8 points)	7.59 (0.70)	6.69 (1.14)	<0.001
RPQ self-report[b]	*n* = 42	*n* = 35	
Patients 5 years and older			
RPQ total acute	11.5 (6.00)	14.9 (7.14)	0.052
Somatic acute	6.69 (3.91)	9.55 (4.23)	0.009
Cognitive acute	2.02 (2.30)	3.03 (2.29)	0.051
Emotional acute	2.82 (2.58)	2.97 (2.85)	0.890
	n = 44	*n* = 42	
RPQ total 6 months	5.05 (5.80)	10.4 (7.64)	<0.001
Somatic 6 months	2.49 (3.57)	4.95 (4.75)	0.003
Cognitive 6 months	1.25 (2.01)	2.98 (2.56)	<0.001
Emotional 6 months	1.30 (2.09)	2.24 (2.70)	0.052
PedsQL[c] 6 months			
All ages self-report	*n* = 44	*n* = 36	
Total score	87.3 (13.3)	84.3 (10.0)	0.037
Psychosocial health function	87.6 (12.3)	81.2 (11.8)	0.006
Emotional	87.6 (17.2)	80.9 (18.4)	0.048
Social	92.8 (12.8)	87.9 (17.7)	0.035
School	82.2 (16.0)	74.3 (13.3)	0.011
Physical	89.3 (14.0)	89.8 (10.7)	0.739
Parental report 6 months	*n* = 48	*n* = 37	
Total score	83.6(15.1)	81.6 (10.5)	0.513
Psychosocial health function	83.4 (15.1)	79.3 (14.6)	0.173
Emotional	79.5 (19.0)	76.0 (22.3)	0.558
Social	89.2 (14.5)	88.0 (16.2)	0,721
School	81.5 (18.7)	74.5(17.5)	0.061
Physical	84.2 (21.0	88.6 (9.5)	0.820

Note: Discrepancies between the total score and subscores are due to rounding.

[a] Impairment assessed using The International Classification of Functioning, Disability, and Health for Children and Youth (ICF-CY). Abbreviations: Cog = cognitive, Phys = physical, Socioem = socioemotional.

[b] RPQ: The Rivermead Post Concussion Symptoms Questionnaire.

[c] PedsQL: The Paediatric Quality of Life Inventory. Self-report by patients of 5 years of age plus.

emotional problems and cognitive symptoms such as forgetfulness and concentration problems. This confirmed other studies on outcomes after paediatric TBIs.[6,7] These symptoms resembled the domains of unmet need reported at follow-up by adult patients with a TBI.[14]

Sequelae from TBIs in childhood may interfere with daily life functioning. In our study, the children with a TBI reported reduced health-related quality of life compared to the control group, with school performance being the main problem. These differences between the TBI and control groups were not present in the parent's reports. These findings illustrate the importance of asking children themselves about their symptom levels, as symptom perception will be experienced differently between children and parents. A low to moderate concordance has been reported between reports form parents and children.[29,30] Multi-informant reports from both parents and paediatric patients are therefore recommended. These results highlight the importance of considering the perspectives of both parents and children and the

TABLE 4 Recovery from symptoms. The difference from the acute phase to 6 months after the injuries.

Recovery	Controls Mean difference (SD)	TBI patients Mean difference (SD)	*p* values
	n = 41	*n* = 33	
RPQ total score difference	−6,12 (6.39)	−4.12 (10.49)	0.158
Somatic difference	−3.89 (3.79)	−5.08 (5,58)	0.164
Cognitive difference	−0.63 (2.96)	−0.33 (3,72)	0.356
Emotional difference	−1.58 (3.12)	−1.21 (3.46)	0.328

Abbreviation: RPQ, The Rivermead Post Concussion Symptoms Questionnaire.

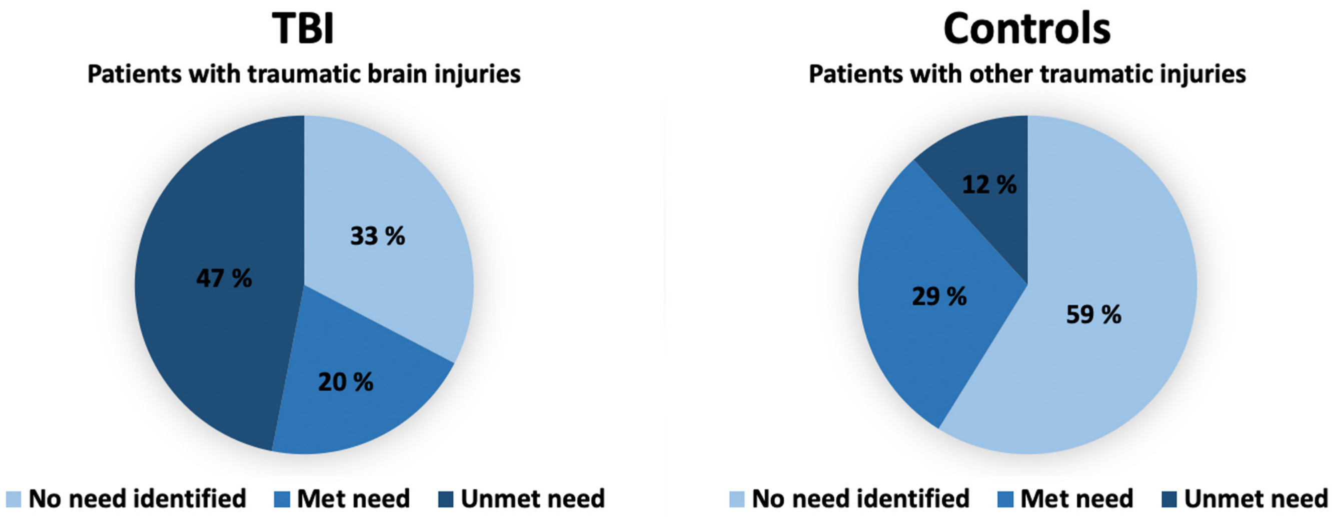

FIGURE 2 Healthcare needs.

advantages of face-to-face interviews and examinations, which allow younger patients to participate. Slomine et al. reached the same conclusions.[13]

This study was one of few longitudinal studies to examine the unmet needs of paediatric patients with TBIs who were treated in a publicly funded healthcare system. They were compared with a control group of paediatric patients, who did not have a TBI, but were hospitalised for other traumatic injuries. We found that the patients with a TBI had a four times higher risk of unmet needs at 6 months after their injury than the control group. Similar levels of physical recovery were reported by the two groups. However, the TBI group experienced persistent symptoms that affected their cognitive and emotional domains, which coincided with the unmet needs announced and observed at the follow-up. The children with a TBI required interventions, such as reduced environmental stimuli and workloads, extra breaks during the school day and guidance in social interactions with peers and adults. The follow-up assessment resulted in referrals to special needs education or psychiatric healthcare services or advising the school on necessary adjustments to help the patient return to school and social activities. Our study supports other studies that have showed that emotional, cognitive and social impairments lead to unmet healthcare needs in patients with a TBI.[3,6]

Unmet needs were recorded for patients with TBIs in all severity groups, especially patients in the complicated mild TBI group. These had traumatic intracranial injuries despite a high GCS score at admission. A significant proportion (42%) of the group who were mildly injured had unmet needs and these are the kind of needs that tend to remain undetected if follow-up visits are not planned. These results were consistent with the findings reported by Fuentes et al.[6] It is challenging to identify and monitor patients' need for rehabilitation and educational services. Parents and schools can have a limited understanding of the educational needs related to TBIs, and information can be lost in the transition between healthcare and educational systems. Haarbauer-Krupa et al. reported the same from the USA.[12] The difference in how perceived healthcare needs were met in the TBI and control groups also emphasises the importance of making plans to follow up paediatric patients with a TBI.

4.1 | Strengths and limitations

The strengths of this study were the prospective design and the inclusion of a surgical control group matched by overall injury severity, sex and age. Having this comparable control group allowed us to minimise the effect of the experience of hospitalisation, injury and treatment when we were exploring symptoms in the acute phase and unmet needs at follow-up.

In addition, clinical examinations and interviews were carried out and we included information from parents and patients when possible. The same experienced paediatric neurologist assessed all the patients in the acute phase and at follow-up and reviewed all the patient's medical charts for all professional observations performed on admission and at discharge. Consensus regarding the classification of met and unmet needs was achieved in collaboration with a specialist in rehabilitation medicine who did not meet the patients. The modest group size was a limitation and poses a threat to statistical power and generalisability. The clinical examination and impairment rating might have been biased, as these procedures were not blinded. However, using an established classification system to assess impaired body functions, based on clinical examinations and medical records, was helpful. Another limitation was that we did not use a validated measure for unmet needs. However, we used a model based on another study that assessed unmet needs in a paediatric TBI population.[13]

5 | CONCLUSION

Many children hospitalised after a TBI experienced persistent cognitive and emotional symptoms that affected their return to school and subsequent social interaction. These were associated with reduced quality of life. Although they had more prolonged symptoms, these patients did not receive planned follow-up visits to the same degree as patients with other traumatic injuries. In fact, nearly half (47%) of the children in the TBI group had unmet needs, compared to 12% of the control group. Targeted assessments to reveal problems following TBIs are essential so that appropriate rehabilitation can be initiated and functional impairments can be improved. Developing a systematic follow-up method for children and adolescents with TBIs of all grades of severity is necessary.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to declare.

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III

Unmet health care needs over the first 2 years after pediatric traumatic brain injury

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Abstract

Aim: Few studies have addressed how children and adolescents with traumatic brain injuries (TBIs) access health care and educational services. This study aimed to investigate the course of symptoms during the first two years after TBI, whether symptoms implied a need for health care and/or educational services, and the extent of unmet needs. The association between unmet needs and health-related quality of life was also explored.

Methods: This prospective cohort study was conducted at Oslo University Hospital, Norway, from 2015-2018. Forty-nine patients aged 1 to 15 years hospitalized due to TBI were included and followed for 24 months. Registration of symptoms and identification of unmet needs was based on clinical assessment, self-reports and interviews with patients and parents during the acute phase and at 6 and 24 months postinjury.

Results:

Twenty-five percent of the sample presented with unmet needs at 24 months. Compared to the group with no needs and met needs, these patients reported lasting cognitive and emotional symptoms affecting school and social interaction and scored lower on health-related quality of life.

Conclusion:

Pediatric patients with TBI may have long-term symptom burden affecting school and social functioning, leading to unmet needs if targeted services are not provided.

- We followed 49 children aged 1-15 years with TBIs for 24 months after injury.
- One-fourth still had unmet needs two years after their acute injury.
- Patients with unmet needs had long-term cognitive and emotional symptoms.
- Their symptoms affected school, social functioning, and quality of life.

Keywords: Pediatric head injury, Traumatic brain injury, recovery, unmet needs, health care utilization, quality of life

1. Introduction

Traumatic brain injury (TBI) in childhood may cause long-term functional, adaptive, and behavioral impairments regardless of its initial severity [1–3]. The complex normal development of physical, psychosocial, and cognitive skills may be interrupted by an injury to the developing brain [4]. Furthermore, the developing brain seems most vulnerable in cerebral maturational spurts, especially in early childhood and adolescence [5]. If the injury alters the developmental trajectories, some impairments may become more evident with older age [6]. After an injury, the functional recovery may slowly result in a return to preinjury baseline levels. However, the baseline function of normal peers may have already moved on, leading to a relative developmental delay [4]. Consequently, early TBI may significantly affect participation and performance in school, social interactions, and extracurricular activities and may result in a need for specialized TBI care, both acute and long-term [3,7,8]. Accordingly, several studies have reported a reduction in health-related quality of life following TBI in childhood due to lasting emotional, physical, and cognitive impairments experienced by children[9,10].

Fuentes et al. [11] followed pediatric patients for two years after TBI. They found that the need for health care and educational services continued and even increased during the two years, resulting in increased unmet needs because of discontinued services for children with moderate and severe TBI or undisclosed needs for milder brain injuries. Children with moderate and severe TBI tend to have more visible functional impairments than those with milder injuries and thus have more readily identified and met needs and more regular use of health care services [11]. However, patients with mild TBI may have cognitive, behavioral, and social problems that may go unnoticed, but nonetheless also need service provision [12]. To better capture these diversities in the outcomes, mild TBI is often divided into uncomplicated TBI (mTBI), defined as the absence of any traumatic intracranial injury on neuroimaging, and complicated mild TBI (cmTBI), implying the presence of traumatic intracranial injury [13]. Patients with cmTBI have been found to have a symptom load resembling those with moderate TBI [14–16]. Even patients with mTBI may have persistent symptoms over time [17]. Due to the high numbers of mTBI, even minor persistent decrements will be important at a population level [14].

There is increasing knowledge about the positive effects of brain injury rehabilitation services for pediatric patients [18,19]. However, several studies on pediatric TBI have described unmet needs due to problems with accessibility and utilization of health care and educational services [11,20,21]. The challenge has been described mainly as difficulty identifying all patients in need of rehabilitation services [12]. Furthermore, the transition of information between the health care and educational systems may be suboptimal [12] This is unfortunate, as the school environment is an essential arena for the rehabilitation of children and adolescents [22]. In addition, good family function may be a protective factor for outcome, and a family-centered approach to pediatric brain injury rehabilitation is of importance [14].

Studies conducted on the adult TBI population in Norway have shown that 31% reported unmet needs in emotional, vocational, and cognitive domains five years after the injury [23]. Equivalent knowledge regarding Norwegian pediatric patients experiencing TBI is scarce. In an earlier study, we demonstrated a significant difference in postinjury follow-up at six months between children and adolescents hospitalized with a TBI compared to patients with other surgical injuries, in favor of the surgically injured. Furthermore, 47% of the TBI group reported unmet needs [21].We have now followed the pediatric patients with TBI for two years after their injuries to assess the course of symptoms and impairments and the access to and utilization of health care and educational systems over time.

1.1 Objectives

This study aimed to describe the course of brain injury related symptoms over the first two years after TBI in pediatric patients and to investigate whether these symptoms implied a need for health care or special educational services. Furthermore, we aimed to examine factors associated with unmet needs two years after TBI and whether unmet needs were associated with reduced health-related quality of life.

2. Methods

2.1 Participants

The participants were included as a pediatric extension of the CENTER-TBI study at Oslo University Hospital (OUH) [24]. The CENTER-TBI study was a multicenter, prospective, longitudinal observational study conducted in Europe and Israel [25]. Enrollment found place from January 2015 to December 2016 and covered the whole spectrum of TBI severity (mild, moderate, and severe). Eligible for inclusion in this study were children aged 1-15 years with a clinical diagnosis of TBI, admitted to a medical center within 24 hours postinjury, were residents in the southeast region of Norway, and underwent computer tomography (CT) scanning. The exclusion criteria were preexisting neurological, psychiatric, or neurodevelopmental disorders that might affect outcome assessments and insurmountable language barriers. This paper reports data from the acute phase and six and 24months postinjury follow-ups.

2.2 Procedure:

All participants were assessed at the hospital in the acute phase and at the follow-ups. The patients were examined clinically, and both patients and parents were interviewed at the control. Patients and parents filled out the questionnaires separately. Patients aged 5-7 years were interviewed face to face by the pediatric neurologist, supported by a visual aid (emotional faces: happy, neutral, and sad) to secure the interpretation of the questions, accepting answers without interfering. Proxy reports from parents were used for children under four years of age.

2.2.1. Injury severity assessed during initial hospital stays

Specific scoring systems were utilized for each patient to determine severity of injury. These scoring systems included: The Glasgow Coma Scale (GCS) [26], the Abbreviated Injury Scale (AIS) [26], The Injury Severity Score (ISS) [27] , and radiological imaging.

GCS is a measure intended to classify TBI severity and is widely used for triage in the acute phase. The pediatric GCS was used for children up to two years of age [28]. The GCS scores assessed at admission were retrieved from the OUH trauma registry (Table 2).

ISS is based on AIS, a system used to describe the severity of injuries to the body that are scored on an ordinal scale ranging from 1-6: minor, moderate, serious, severe, critical, and maximal/currently untreatable. AIS assesses six body regions (head, face, thorax, abdomen, extremities, and external/other). ISS is calculated by taking the highest AIS score from the three most severely injured body regions, squaring each value, and adding these numbers. ISS scores were retrieved from the OUH trauma registry (Table 2).

All patients had a CT scan within 24 hours after the injury. Twenty-five patients had Magnetic Resonance Imaging (MRI) scans during the hospital stay. A neuroradiological trauma specialist at OUH assessed the CT scans according to the Rotterdam score and described the MRI scans. The Rotterdam Classification [29] includes four independently scored elements: 1) degree of basal cistern compression and 2) degree of midline shift. It does not include contusions but restricts mass lesions to 3) epidural hematomas and adds 4) intraventricular and/or subarachnoid blood. A normal scan has a Rotterdam score of 1; the worst possible score is 6 (Table 2).

For outcome comparison, we categorized the patients into three severity groups: mild, complicated mild, and moderate/severe TBI. The patients with moderate and severe TBI were collapsed into one group due to small numbers.
The classification of mild TBI (GCS 13-15) as uncomplicated (mTBI) or complicated mild TBI (cmTBI)was performed by evaluating CT and MRI scans; those with findings of skull fractures, intracranial hemorrhage, contusion, edema, or traumatic axonal injury were considered cmTBI, those without any findings as mTBI.

The level of treatment in the acute phase was categorized in line with CENTER-TBI [24]: 0 = no injury, 1 = no treatment needed, 2 = outpatient treatment, 3 = admitted to a ward, 4 = observation/basic treatment in the ICU, 5 = intubation, mechanical ventilation, or vasopressor treatment in the ICU, and 6 = nonsurvivable.

2.2.2 Outcome measures assessed in the acute phase and 6 and 24 months postinjury.

The Glasgow Outcome Scale Extended (GOS-E) [30] was used to assess global outcomes six- and 24-months postinjury (Figure 2). A manual for an age-appropriate assessment was used for children younger than 12 years [24]. The GOS-E is considered the gold standard for measuring TBI outcomes and is sensitive to changes in functional status over time [30]. The score is classified into eight categories, from 1 to 8: dead, vegetative state, lower severe disability, upper severe disability, lower moderate disability, upper moderate disability, lower good recovery, and upper good recovery.

The GOS-E scores were retrieved from the CENTER-TBI database at six months. The first author (HMD) scored the outcome for patients with missing information at 24 months according to the information in the patient's medical chart. The scoring was validated and confirmed by a rehabilitation physician, i.e., author N.A.

The Rivermead Post Concussion Symptoms Questionnaire (RPQ) [31,32] is a self-reported measure of post-concussion symptoms relative to premorbid levels. The questionnaire consists of 16 items that measure somatic (nine items), emotional (four items), and cognitive symptoms (three items). It has been validated in Scandinavia for children aged five years and older [33]. Symptoms are reported based on a 5 -point Likert scale ranging from zero (not experienced) to four (severe problem). The questionnaire addresses common long-term symptoms after TBI of all severities, such as fatigue, memory complaints, emotional problems, headache, and dizziness, and was administered both in the acute phase and at six- and 24 months postinjury [17,34,35]. Total and subscale scores in the acute phase and after 6 and 24 months were reported.

The Pediatric Quality of Life Inventory 4.0 (PedsQL) [36,37] covers core health dimensions, including daily living and health-related emotional and behavioral problems. There is a parent proxy report for patients aged 2-4 years. From the age of five years, there is also a self-report. There is a simplified version for the youngest children aged 5-7, with 21 items. Responses are provided on a 3-point Likert scale divided into 0 = not at all, 2 = sometimes, and 4 = a lot. The scale is supported with a visual aid containing pictures of happy, neutral, and sad faces. For children aged 8-18 years and in the parents' reports, the instrument consists of 23 items divided into four subscales: Physical (eight items), Emotional (five items), Social (five items), and School functioning (five items). The items are scored on a Likert scale of 0-4, from never a problem to almost always a problem. The scores are transformed as follows: 0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0. A higher total score indicates better quality of life. The cutoff for scores that indicate special health care needs in a mild to severe grade is 82-77 for children under eight years and 78-70 for children ≥ 8 years of age [38].

2.2.3 Health care utilization and unmet needs:

The parents were asked, via semi-structured interview, if their child had received services from a medical or surgical specialist at a hospital, family doctor, public health nurse at school, physiotherapist, speech pathologist, social worker, or the Pediatric Habilitation Unit in the community. Furthermore, we mapped services from the special needs educational service, psychiatric service for children and adolescents, and admission to rehabilitation units after the acute phase. The answers to these questions were categorized into the following overarching health domains according to Slomine et al. [39]: cognitive, physical, and socioemotional (Table 1).

Table 1 Health care utilization domains

Domain	Health care service
Cognitive need	Speech therapy Special education needs services Pediatric habilitation unit Inpatient rehabilitation unit
Physical need	Hospital follow-up Family doctor Physiotherapy
Socioemotional need	Social services Psychiatric services for children and adolescents Public health nurse at school

Needs were categorized into no need identified, need met, and need unmet, consistent with the studies by Slomine [39] and Greenspan [40]. We based the classification on a) cognitive, physical, and socioemotional impairments in the child or youth as assessed by the pediatric neurologist and b) caregiver and patient reports on health care services that were or were not received by the follow-up visits at six and 24 months.

We considered no need identified if the patient or caregiver did not report receiving any health care services and the patient exhibited normal function in all domains. A need was categorized as met if the patient had received follow-up or treatment initiated before the follow-up at six months and again at 24 months. A need was registered as unmet if the parents or patients reported unmet needs, regardless of the level of function or impairment. The pediatric neurologist performed patient allocations to the need groups in consensus with a rehabilitation specialist (NA). The patient´s need for services was assessed in the acute phase and at the 6- and 24-month follow-ups and is reported in this study.

2.3. Ethics

The study was approved by the Regional Committee for Medical and Health Research Ethics (REC: 2014/1454) and was conducted in accordance with the Declaration of Helsinki and the Vancouver Rules [41]. We obtained informed consent adhering to local and national ethical and legal requirements. Children aged seven years and older provided their assent to participate in the study, and informed written consent was provided by the legal guardians of children of all ages.

2.4 Statistics

The statistical analyses were performed with IBM SPSS Statistics version 26.0 software (IBM Corp., New York USA) and linear mixed model analyses were performed using Stata (StataCorp LP, College Station, TX).

Sample demographics, injury characteristics, and hospital treatment are presented descriptively. Mann-Whitney U test was used to compare groups with met and unmet needs at 24 months postinjury using the Pediatric Quality of Life Inventory.

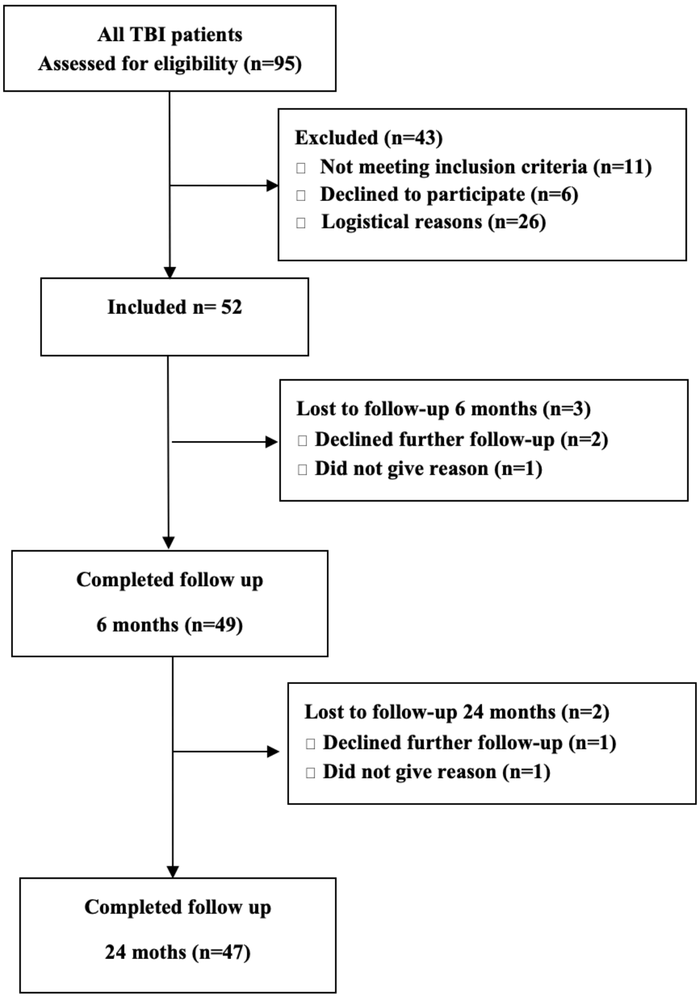
Univariable logistic regression was used to compare the symptoms reported by the patients with unmet and no/met needs in the Rivermead Post Concussion Symptoms Questionnaire at 24 months, and the results are reported as odds ratios (ORs) with 95% confidence intervals (CIs).

Linear mixed model analyses were used to compare data at the acute phase and at 6 and 24 months for the Rivermead Post Concussion Symptoms Questionnaire to account for repeated measures by patients. All models included a random intercept.
Missing values on single items were imputed according to the manual for each questionnaire. The results are presented with a significance level of $p < 0.05$.

3. Results

3.1 Sample

Figure 1: Flowchart of the study group



We identified 95 eligible patients. Fifty-two of these consented to participate, and 47 completed the 6- and 24- month follow-ups. Of the 43 patients who were excluded, six declined participation, while the remining 37 had premorbid conditions, were tourists, or were lost to inclusion due to logistic reasons (Figure 1).

Table 2 Demographics and injury characteristics

	TBI **N=47**
Demographics	
Age at injury (1-15 years) **mean (SD)**	9.6 (4.08)
Sex **(% male)**	63.8
Caregiver education (years) **mean (SD)**	15 (2.50)
Injury characteristics	
Mechanism of injury **n (%)**	
1.transport	17 (36.2%)
2.fall	17 (36.2%)
3.sport	9 (18.8%)
4.other	4 (8.5%
GCS at arrival by severity group **mean (SD)**	
uncomplicated mild TBI	14.43 (0.712)
complicated mild TBI	14.17 (0.937)
moderate/severe TBI	8.0 (3.633)
Severity groups* **n (%)**	
uncomplicated mild TBI	19 (40.4%)
complicated mild TBI	15 (31.9%)
moderate/severe TBI	13 (27.7%)
Rotterdam score, **mean (SD)**	
uncomplicated mild TBI	1.00 (0.0)
complicated mild TBI	1.27 (0.5)
moderate/severe TBI	1.54 (0.7)
Total Injury Severity (ISS) **mean (SD)**	11.5 (13.11)
Days hospitalized **mean (SD)**	7.72 (11.13)
Level of treatment (level 0-6) **mean (SD)**	3.47 (0.75)

* Severity by GCS combined with intracranial injury.

3.1 Demographics and injury severity

The boy: girl ratio in this sample was 1.8:1, and the mean age at injury was 9.6 years. The main mechanisms of head injury were transport accidents, falls, and sports accidents.

This sample was skewed toward the severe end of the severity scale, with 72.3 % mild (mTBI and cmTBI) and 27.7% moderate and severe brain injuries based on GCS scores (Table 2). The injury severity estimated by ISS also places the study group into a somewhat more severe part of the pediatric TBI population than the population usually hospitalized at OUH [42].

The Rotterdam score showed low scores (Table 2), and only five patients needed neurosurgical intervention. Furthermore, four patients were monitored with intracranial pressure measurement (ICP) but treated conservatively.

Figure 2: GOS-E

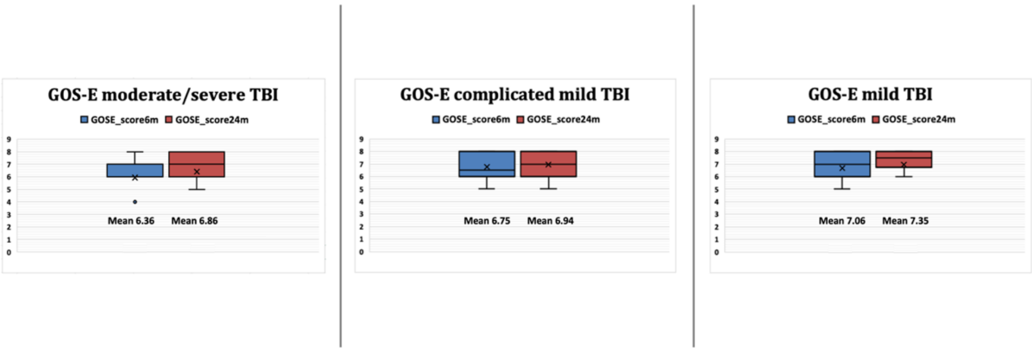


Figure 3a **Rivermead questionnaire (RPQ)**

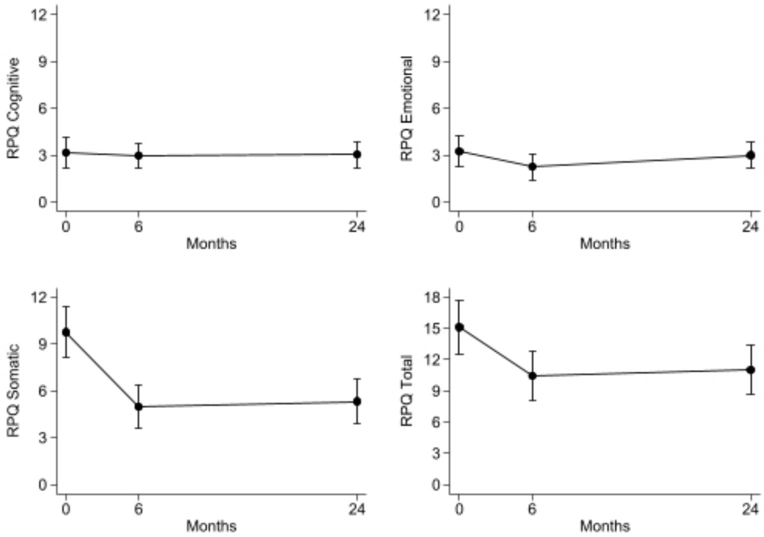
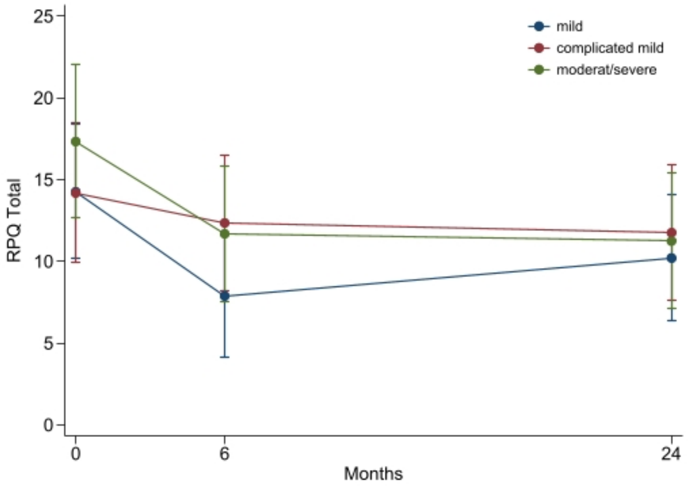


Figure 3b: RPQ total values by severity group



3.2 Outcome and symptoms

All severity groups showed recovery from six to 24 months postinjury, as assessed with the GOS-E (figure 2). However, the patients with cmTBI tended to have poorer recovery rates than both the uncomplicated mild and moderate to severely injured patients but not at a statistically significant level (Figure 2).

Self-reported brain injury symptoms on the RPQ improved significantly for the total scores, mainly driven by the somatic subscale from the acute phase to 24 months (Figure 3a). However, the emotional and cognitive symptoms did not improve significantly from the acute phase to 24 months. Pairwise comparisons revealed significant improvement between the acute phase compared to 6 and 24 months, respectively, for the total score (p=0.003/p= 0.009) and the somatic subscale (p<0.000/p=0.000) but not for the emotional (p= 0.102/p=0.710) and cognitive subscales (p= 0.760/p=0.834). Furthermore, there was no significant change between 6 and 24 months neither in total scores (p=0.714) or any of the subscales: cognitive (p=0.916), emotional (p=0.163), or somatic (p=0.676) (Figure 3a).

When exploring the severity groups separately (figure 3b), we found that the mTBI and moderate/severe TBI groups had significant improvement between the acute phase and six months (p=0.013, 95% CI -11.4-1.36, and p=0.048; 95% CI -11.3, -0.043) but not between 6 and 24 months (p= 0.342, CI -2.46, -7.10 and p=0.861, 95% CI -5.63, 4.70). For cmTBI, there were no significant differences between the acute phase and six months or between 6 and 24 months (p= 0.498, 95% CI -7.18, 3.49 and p=0.817, 95% CI -5.82, 4.5) (Figure 3b).

Assessed by RPQ at 24 months, the odds of having ongoing concentration problems and fatigue were three times higher in the unmet need group compared to the groups with no and met needs (OR 3.219, 95% CI 1.495-6.929) and (OR 3.125, 95% CI 1.382-7.066), respectively. Furthermore, the odds of feeling depressed and having headaches were approximately two times higher in the unmet need group (OR 2.040, 95% CI 1,083-3.842) and (OR 1.896, 95% CI 1.062-3.387), respectively (Table 3).

Table 3 Symptoms reported at 24 months on RPQ, unmet needs vs. no/met needs

Symptoms	OR	CI (95%)	p value
Headaches	**1.896**	1.062-3.387	**0.031**
Feelings of dizziness	1.610	0.691-3.749	0.269
Nausea and/or vomiting	0.896	0.282-3.031	0.896
Noise sensibility	1.764	1.004-3.099	0.049
Sleep disturbance	1.222	0.626-2.386	0.557
Fatigue	**3.125**	1.382-7.066	**0.006**
Being irritable	1.649	0.845-3.221	1.134
Feeling depressed or tearful	**2.040**	1.083-3.842	**0.027**
Forgetfulness, poor memory	1.812	1.008-3.259	0.047
Poor concentration	**3.219**	1.495-6.929	**0.003**
Taking longer to think	1.396	0.797-2.444	0.243
Light sensitivity	1.422	0.722-2.797	0.308
Blurred vision	0.849	0.330-2.187	0.735

Unmet needs N=10 vs No/met needs N= 30
RPQ: The Rivermead Post Concussion Symptoms Questionnaire. OR: Odds ratio, CI: Confidence interval
Children 6 years and older

Figure 4: Unmet needs

Table 4 Unmet needs

Time Domaine	6mnd N=22	24mnd N=12
Cognitive		
Special education needs services	8	4
School adjustments	5	6
Physical	1	0
Socioemotional	8	2

3.3 Unmet needs

There was a reduction from 22 (45%) to 12 (25%) patients with unmet needs from six to 24 months (Figure 4). Of the 22 having unmet needs at six months, ten still reported unmet needs at 24 months, consisting of two with mTBI, five with cmTBI, and three with moderate/severe TBI. Of the remaining 12, five reported no longer needs, six had met needs at 24 months, and one missed the control. Two patients who reported no and met needs at 6 months had unmet needs at 24 months.

The group that reported no needs increased from 33% at six months to 47% at 24 months (Figure 4). Fourteen patients reported no need at both controls, of which 10 had mTBI, and another eight patients had no more symptoms affecting daily life at 24 months.

There was a slight increase from 11 patients (22%) at six months to 13 patients (28%) at 24 months, who reported met needs (Figure 4). According to information from patients and parents at the 24-month follow-up, the patients with met needs had implemented adequate services that addressed their needs by facilitating at school, involving special educational needs services, or psychiatric services for children and adolescents at the six-month follow-up (Table 4). Furthermore, they reported a satisfactory transition of information between the health care and educational systems.

At the 24-month follow-up, 12 patients reporting unmet needs also reported problems with concentration, fatigue, sensibility to environmental stimuli, and emotion regulation (Table 3). Six patients reported a need for more or renewed information about brain injury and necessary accommodations after changing schools (three with severe TBIs, two with cmTBI, and one with mTBI). At the 24-month follow-up, this was addressed, and four patients were referred to special education needs services (one with mTBI and three with cmTBI), and two patients with cmTBI were referred to psychiatric services for children and adolescents (Table 4).

Table 5 PedsQL unmet needs vs. met needs 24 months after injury.

PedsQL	**Unmet need**	**No/met need**	p value
All ages self-report	N=10	N=30	
Total score	78.61 (15.7)	88.04 (9.2)	0.050
Psychosocial health function	77.00 (13.4)	85.94 (11.4)	0.036
Emotional	68.50 (22.4)	83.83 (16.9)	0.058
Social	92.50 (7.5)	92.17 (10.8)	0.747
School	67.78 (25.8)	83.50 (13.7)	0.086
Physical	81.88 (26.1)	92.08 (7.9)	0.331
Parental report	N=10	N=32	
Total score	73.48 (17.6)	87.93 (10.4)	0.013
Psychosocial health function	77.00 (13.4)	86.40 (10.2)	0.052
Emotional	80.62 (14.7)	80.63 (14.7)	0.102
Social	88.50 (13.1)	93.59 (13.3)	0.300
School	71.00 (17.0)	88.50 (13.1)	0.028
Physical	71.88 (29.5)	92.03 (12.6)	0.024

PedsQL= The Pediatric Quality of Life Inventory 4.0,

The patients and parents in the groups with no needs and met needs 24 months after injury reported good quality of life (Table 5). For the patients who reported ongoing unmet needs, quality of life was reduced at 24 months, with a significant difference in total score (p=0.050) and psychosocial health score (p=0.036) compared to the ones with no or met needs. The children with unmet needs reported problems regarding emotional symptoms and school performance by scoring the emotional and school items under the cut of value for identifying specialist health care needs [38]. Their parents also reported that their children had significantly more problems at school (p=0.028) and with participation in activities due to physical symptoms (e.g., fatigue) compared to those with no and met needs (p=0.024) (Table 5).

4. Discussion

This study explored symptom development in the first two years after pediatric TBI. Clinical assessment, self-reports, and interviews were used to investigate whether TBI-related symptoms necessitated health care or educational services. One-quarter of the patients reported unmet needs after 24 months. Ongoing symptoms and unmet needs were related to decreased health-related quality of life compared to those without unmet needs.

4.1 Global Outcome and self-reported symptoms

A fourth of our study group had symptoms affecting everyday life after 24 months, which aligns with other studies [3,11]. Patients' recovery differed by injury severity level, with the most striking result being only a minor improvement for the group with cmTBI from 6 to 24 months follow-up assessed by GOS-E (figure 2). Furthermore, the reported level of functioning in cmTBI patients was equivalent to that in mTBI patients at six months but tended to be lower at 24 months, but the difference was not statistically significant.

Moreover, the result from neuropsychological assessments of our study group at the six-month follow-up underlined the need for thorough assessments regardless of severity, as the children with cmTBI showed cognitive difficulties in line with those with moderate and severe TBI [16]. Fuentes et al. [11] found that patients with cmTBI were most affected in academic, mental, and cognitive domains and that a third of the cmTBI group still had dysfunction at 24 months. Emotional and cognitive symptoms are often invisible if not addressed and were, in this study, the dominant symptoms affecting daily life in the group reporting unmet needs.

4.2. Unmet need and health-related quality of life.

One-fourth of the patients had no needs, and thirteen (28%) met needs after interventions implemented at the six-month control. Those with met needs reported that the child had received emotional support and had adequate accommodation in school due to satisfactory information transmission and implementation of recommended measures. These groups reported a good quality of life.

The twelve patients with unmet needs reported difficulties at school with concentration, forgetfulness, headaches, and fatigue 24 months after injury. Most of these patients had complicated mild or moderate/severe TBI, but a few had mTBI. These symptoms may have contributed to the reduced quality of life, as reported by both patients and parents, highlighting the need to assess and address symptoms following TBI in childhood. Our findings align with other studies that have found that children and adolescents report persistent physical and cognitive symptoms affecting health-related quality of life several years after TBI, regardless of severity levels [9,11]. Correspondingly, Fried et al. have advocated for follow-up also for patients with mTBI if they showed persistent symptoms six months after the injury [17].

The patients with unmet needs at 24 months reported a need for help with the mediation of information regarding symptoms and dysfunction following TBI. These patients had missed necessary accommodation and support for educational and emotional needs. Our findings are in line with those of Fuentes et al., who found that pediatric patients with TBI had an ongoing need for psychiatric and educational services with increased time since the injury, and that the unmet needs were partly due to discontinued services [11].

Minney et al. [19] recommended tailored information for both families and schools and cooperation between the health care and educational services over time to improve outcomes after TBI in childhood. Parents and schools can have a limited understanding of the educational needs related to children with TBIs, and information may be lost in the transition between health care and educational systems, and in school transitions. Consequently, it is important to actively involve and educate parents since they participate in the treatment and recovery process after pediatric brain injuries, including their children's return to school, sports, social, and home activities. Furthermore, there seems to be a need to educate the health care and educational systems regarding the long-term effects of TBI in childhood, and a need to improve the transition of information between the health care and education systems and between the grade levels in the school system. Haarbauer-Krupa [12] emphasized the need to improve the transition of information between the health care and education systems and standardize systems for transition services during childhood and adolescence in the US. Our publicly funded service system shows a corresponding need for improvement, although the goal is adequate and accessible help for health care and education needs.

There is a need for better tools to identify patients at risk for longstanding symptoms in need of follow-up over time [12]. This study demonstrates that the level of consciousness assessed by GCS at admission after injury was insufficient to forecast which patients would need the follow-up over time. In our former paper investigating the pediatric population hospitalized with TBI in the southeast region of Norway [42], we found that in the youngest age group (0-7 years), 24% of the patients vs.10% of patients in the older group (8-15 years) had no CT scan performed at admission. This is related to a restrictive approach to using CT scans, especially for toddlers, that may be influenced by the sensitivity to radiation-induced malignancy for children increasing with lower age [43]. However, neuroimaging is necessary to identify those with complicated mild injuries and risk for prolonged symptoms. This study consequently strengthens the indication for neuroradiological investigations, preferably MRI, before discharge if the patients have prolonged hospital stays and advises against evaluating severity exclusively based on initial clinical symptoms.

There is a need for improved follow-up for pediatric patients with TBI. In a former paper describing the outcome for these patients at six months postinjury, we uncovered unmet needs in nearly half of the sample [21]. At 24 months, we found that a significant proportion of patients still had unmet needs. This underpins the need for a planned follow-up and an extended follow-up period. Planning follow-ups with neurological pediatricians, preferably in an interdisciplinary rehabilitation setting, would be beneficial. There is also reason to follow the children and adolescents experiencing TBI over several years to ensure that accommodations to care and referrals are initiated and continued as the children meet increasing challenges at school and in social interactions.

4.3 Strengths and limitations

We consider the prospective design as a strength of this study. In addition, a thorough assessment with clinical examinations and interviews with both parents and patients was conducted when possible, and supplementary information from the medical records and the CENTER-TBI database was valuable. The same experienced pediatric neurologist assessed the patients in the acute phase and at follow-up and reviewed all the patient's medical charts for all professional observations performed at admission and discharge. A consensus regarding the classification of met and unmet needs was achieved in collaboration with a specialist in rehabilitation medicine who did not meet the patients.

The modest group size from a single center is a limitation and poses a threat to statistical power and generalizability. However, the sample seems to be representative of pediatric patients hospitalized with TBI in our region [42]. The boy: girl ratio, age at injury, and injury mechanism correspond with the results regarding the epidemiology of the pediatric population of patients hospitalized with TBI in the southeast region of Norway [42]. The relatively low number of mild TBI cases might be due to the inclusion of hospitalized children and adolescents with TBI and easier recruitment of those with hospital stays of more than 24 hours. Furthermore, a performed CT scan as an inclusion criterion may have excluded some mildly injured patients.

Moreover, it is a limitation that we did not have a comparison group at 24 months. However, we did so at six months, and systematic differences between children with TBI and surgical controls were demonstrated [21]. Another disadvantage is that we did not use a validated measure for unmet needs. However, we used a model based on previous study assessing unmet needs in a pediatric TBI population [39].

5. Conclusions

This study demonstrated that patients with TBI in childhood might experience ongoing cognitive and emotional symptoms affecting school functioning and social interaction, implying a need for long-term health care and educational services. In particular, patients with cmTBI may be clinically expected to have a good prognosis at admission. However, they may have symptoms that remain undetected if follow-up visits are not planned. One-fourth of the patients reported unmet needs associated with reduced quality of life. Thus, there is a need for better follow-up, over several years, of the children and adolescents experiencing TBI to ensure that accommodation to care and referrals are initiated and continued as the children meet increasing challenges at school and in social interactions.

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Declaration of competing interests

None

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10. APPENDIX

Semi-structured interview and clinical examination

UNDERSØKELSESPROTOKOLL LEGE
6, 12 og 24 MND ETTER SKADE:

DEMOGRAFISKE DATA

Omsorgspersoner/foreldreansvar:
Begge foreldre ☐, Skilte **ID.nummer:** ....
Kjønn: ☐ Mann ☐ Kvinne ☐
Fødselsår: ☐☐☐☐

I hvilket land er du født?
Etnisitet: ....
Morsmål: ....
Annet/kommentar:

____

____

____

Familieanamnese:
Familiestruktur/ Omsorgssituasjon?

foreldre, bor hos begge ☐ ,
Skilte foreldre, bor hos en ☐ En forelder ☐

Antall søsken, nr i søskenflokken.:

TIDLIGERE SYKEHISTORIE:

Kjente sykdommer i familien, inkludert nevrologiske:

Tidligere utviklingsanamnese:
Graviditet, fødsel, neonatalforløp:
-Normalt forløp ☐
-Komplikasjoner:

____

____

____

-Innleggelser /Oppfølging i helsevesenet:

____

____

____

Utvikling:

- Gikk selvstendig, alder :
- Begynnende verbalspråk, alder :
- Sosial omgang med jevnaldrende:
    - Normal funksjon ☐
    - vansker ☐:

  Kommentarer:

- Ernæringsvansker ja ☐ nei ☐

Tiltak i tidlig barnealder mht motorikk, språk eller adferd:

Tiltak i barnehage, på skole:

Involvering av PPT

- før skolestart ja ☐ nei ☐
- etter skolestart ja ☐ nei ☐
- Hva bestod tiltaket i :

Involvering av BUP

- før skolestart ja ☐ nei ☐
- etter skolestart ja ☐ nei ☐

Oppfølging hos fysioterapeut

- første leveår ja ☐ nei ☐
- småbarnsalder (1-6 år) ja ☐ nei ☐
- Hva besto oppfølgingen i:

Tidligere situasjon:

Barnehageplass ja ☐ nei ☐

Skole (Hvilken studiesituasjon hadde du siste år før hodeskaden)

Skolefravær før hodeskaden samlet antall måneder: ......

Karakterer Norsk ☐ Engelsk ☐ Matte ☐

Annet/kommentar:

SOMATISKE SYKDOMMER

Har du, eller har du noen gang hatt noen av de følgende medisinske tilstandene

Helsetilstand	Ja	Nei	Vet ikke	Utdyp/presiser
Øyesykdom	☐	☐	☐	
Øresykdom	☐	☐	☐	
Hjertesykdom	☐	☐	☐	
Lungesykdom	☐	☐	☐	
Hudsykdom	☐	☐	☐	
Stoffskifte sykdom	☐	☐	☐	
Diabetes	☐	☐	☐	
Revmatisme	☐	☐	☐	
Muskelskjelettsykdom	☐	☐	☐	
Nevrologiske sykdommer	☐	☐	☐	
Annen sykdom/plage (spesifiser):	☐	☐	☐	

ETTER SKADEN:

Rehabiliteringsopphold
ja ☐ , hvor mange mnd: ....
nei ☐

Har barnet fått hjelp med :

1. Fysiske vansker (gange, håndfuksjon, ballanse)?	Ja	Nei
2. Problemer med kognitive vansker: (hukommelse, konsentrasjon, tenkning, problemløsning skole)	Ja	Nei
3. Emosjonelt (tristhet, sinne, impulskontroll)	Ja	Nei
4. Sosial interaksjon (tilpasningsevne, responsivitet, tilnærmelighet)	Ja	Nei
Har familien fått hjelp med håndtering av ny situasjon?	Ja	Nei

Oppfølging lokalt:

fastlege	ja ☐	nei ☐	hatt behov for ☐
lokal habilitering	ja ☐	nei ☐	hatt behov for ☐
skolehelsetjeneste	ja ☐	nei ☐	hatt behov for ☐
PPT	ja ☐	nei ☐	hatt behov for ☐
Statsped	ja ☐	nei ☐	hatt behov for ☐
BUP	ja ☐	nei ☐	hatt behov for ☐
Fysioterapeut	ja ☐	nei ☐	hatt behov for ☐
Ergoterapeut	ja ☐	nei ☐	hatt behov for ☐
Sosialkontoret	ja ☐	nei ☐	hatt behov for ☐
Logoped	ja ☐	nei ☐	hatt behov for ☐

Hvis nei, ved behov: Hva er grunnen?

Hvis ja: Hvilke tiltak er igangsatt:

Ytelse fra Nav (sett ett eller flere kryss)

100% pleiepenger	Ja	Nei
Graderte pleiepenger	Ja	Nei
Stønader (grunn/hjelpestønad)	Ja	Nei
Ingen av de overnevnte ytelser fra NAV	Ja	Nei

<u>Nåværende boforhold?</u>

Boform:

☐ Med familie, ingen tiltak ☐ Tilpasset bolig ☐ Avlastning

Annet/kommentar:

<u>Nåværende dagligliv:</u>

Er du tilbake i barnehage (hel- eller deltid, minst 50%)	Ja	Nei
Er du i student eller skoleelev (hel- eller deltid, minst 50%)	Ja	Nei
Tilbake i fritidsaktiviteter	Ja	Nei
Sosial aktivitet/ samvær med venner		
Mindre enn før	Ja	t/ uke……
Som før	Ja	t /uke ……

Varighet av fravær fra barnehage eller skole etter hodeskaden, samlet antall måneder: …………

Karakterer Norsk ☐ Engelsk ☐ Matte ☐

Annet/kommentar (lekser, redusert fagkrets, spes.ped):

SOMATISK STATUS

Generell

BT:_________ Puls:________ Høyde:_______cm Vekt:_______kg

Kommer til undersøkelsen Gående Rullestol

Annet, beskriv:

Plager i øyeblikket Ingen Ja

Evt . utdyp:

Kommentar(er):

Mentale funksjoner:

Bevissthetsnivå normalt	Ja	Nei
Oppmerksomhet normal	Ja	Nei
Hukommelse normal	Ja	Nei
Interaksjon normal	Ja	Nei
Aktivitetsnivå normalt	Ja	Nei
Psykisk helse		
Nøytralt stemningsleie	Ja	Nei
Gjør greit rede for seg	Ja	Nei
Samarbeider godt	Ja	Nei
Orientert for tid, sted og situasjon	Ja	Nei

Kommentar

Tale og svelgfunskjon

Dysartri	Ja	Nei
Afasi	Ja	Nei

Dysfagi Ja Nei
Kommentar:

Sansefunskjoner og smerte:

Endret luktesans Ja Nei
Endret synsfunksjon Ja Nei
  Ptose Ja Nei
  Nystagmus Ja Nei
  Dobbeltsyn Ja Nei
Normal sensibilitet Ja Nei
Smerter Ja Nei
Søvnvansker Ja Nei
Kommentar:

Nerve-muskel-skjelett og bevegelsesrelaterte funksjoner

Synlige feilstillinger eller ufrivillige bevegelser Ja Nei
Muskelkraft:
Normal Ja Nei
  Hvis nei: nedsatt i overeks Ja Nei
  nedsatt i undereks Ja Nei

Motorikk:

Normal tempo og finmotorikk i ekstremitetene Ja Nei
Normal gange Ja Nei
Normal ballanse Ja Nei
Kommentar:

Reflekser

Normalt livlige reflekser (2+ til 3+) bilateralt i biceps Ja Nei
triceps Ja Nei
brachioradialis Ja Nei
patella Ja Nei
akilles Ja Nei
Nedadvendt plantarrefleks bilateralt Ja Nei