POPULATION STUDY AND LONG-TERM OUTCOME IN PEDIATRIC TRAUMA

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POPULATION STUDY AND LONG-TERM OUTCOME IN PEDIATRIC TRAUMA

ONDERZOEK NAAR DE POPULATIE EN DE UITKOMSTEN OP DE LANGE TERMIJN VAN KINDEREN MET EEN LETSEL DOOR EEN ONGEVAL

(met een samenvatting in het Nederlands)

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door

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geboren op 26 januari 1981
te Breda

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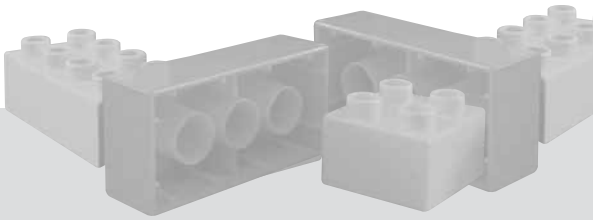
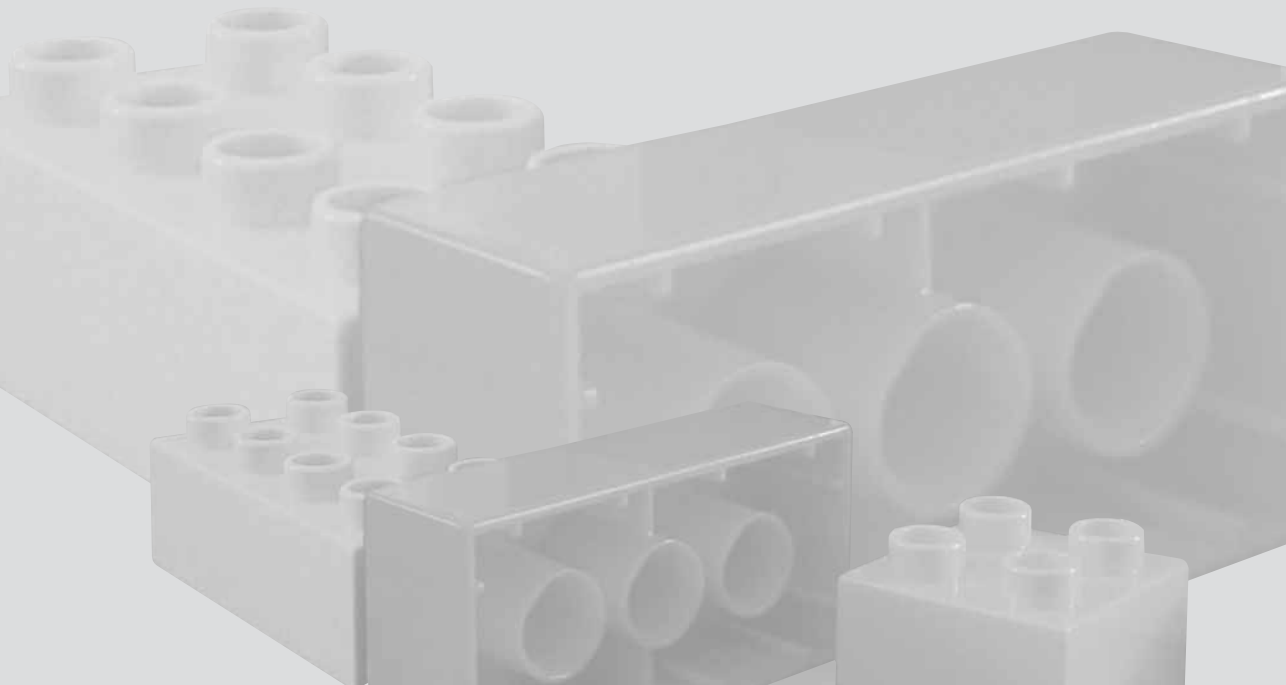




1

GENERAL INTRODUCTION

General introduction

Trauma is the leading cause of death among children of Western societies.[1-3] In the Netherlands about 200 children and adolescents die every year from trauma.[1,4] Fortunately, the mortality rate for pediatric trauma in the Netherlands was halved in the last 15 years.[1,4] So, the combined effort of prevention activities and improvements of prehospital and hospital care seemed fruitful. However, the burden of pediatric trauma is not only based on mortality rates. Trauma is also the leading cause of disability among children of Western societies.[5-9] In these children the health condition and perhaps the health-related quality of life can be affected lifelong. The focus of this thesis is the group of children that survived a trauma, and might have to live with disabilities.

The amount of survivors of pediatric trauma increased, as a result of the decreased mortality rate. In literature, the switch from the main focus on mortality towards morbidity has yet to be made. Instead of survival, the outcome of pediatric trauma research should rather be health condition or quality of life. Especially the long-term outcome in major pediatric trauma is relatively unknown. Recent developments in pediatric trauma care were analyzed with short-term outcomes and with mortality rates.[10-21] Prevention of death is a good start in pediatric trauma care, but after that, the biggest challenge should be to improve the long-term outcome. The main goal of this thesis is to increase the awareness that further development of pediatric trauma care is necessary. Hopefully, it initiates a research cascade that will improve the pediatric trauma care of the future, and eventually lead to an increased health condition and health-related quality of life of pediatric trauma survivors.

Recent developments in pediatric trauma care

In the past decades multiple changes were made to pediatric trauma care in Western societies. Helicopters were brought into action more frequently, for a quick transportation of injured children to the nearest suitable trauma center.[10,11] Triage systems were introduced for a quick assessment of the urgency of care.[12-14] And trauma care was increasingly regionalized towards referral of severely injured children to specialized trauma centers.[15,16] In the Netherlands trauma care was regionalized in 1999 / 2000. Eleven level-one trauma centers were designated spread throughout the country. Still, pediatric trauma was treated at adult trauma centers, since no specialized pediatric trauma centers were designated. In Australia and the United States regionalization of pediatric trauma care resulted in lower mortality and better functional outcome of children after major trauma.[17-21] The effect of regionalization of trauma care for the pediatric population in the Netherlands was never analyzed before. It may provide us with information on what to expect from a future introduction of a specialized pediatric trauma center.

What is functional outcome?

Many terms are being used to describe functional outcome in health care. For example: health condition, health status, functional status, health related quality of life, well-being, etc. In this thesis a distinction is made between health condition and health-related quality of life. The definition of health-related quality of life according to the World Health Organization (WHO) is the individuals' perception of their position in life in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns.[22] Health condition is described by three domains: body function and structure, activities, and participation. These three domains are interrelated and also influenced by personal and environmental factors. This WHO model to describe health condition is called the International Classification of Functioning, Disability, and Health (ICF), and is shown in figure 1.[23] Building from that definition it could be argued that health-related quality of life is the individuals' perception of their health condition.

Measuring functional outcome

Health-related quality of life and health condition are both comprehensive concepts. There is a continuing discussion on what is the best way to measure these concepts. According to the above-mentioned definitions of the WHO, health-related quality of life is the subjective derivative of the health condition. So, logically, the best way to measure health-related quality of life is by asking the person itself. Health condition is an objective concept; therefore, it is less important who the source of the information is. So, measuring the health-related quality of life in very young children that cannot

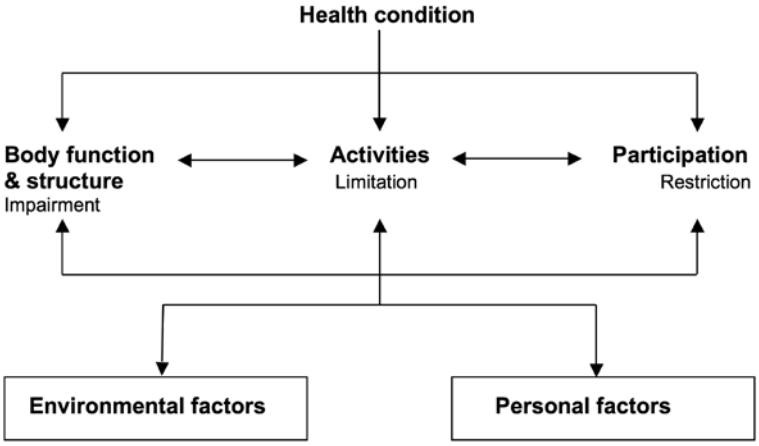


Figure 1 The International Classification of Functioning, disability and health of the World Health Organization.[23]

report for themselves is not very useful, whereas health condition can be measured with the information given by parents and/or caretakers. However, the distinction between these concepts is not always that clear in practice.

Classification of injury severity, diagnosis and trauma mechanisms

In trauma care research the use of classifications is popular: codes to describe the diagnosis and the mechanism of injury, and scores for the severity of injury, the urgency of care, and to predict outcome. In this thesis three of these classifications are used frequently: the Injury Severity Score (ISS), the International Classification of Diseases diagnostic code (ICD-9), and the External Causes of Injury and Poisoning codes (E-codes). These three classifications will now be explained.

The first publication about the ISS was by Baker et al. in 1974.[24] The ISS is a method to describe the overall severity of injury in patients with multiple trauma that affect more than one area of the body. The ISS is based on the Abbreviated Injury Scale (AIS), which is an anatomical scoring system for the severity of injury. Injuries are ranked on a scale from 1 minor to 6 unsurvivable.To calculate the ISS the squares of the highest AIS rating for each of the three most severely injured body areas are added.[24,25] For example when a patient has multiple rib fractures (AIS2 thorax), and a superficial laceration on the thorax (AIS1 external), the ISS would be 5 (2^2+1^2). When there was also a unilateral hemothorax (AIS3 thorax) and a cerebral contusion (AIS3 head) diagnosed, the ISS would be 19 ($3^2+3^2+1^2$). The ISS has proven to be a good predictor for mortality in children with trauma.[26-28] An ISS ≥ 16 is defined as major trauma.

The World Health Organization published the ICD-9 in 1979. It is an international standard in mortality and morbidity statistics and is designed to promote international comparability.[29] All diseases and other health problems are assigned a 3 digit number with a possible 1 or 2 digits behind the dot for further specification. Injury and poisoning together are assigned ICD-9 codes from 800 to 999. The E-codes are an addition to the trauma-related ICD codes and are used to identify the cause and intent of the injury. E-codes are numbered from E800-E999, and can also have 1 or 2 digits behind the dot for further specification.

Aims of the thesis

The first aim is to describe trends in moderate to severe pediatric trauma in the Netherlands, and to describe changes in mortality and referral behavior after regionalization of trauma care. The second aim is to describe the health condition and health-related quality of life long-term after major pediatric trauma, and to select the best suitable measures to do so.

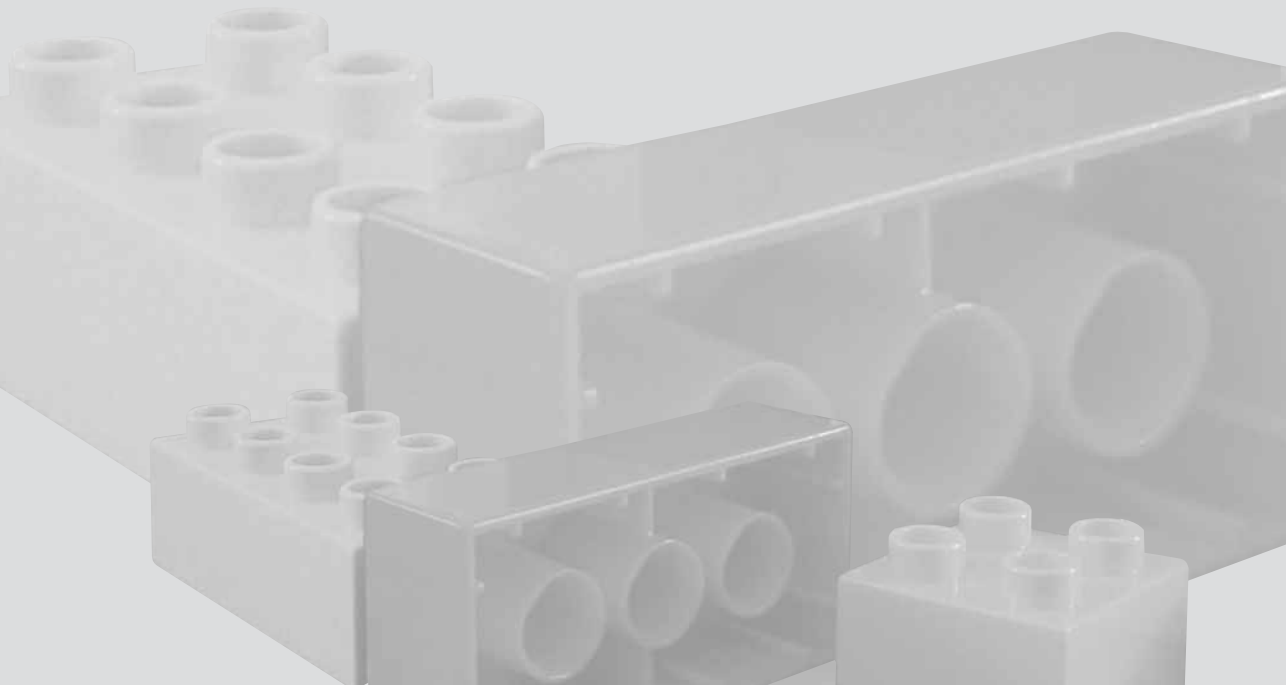
Outline of the thesis

In chapter 2 trends in moderate to severe pediatric trauma of trauma care region Central Netherlands are described from 1996 to 2009, and target groups for prevention activities are selected. The changes in mortality rates and referral behavior after regionalization of trauma care in 1999 / 2000 are described in a surveillance-based before-after study in chapter 3. In chapter 4 a systemic review is presented, in which health-related quality of life measures are compared for their use in children after major trauma. The assessment includes the suitability of the measures to be used in large age-ranges, the reliability and validity of the measures, and whether the measures cover a substantial amount of the domains of functioning using the International Classification of Functioning, Disability, and Health of the World Health Organization. Chapter 5 and 6 present a pilot study about the outcome in children long-term after major trauma. The health condition for these children is described in chapter 5 and the health-related quality of life in chapter 6. Finally, the results of this thesis are discussed in chapter 7.

References

1. World Health Organization mortality database 2010. www.who.int/healthinfo/morttables
2. Peden M, Oyegbite K, Ozanne-Smith J, et al. World report on child injury prevention. Geneva: World health Organization 2008.
3. O'Neale Roach J. Injuries kill over 20.000 children a year in developed countries. Biomedical Journal 2001;322:317.
4. Central Bureau of Statistics, Statline, the Netherlands. Statline.cbs.nl/statweb/
5. Polinder S, Haagsma JA, Toet H, Brugmans MJP, van Beeck EF, the EUROCOST and APOLLO reference group. Burden of injury in childhood and adolescence in 6 European countries. BMC Public Health 2010;10:45.
6. Polinder S, Meerding WJ, Toet H, Mulder S, Essink-Bot ML, van Beeck EF. Prevalence and prognostic factors of disability after childhood injury. Pediatrics 2005;116(6):810-817.
7. Evans SA, Airey MC, Chell SM, Connelly JB, Rigby AS, Tennant A. Disability in young adults following major trauma: 5 year follow up of survivors. BMC Public Health 2003;3:8.
8. Hu X, Wesson DE, Logsetty S, Spence LJ. Functional limitations and recovery in children with severe trauma: a one-year follow-up. J Trauma 1994;37(2):209-213.
9. Wesson DE, Williams JI, Spence LJ, Filler RM, Armstrong PF, Pearl RH. Functional outcome in pediatric trauma. J Trauma 1989;29(5):589-592.
10. Schmidt U, Geerling J, Fuehler M, Hubrich V, Richter M, Krettek C. Die Praeklinische versorgung des pediatrischen traumapatienten: ein retrospectiver vergleich zwischen luft- und bodengebundener rettung. Unfallchirurg 2002;105(11):1000-1006.
11. Moront ML, Gotschall CS, Eichelberger MR. Helicopter transport of injured children: system effectiveness and triage criteria. J Ped Surg 1996;8:1183-1188.
12. Veen van M, Steyenberg EW, Ruige M, van Meurs AH, Roukema J, van der Lei J, Moll HA. Manchester triage system in paediatric emergency care: prospective observational study. BMJ 2008;337:a1501.
13. Engum SA, Mitchell MK, Scherer LR, Gomez G, Jacobson L, Solotkin K, Grosfeld JL. Prehospital triage in the injured pediatric patient. J Ped Surg 2000;35(1):82-87.
14. Jubelirer RA, Agarwal NN, Beyer FC, Ferraro PJ, Jacobelli MC, Pfeifer WF, Shah MA. Pediatric trauma triage: review of 1,307 cases. J Trauma 1990;30(12):1544-1547.
15. Nathens AB, Jurkovich GJ, Rivara FP, Maier RV. Effectiveness of state trauma systems in reducing injury-related mortality: a national evaluation. J Trauma 2000;48:25-31.
16. Mullins RJ. A historical perspective of trauma system development in the United States. J Trauma 1999;47(3 suppl):S8-S14.
17. Pracht EE, Tepas III JJ, Langland-Orban B, Simpson L, Pieper P, Flint LM. Do pediatric patients with trauma in Florida have reduced mortality rates when treated in designated trauma centers? J Ped Surg 2008; 43:212-221.
18. American academy of pediatrics, pediatric orthopaedic society of North America. Management of pediatric trauma. Pediatrics 2008;121:849-854.

19. Potoka DA, Schall LC, Ford HR. Improved functional outcome for severely injured children treated at pediatric trauma centers. J Trauma 2001;51:824-834.
20. Potoka DA, Schall LC, Gardner MJ, Stafford PW, Peitzman AB, Ford HR. Impact of pediatric trauma centers on mortality in a statewide system. J Trauma 2000;49:237-245.
21. Doolin EJ, Browne AM, DiScala C. Pediatric trauma center criteria: an outcome analysis. J Pediatr Surg 1999;34:885-890.
22. WHOQOL Group. The World Health Organization Quality of Life assessment (WHOQOL): Position paper from the World Health Organization. Social Science & Medicine 1995;41:1403–1409.
23. World Health Organization. International classification of functioning, disability and health: ICF. Geneva, Switserland: World Health Organization; 2001.
24. Baker SP, O'Neill B, Haddon W, Long WB. The injury severity score: a method for describing patients with multiple injuries and evaluating emergency care. J Trauma 1974;14(3): 187-196.
25. Baker SP, O'Neill B. The injury severity score: an update. J Trauma 1976;16(1):882-885.
26. Cantais E, Paut O, Giorgi R, Viard L, Camnoulives J. Evaluating the prognosis of multiple, severely traumatized children in the intensive care unit. Intensive care medicine 2001;27:1511-1517
27. Ott R, Krämer R, Martus P, Bussenius-Kammerer M, Carbon R, Rupprecht H. Prognostic value of trauma scores in pediatric patients with multiple injuries. The journal of trauma injury, infection, and critical care 2000;49:729-736
28. Orliaguet GA, Meyer PG, Blanot S, Jarreau MM, Charron B, Buisson C, Carli PA. Predictive factors of outcome in severely traumatized children. Anesthesia and analgesia 1998;87:537-542
29. World Health Organization International Classification of Diseases www.who.int/classifications/icd



2

TRENDS IN MODERATE TO SEVERE PEDIATRIC TRAUMA

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Caspar W.N. Looman, Ed F. van Beeck

Submitted

Abstract

Background Trend analyses of hospital discharge data can raise signals for prevention policies, but are often flawed by changes in health care consumption. This is the first trend analysis worldwide of the clinical incidence of pediatric trauma that used international criteria to overcome this bias. The objective is to describe trends in clinical incidence of moderate to severe pediatric trauma, and to identify target groups for prevention activities.

Methods Included were all pediatric trauma patients (0-18 years) that were discharged from one of the hospitals of trauma care region Central Netherlands from 1996 to 2009. Selection was made on Injury Severity Score (ISS) ≥ 4, and on trauma related International Classification of Diseases (ICD-9) diagnostic codes, and trauma related External Causes of Injury and Poisoning code (E-codes). Trend analyses were performed using Poisson loglinear regression and linear regression, with correction for age and gender.

Results 23 682 patients were included, the mean incidence rate was 477 / 100 000 person-years. Since 2001 the incidence rate of moderate to severe trauma increased with 1.1% annually (95% CI 0.7-1.5), caused by an increase of falls (3.9%, 95% CI 3.3-4.5), sport injuries (5.4%, 95% CI 4.3-6.5), and bicycle injuries (3.8%, 95% CI 2.8-4.8). The incidence of falls and sport injuries peaked in young children (0-9) and older boys (10-18) respectively. Bicycle injuries affected all children between 5 and 18.

Conclusions The incidence of pediatric trauma in the center of the Netherlands increased since 2001. Trend analyses on moderate and severe injuries may identify target groups for prevention in a trauma region.

Introduction

Trauma is one of the leading causes of death among children and adolescents around the globe.[1-3] But in Western societies, the combined efforts of prevention activities and improvements of pre-hospital and hospital care have sharply reduced pediatric trauma mortality rates over the past decades.[1,4-8] In addition to mortality data, health policy in the new millennium needs other indicators to identify target groups for prevention.

Recent studies in Finland and Australia based on hospital discharge data showed that the incidence rate of pediatric trauma increased, despite a decrease of the mortality rate for those countries during that same period.[4,6] Trend analyses of hospital discharge data can raise signals for prevention policies, but it must be considered that they are often flawed. Langley et al. have shown that significant overestimates of incidence and incorrect conclusions about trends would lurk, if the crude hospital discharge data were used for estimating injury incidence.[9] If crude hospital discharge data are used, injuries of low severity are also included, which introduces bias resulting from changes in health care consumption patterns (e.g. changes in admission policies of hospitals and/or help seeking behavior of patients). Therefore, Langley et al. provided a set of selection criteria, including the restriction to injuries of moderate and high severity (ISS $\geq$ 4).[9] This helps to overcome bias related to health care consumption and focuses on injuries with the highest risks of unfavorable consequences. Higher injury severity scores are related to higher disability rates.[10] A study in severely injured children showed that after 7 years, still 40% of the patients had restrictions in their daily activities.[11]

Children with moderate to severe trauma form a heterogeneous group. Not only the kind of injury has an enormous variety, but also the mechanisms of injury are various. Gender specific differences are found, and there are differences between age categories. For example males are affected in 58 to 70% of the severe trauma cases.[12-15] Falls occur mainly in young children, whereas traffic and sport accidents mostly affect older children.[13,15,16] Large differences between countries and cultures are also seen, for example the differences between countries of Eastern and Western Europe, between races in the USA, and between aboriginal and non-aboriginal cultures in Canada.[5,12,17]

The World Health Organization called for 'greater commitment and action from policymakers and practitioners to decrease the burden of injuries in children', as cited from the European report on child injury prevention.[18] A first step towards decreasing this burden would be to understand how pediatric trauma populations are composed, and what trends can be observed in specific countries or regions. Patient categories that are affected most, or who are increasingly affected over time, can be selected as target groups for prevention activities.

The objective of this study is to describe trends in clinical incidence of moderate to severe pediatric trauma from 1996 to 2009, and to identify target groups for prevention activities in a Dutch trauma region.

Methods

Trauma care region Central Netherlands includes 9 hospitals that cover an urban area of about 2100 km^2 in the center of the Netherlands. The area is densely populated with about 800 inhabitants per square kilometer.[19] The university hospital is designated as a level one trauma center, three hospitals are designated as level two, and the remaining five hospitals are designated as level three. In the Netherlands there are no specialized pediatric trauma centers, so pediatric trauma is treated at adult trauma centers.

Data collection

Data was extracted from the Dutch Medical Register, which is a continuous registration of all hospital admissions in the Netherlands. It has a 100 percent coverage in the study region. The Dutch Medical Register includes patient demographics, date of admission and discharge, in-hospital mortality, International Classification of Diseases (ICD-9) diagnostic codes, and external causes of injury and poisoning codes (E-codes). The Injury Severity Score (ISS) was calculated from the ICD-9 diagnostic codes. We used the software program designed and validated by MacKenzie et al.[20] Population sizes were obtained from the Dutch Central Bureau of Statistics.[19]

During the study period 6 hospital fusions or takeovers took place in Central Netherlands. This resulted in missing data for two hospitals in 1999 and 2000, and for one hospital in 2007 to 2009. The two hospitals with missing data in 1999 and 2000 together treated an estimate of 14% of the pediatric trauma patients (ISS ≥ 4) of the region. This estimation was based on the amount of patients that these hospitals treated in the three years before and the three years after the two missing years. The hospital with missing data from 2007 to 2009 treated an estimate of 13% of the severe pediatric trauma patients of the region. This estimation was based on the amount of patients treated in the 3 years before the missing years. To calculate incidence rates in 1999 / 2000 and 2007-2009, 14% and 13% was added to the total amount of patients respectively to adjust for the missing data.

Patients

Included were pediatric trauma patients aged 0 to 18 years that were discharged from one of the hospitals of trauma care region Central Netherlands between January 1st 1996 and December 31st 2009. Only patients with an ISS of at least 4 and with an admission of at least one day were included. Further selection was made based on the ICD-9 diagnostic code of the principal diagnosis and the E-code of the principal

diagnosis. Included were patients with an ICD-9 between 800 and 904.9, or between 910 and 959.9, and with an E-code between E800 and E999. Excluded were E850-E879.9, E903.04-904.99, E929-E949.9, E959, E969, E977-E982.9, E989, and E999, because these E-codes are not directly trauma related. Readmissions and patients who died before admission to the hospital were excluded.

Data analysis

Causes of injury recorded by the E-codes were divided into six categories: falls, traffic, sports, other unintentional, intentional and unspecified. The category other unintentional included causes of injury with low frequencies like: machine or tool, fire, drowning, or choking. The category intentional included assault as well as self-inflicted injuries. According to the WHO standards, patients were divided into gender-specific 5-year age groups. To analyze trends in incidence rates Poisson loglinear regression with offset was used with correction for age and gender. To analyze trends in mean ISS and mean age linear regression was used with correction for age and gender. The Statistical Package for the Social Sciences (SPSS) version 17.0 was used to perform the statistical analyses.

Results

The inclusion criteria were met by 23 682 patients of which 62% was male. Mean age was 9.9 years (SD 5.2) and mean ISS was 5.6 (SD 4.7). The mean incidence rate of moderate to severe pediatric trauma was 477 / 100 000 person-years. In total 91 patients died during hospitalization of which 73 in traffic. The mean age decreased with 6.1% annually (95% CI 4.6-7.7), and the mean ISS with 5.8% (95% CI 4.3-7.2). The incidence rate of pediatric trauma initially decreased, but increased since 2001 with 1.1% annually (95% CI 0.7-1.5). (table 1 and figure 1)

Cause of injury

The incidence of falls was stable from 1996 to 2000 at around 145 / 100 000 person-years. Since the year 2000 the incidence of falls had an annual increase 3.9% (95% CI 3.3-4.5). The incidence of sport injuries has almost doubled over time, with an annual increase of 5.4% (95% CI 4.3-6.5). The incidence of traffic injuries decreased with 2.2% annually (95% CI 1.9-2.6). When further specifying traffic injuries into pedestrian, bicycle, moped/motorcycle, and car/bus/train injuries, a different trend is found for bicycle injuries compared to the other modes of transport since 2001. The incidence of bicycle injuries increased with 3.8% (95% CI 2.8-4.8) from 2001 to 2009, whereas the incidence of other traffic injuries decreased or stabilized. So, since 2001 there has been an increase of fall, sport, and bicycle injuries. (figure 2 and figure 3).

Table 1 General characteristics of moderate to severe pediatric trauma in trauma region Central Netherlands from 1996 to 2009. N: Total amount of patients that meet the inclusion criteria (see methods section). CN 0 - 18y: Inhabitants of Central Netherlands aged 0 - 18.

Year	N	Mean age (SD)	Mean ISS (SD)	n death (%)	CN 0-18y
1996	1564	10.4 (5.36)	5.9 (5.40)	6 (0.38)	347 325
1997	1681	10.2 (5.35)	5.9 (5.49)	12 (0.71)	350 204
1998	1605	10.3 (5.21)	5.9 (5.54)	10 (0.62)	352 184
1999	1456	10.3 (5.14)	5.8 (4.89)	7 (0.48)	355 482
2000	1414	10.1 (5.17)	6.1 (5.88)	10 (0.71)	358 425
2001	1485	10.3 (5.19)	5.5 (4.16)	6 (0.40)	362 974
2002	1717	10.0 (5.03)	5.7 (4.71)	8 (0.47)	372 439
2003	1818	9.8 (5.21)	5.6 (4.52)	4 (0.22)	377 100
2004	1849	9.7 (5.14)	5.5 (4.33)	3 (0.16)	381 326
2005	1869	9.7 (5.22)	5.3 (4.16)	4 (0.21)	384 135
2006	1910	9.5 (5.41)	5.4 (4.16)	6 (0.31)	385 304
2007	1771	9.6 (5.14)	5.4 (4.22)	8 (0.45)	386 771
2008	1807	9.8 (5.30)	5.4 (4.38)	4 (0.22)	387 936
2009	1736	9.6 (5.32)	5.1 (3.37)	3 (0.17)	388 756

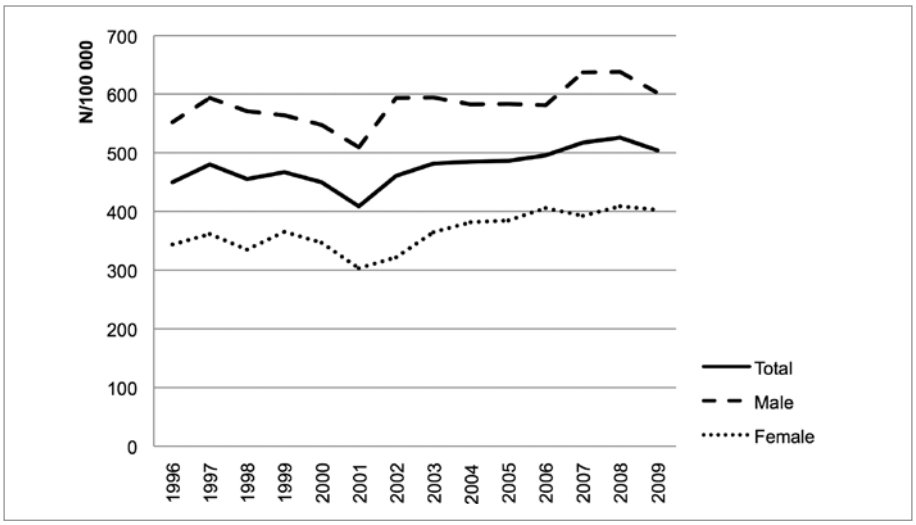

Figure 1 Gender specific incidence rates (N / 100 000) of moderate to severe pediatric trauma (ISS ≥ 4, age 0 -18) in trauma care region Central Netherlands from 1996 to 2009.

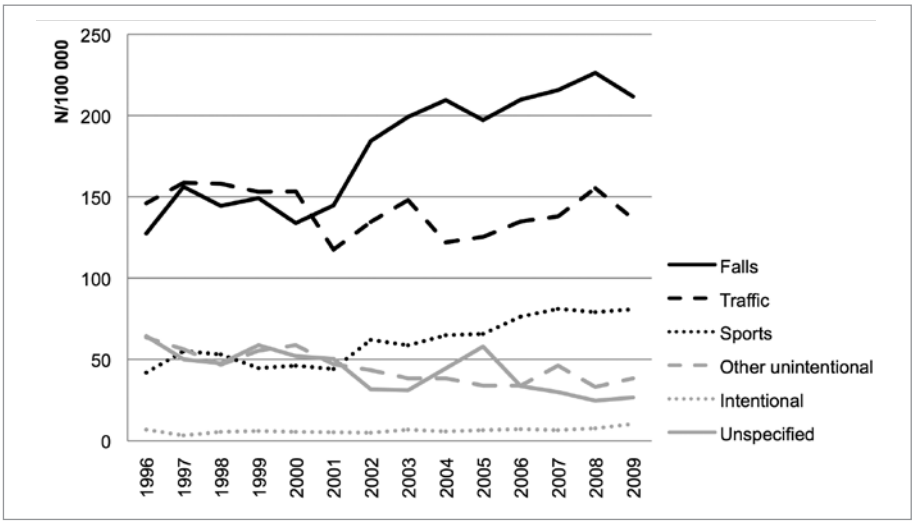

Figure 2 Causes of injury of the principal diagnosis of moderately to severely injured children (ISS ≥ 4, age 0 -18) in trauma care region Central Netherlands from 1996 to 2009.

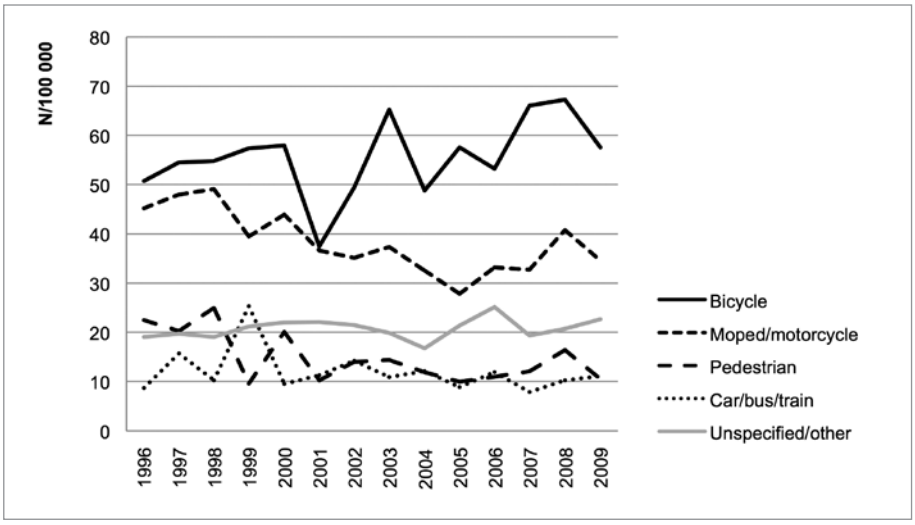

Figure 3 Incidence of moderate to severe traffic injuries in children of trauma care region Central Netherlands from 1996 to 2009.

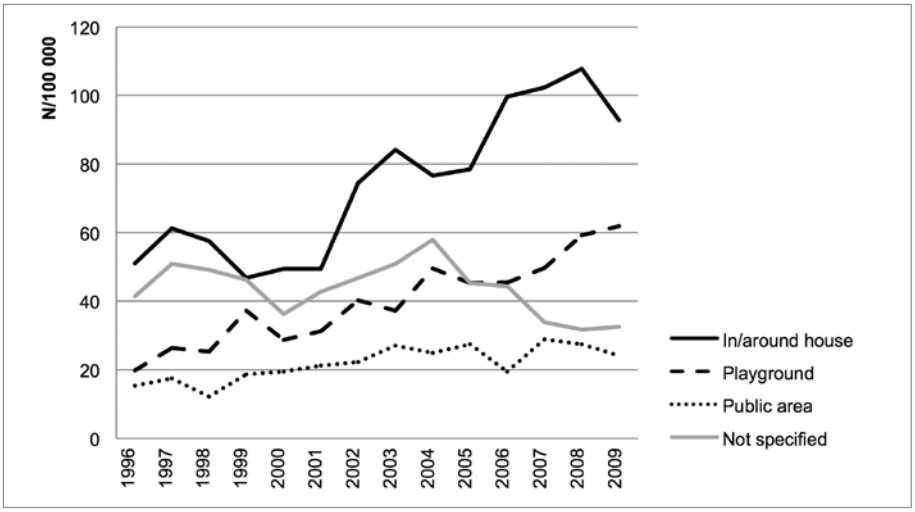

Figure 4 Incidence of moderate to severe fall injuries in children of trauma care region Central Netherlands from 1996 to 2009.

Falls

The male-female ratio of falls was 1.4:1. The incidence of falls was highest in the age categories 0-4 and 5-9 and lowest in the age category 15-18. In 67% of the patients the principal diagnosis affected the extremities, in 30% of the patients the head or the neck was affected. These proportions did not change over time. Most fall-related injuries occurred in or around the house (41%) or at the playground (22%) (figure 4). The mean ISS of fall-related injuries was 5.1 (SD 3.5) and had an annual decrease of 3.0% (95% CI 1.2-4.8).

Sport injuries

The male-female ratio of sport injuries was 2.5:1. The incidence of sport injuries was highest in 10 to 18 year old males and lowest in the age category 0-4. In 85% of the patients the principal diagnosis affected the extremities, in 11% of the patients the head or the neck was affected. These proportions did not change over time. The upper extremities (64%) were affected more frequently than the lower extremities. The mean ISS of sport injuries was 4.6 (SD 2.9) and did not change over time.

Bicycle injuries

The male-female ratio of bicycle injuries was 1.6:1. The incidence of bicycle injuries was highest in the age category 10-14, followed by age categories 15-18 and 5-9,

and lowest in the age category 0-4. In 49% of the patients the principal diagnosis affected the extremities, in 42% the head or the neck, and in 6% the abdomen or pelvic. The mean ISS of bicycle injuries decreased from 6.7 (SD 6.2) in 1996 to 5.3 (SD 3.7) in 2009, the annual decrease was 5.6% (95% CI 0.3-10.7).

Discussion

Pediatric trauma causes a high burden of injury in spite of low mortality figures. We observed a mean incidence rate of 477 / 100 000 children, i.e. one out of 200 children in the region suffers from moderate to severe trauma each year. The mean ISS and the mean age of children with moderate to severe trauma decreased between 1996 and 2009. However, the incidence rate increased since 2001. This increase could be attributed to fall, sport, and bicycle injuries. Each group had its own characteristics. Fall-related injuries occurred mainly in patients under 10 years old and affected the extremities in two-thirds, and the head or neck in about one-thirds of the cases. Sport injuries occurred mainly in boys from 10 to 18 years old and affected the extremities primarily. Bicycle injuries occurred in all age- and gender categories except for the youngest (0-4). Compared to the other groups, the amount of head/neck and abdomen/pelvic injury was high for bicycle injuries.

Methodological issues

The inclusion criteria used were based on the standard set by Langley at al. for the use of hospital discharge data to estimate injury incidence.[9] As far as we know of, this is the first trend analysis worldwide of hospital discharge data of pediatric trauma, that used Langley's international criteria to overcome registration bias. Patients were selected by their ICD-code of the principal diagnosis and a hospital stay for at least one day. Only first admissions were included. Injuries due to medical procedures were excluded. Langley et al. stated that when examining trends in injury, it would be necessary to select injury cases which meet an anatomical severity threshold.[9] So, the ISS was used to further select our cases with a cut-off point of 4.

A generic limitation of using administrative databases concerns data validity, but a quality survey conducted during the study period has shown a high accuracy of coded injury data in our database: correctly coded in 91% of cases and in 9% incomplete.[21] In addition, the vast majority of cases was registered with a specific External Cause of Injury Code (E-code). However, the use of unspecified E-codes changed from 14% in 1996 to only 5% in 2009, which could have potentially affected the results on trends by external cause of injury. We therefore conducted additional analyses on

the coding performances of the 9 separate hospitals and found that the decrease of the use of unspecified E-codes was solely caused by 2 out of 9 hospitals. These two hospitals covered 26% of the pediatric trauma care in the region. When these two hospitals were excluded, the amount of unspecified E-codes used was stable over time at about 7%. And after excluding these 2 hospitals, the trends in fall, traffic and sport injuries were similar to our primary analysis shown in figure 2. So, the results were not noticeably affected by the changing in the use of unspecified E-codes.

As mentioned in the patients and methods section, 14% and 13% of the data of the years 1999 / 2000 and 2007-2009 respectively, was based on extrapolations because of missing data due to hospital fusions and takeovers. It was decided to not exclude these hospitals, because denominator data were only available for the whole region, and calculating incidence rates would become impossible. If all three hospitals with missing data were excluded, covering 37% of the pediatric trauma care in the region, the incidence trend was similar to the one shown in figure 1. So, it is not likely that the estimation of the missing data has largely affected our results.

Results in relation to the international literature

Falls were the most frequent (38%) cause of injury in children. This was also seen on emergency departments and in discharge databases of other countries, where fall injuries caused 26 to 41% of the injuries.[7,13,15,16,22,25,26] In pediatric patients with ISS > 9 in New Zealand, traffic was the primary cause of injury (68%), falls became second with 34%, without specification to age.[27] Risk factors for injuries due to falls in children were reviewed by Khambalia et al. in 2006.[28] The most frequent risks were being dropped by a care taker, rolling off a bed or furniture, the use of bunk beds in children under 6, and falling down a staircase.[28] In the Netherlands the use of stair gates was investigated in homes with toddlers in 2004.[29] Most parents (83%) reported to have at least one stair gate installed, but only half of them used it consequently.[29] At the playground the risk of severe injury due to falls can be reduced by a maximum height for playground equipment of 1.5m and a soft ground surface.[30,31]

We found that sport injuries were a frequent cause of injury of the extremities in males in their second decade of life. This was also seen in the pediatric population of the emergency departments in Sweden, Belgium, Canada, and the United States.[7,25,26,32] In the United States more than half of the pediatric sports-related hospitalizations were attributed to fractures.[33] Abernethy et al. performed a systematic review on prevention strategies for sport injuries in adolescents. Effective strategies were preseason conditioning, functional training, education, balance, and sport-specific skills.[34]

In Central Netherlands the most severe pediatric injuries were caused by bicycle injuries, which made up 12% of the database. Children from 5 to18 years old were affected mostly. The amount of bicycle injuries that were treated and admitted in the United States was 19 / 100 000 and in France 14 / 100 000, compared to 67 / 100 000 for that same period in Central Netherlands.[35,36] A probable explanation for the high amount of cycling injuries in Dutch children is the popularity of the bicycle for transportation. In contrast, a bicycle helmet law for children is lacking, and the use of a bicycle helmet is very unpopular in the Netherlands.[37] In other countries a decrease in mild and severe head injuries in children was found when bicycle helmets were used more often.[38] It seemed difficult to convince children and adolescents to use a bicycle helmet with legislation.[39] The best ways to increase the use of bicycle helmets were community-based interventions and providing free helmets.[40]

Conclusions

The incidence of moderate to severe fall, sport, and bicycle injuries in the pediatric population in the center of the Netherlands has increased since 2001. Trend analyses on moderate and severe injuries may identify target groups for prevention in a trauma region.

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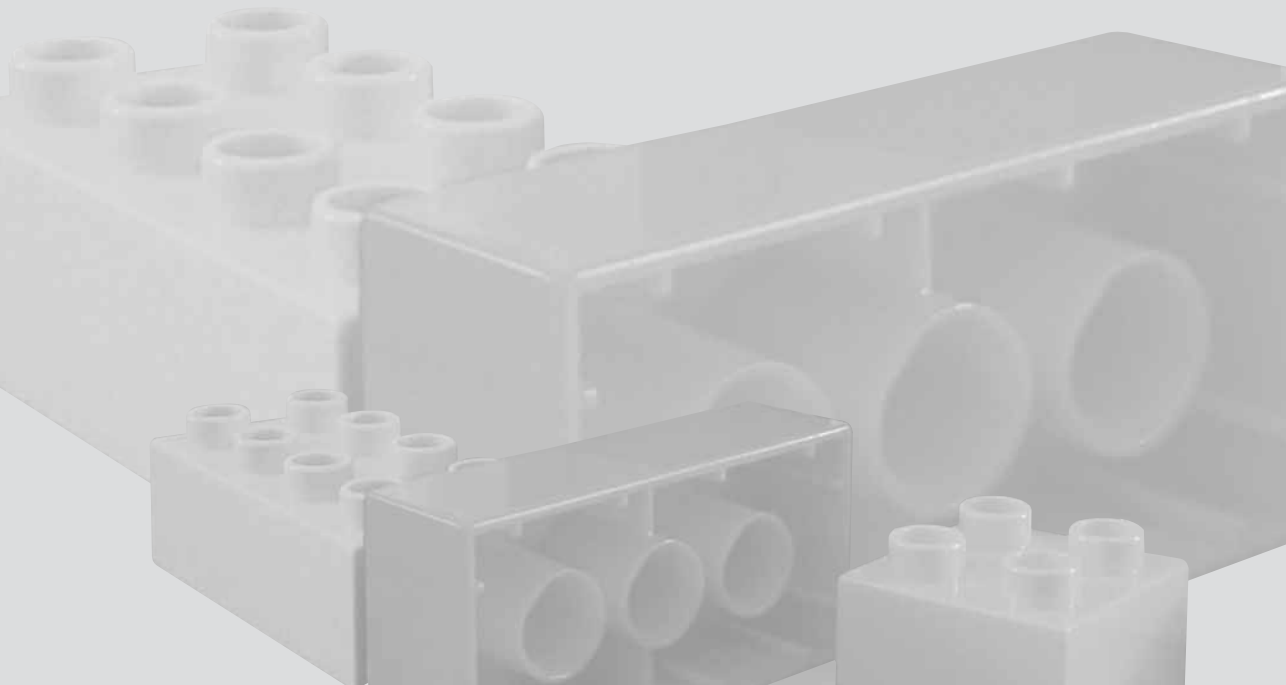
References

1. World Health Organization mortality database 2010. www.who.int/healthinfo/morttables/en/
2. Peden M, Oyegbite K, Ozanne-Smith J, et al. World report on child injury prevention. Geneva: World health Organization 2008.
3. O'Neale Roach J. Injuries kill over 20.000 children a year in developed countries. BMJ 2001;322:317.
4. Suominen JS, Pakarinen MP, Kaariainen S, Impinen A, Vartiainen E, Helenius I. In-hospital treated pediatric injuries are increasing in Finland: a population based study between 1997 and 2006. Scan J Surg 2011;100:129-135.
5. Polinder S, Haagsma JA, Toet H, Brugmans MJP, van Beeck EF, the EUROCOST and APOLLO reference group. Burden of injury in childhood and adolescence in 6 European countries. BMC Public Health 2010;10:45.
6. Shephard M. Trends in pediatric injury rates using emergency department based injury surveillance. Aust NZ Public Health 2010;34:262-268.
7. Stewart TC, Grant K, Singh R, Girotti M. Pediatric trauma in Southwestern Ontario: linking data with injury prevention initiatives. J Trauma 2004;57:787-794.
8. Roberts I, DiGuiseppi C, Ward H. Childhood injuries: extent of the problem, epidemiological trends, and costs. Inj Prev 1998;4:S10-S16.
9. Langley J, Stephenson S, Cryer C, Borman B. Traps for the unwary in estimating person based injury incidence using hospital discharge data. Injury Prevention 2002;8:332-337.
10. Sullivan T, Haider A, DiRusso SM, Nealon P, Shaukat A, Slim M. Prediction of mortality in pediatric trauma patients: new injury severity score outperforms injury severity score in the severely injured. J Trauma 2003;55:1083-1088.
11. Janssens EL, Gorter JW, Ketelaar M, Kramer WLM, Holtslag HR. Long-term health condition in major pediatric trauma: a pilot study. J Pediatr Surg 2009;44(8):1591-1600.
12. Alaghehbandan R, Sikdar KC, MacDonald D, Collins KD, Rossignol AM. Unintentional injuries among children and adolescnets in aboriginal and non-aboriginal communities, Newfoundland and Labrador, Canada. Int J Circumpolar Health 2010;69(1):61-71.
13. Cyr C, Xhignesse M, Lacroix J. Severe injury mechanisms in two paediatric trauma centres: determination of prevention priorities. Paediatr Child Health 2008;13(3):165-170.
14. Kypri K, Chalmers DJ, Langley JD, Wright CS. Adolescent injury morbidity in New Zealand, 1987-96. Inj Prev 2002;8:32-37.
15. Navascues del Rio JA, Romero Ruiz RM, Soleto Martin J, et al. First Spanish trauma registry: analysis of 1500 cases. Eur J Pediatr Surg 2000;10:310-318.
16. Agran PF, Anderson C, Winn D, Trent R, Walton-Haynes L, Thayer S. Rates of pediatric injuries by 3-month intervals for children 0 to 3 years of age. Pediatrics 2003;111(6):e683-e692.

17. Bernard SJ, Paulozzi LJ, Wallace DL, Center for Disease Control and Prevention (CDC). Fatal injuries among children by race and ethnicity: United States, 1999-2002. MMWR Surveill Summ 2007;56:1-16.
18. Sethi D, Towner E, Vincenten J, Segui-Gomez M, Racioppi F. European report on child injury prevention. World Health Organization Regional Office for Europe, Copenhagen 2008. ISBN 978 92 890 4295 6.
19. Central Bureau of Statistics, Statline, the Netherlands. Statline.cbs.nl/statweb/
20. MacKenzie EJ, Steinwachs DM, Shankar B. Classifying trauma severity based on hospital discharge diagnoses. Validation of an ICD-9CM to AIS-85 conversion table. Med Care 1989;27(4):412-422.
21. Paas G, Veenhuizen K. Utrecht: Prismant; 2002. Reliability of the LMR database.
22. Edwards P, Green J, Lachowycz K, Grundy C, Roberts I. Serious injuries in children: variation by area deprivation and settlement type. Arch Dis Child 2008;93:485-489.
23. Otters H, Schellevis FG, Damen J, van der Wouden JC, van Suijlekom-Smit LWA, Koes BW. Epidemiology of unintentional injuries in childhood. Br J Gen Pract 2005;55:630-633.
24. Hambidge SJ, Davidson AJ, Gonzales R, Steiner JF. Epidemiology of pediatric injury-related primary care office visits in the United States. Pediatrics 2002;109:559-565.
25. Hedstrom EM, Bergstrom U, Michno P. Injuries in children and adolescents: analysis of 41,330 related visits to an emergency department in northern Sweden. Injury 2011;Epub ahead of print.
26. Van de Voorde P, Sabbe M, Calle P, et al. Paediatric trauma and trauma care in Flanders (Belgium): methodology and first descriptive results of the PENTA registry. Eur J Pediatr 2008;167(11):1239-1249.
27. Couch L, Yates K, Aickin R, Pena A. Investigating moderate to severe paediatric trauma in the Auckland region. Emerg Med Australas 2010;22:171-179.
28. Khambalia A, Joshi P, Brussoni M, Raina P, Morrongiello B, MacArthur C. Risk factors for unintentional injuries due to falls in children aged 0-6 years: a systemic review. Inj Prev 2006;12:378-385.
29. Beirens TMJ, Brug J, van Beeck EF, Dekker R, Juttmann RE, Raat H. Presence and use of stair gates in homes with toddlers (11-18 months old). Accid Anal Prev 2007;39:964-968.
30. Sherker S, Ozanne-Smith J, Rechnitzer G, Grzebieta R. Out on a limb: risk factors for arm fracture in playground equipment falls. Inj Prev 2005;11:120-124.
31. Laforest S, Robitaille Y, Lesage D, Dorval D. Surface characteristics, equipment height, and the occurrence and severity of playground injuries. Inj Prev 2001;7:35-40.
32. Centers for Disease Control and Prevention (CDC). Nonfatal sports- and recreation-related injuries treated in emergency departments: United States, July 2000-June 2001. MMWR Morb Mortal Wkly Rep 2002;51(33):736-740.
33. Yang J, Peek-Asa C, Allareddy V, Phillips G, Zhang Y, Cheng G. Patient and hospital characteristics associated with length of stay and hospital charges for pediatric sports-related injury hospitalizations in the United States, 2000-2003. Pediatrics 2007;119:e813-e820.

34. Abernethy L, Bleakley C. Strategies to prevent injury in adolescent sport: a systemic review. Br J Sports Med 2007;41:627-638.
35. Mehan TJ, Gardner R, Smith GA, McKenzie LB. Bicycle-related injuries among children and adolescents in the United States. Clin Pediatr 2009;48:166-173.
36. Amoros E, Chiron M, Thelot B, Laumon B. The injury epidemiology of cyclists based on a trauma registry. BMC Public Health 2011;11:653-664.
37. Villamor E, Hammer S, Martinez-Olaizola A. Barriers to bicycle helmet use among Dutch paediatricians. Child Care Health Dev 2008;34(6);743-747.
38. Berg P, Westerling R. A decrease in both mild and severe bicycle-related head injuries in helmet wearing ages: trend analyses in Sweden. Health Promot Int 2007;22(3):191-197.
39. Castle SL, Burke RV, Arbogast H, Upperman JS. Bicycle helmet legislation and injury patterns in trauma patients under 18. J Surg Res 2010;Epub ahead of print.
40. Owen R, Kendrick D, Mulvaney C, Coleman T, Royal S. Non-legislative interventions for the promotion of cycle helmet wearing by children. Cochrane Database Syst Rev 2011;11:CD003985.



3

THE EFFECTS OF REGIONALIZATION OF PEDIATRIC TRAUMA CARE IN THE NETHERLANDS: A SURVEILLANCE BASED BEFORE-AFTER STUDY

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Abstract

Background System changes in pediatric trauma care may reduce childhood injury mortality. The Dutch system of trauma care has been regionalized in 1999 / 2000. We evaluated changes in referral behavior and in-hospital mortality before and after regionalization of trauma care in the Netherlands.

Methods A surveillance based before-after study was performed of all children aged up to 18 years that were discharged from one of the hospitals of the trauma care region Central Netherlands between 1996 and 1998, and between 2001 and 2006. The in-hospital mortality rate and referral behavior was compared before (1996-1998) and after (2001-2006) regionalization of trauma care in the Netherlands.

Results 21 585 children were included, with a mean age of 9.6 (SD 5.5) and a mean ISS of 4.3 (SD 4.4). After regionalization, the mean Injury Severity Score (ISS) was lower ($p = 0.000$) and the mean length of stay was lower ($p = 0.000$). The in-hospital mortality rate was significantly lower for the adolescent group (age 13-18, $n = 7\,846$, SMR 0.64, 95% CI 0.34-0.93) after correction for the ISS. No changes were found for the younger children (age 0-12, $n = 13\,739$). No significant differences were found in referral behavior for both age categories.

Conclusions Regionalization of trauma care in the Netherlands reduced the in-hospital mortality rates for adolescents in the last decade. However, this reduction was not caused by a change in referral behavior.

Background

In Western societies trauma is the leading cause of death and disability among children and adolescents.[1-9] But it has been shown that childhood injury mortality can be largely reduced, both by preventive measures and by system changes in pediatric trauma care.[10]

In order to improve the outcome of severe childhood injury multiple changes were made to pediatric trauma care in Western societies over the past decades. In prehospital care, helicopters were brought into action more frequently for a quick transportation of injured children to the nearest trauma center.[11,12] Triage systems were introduced that made a quick assessment possible of the urgency of care.[13-15] And last but not least, trauma care was increasingly regionalized towards referral of severely injured children to specialized trauma centers.[16,17] The Committee on Trauma of the American College of Surgeons has established a list of requirements for level one pediatric trauma centers. In Australia and the United States of America all major pediatric trauma patients of the country are treated in a limited number of specialized pediatric trauma centers. This regionalization of pediatric trauma care resulted in lower mortality and a better functional outcome of children after major trauma.[18-22]

In the Netherlands major pediatric trauma is treated at level-one adult trauma centers, since no specialized pediatric trauma centers are designated. Currently, the Netherlands count eleven adult level-one trauma centers spread throughout the country (16.7 million inhabitants). Regionalization of adult trauma care was established in the years 1999 and 2000. Pediatric trauma accounts for about 10% of the complete trauma population in developed countries.[9] The treatment of pediatric trauma is often different from the treatment of the adult trauma population. Compared to adult trauma patients children have different injury patterns and pathophysiology.[23] For example, due to the relatively large head size the child is at particular risk of head injury and because of the small body mass multi system injury is more likely to occur.[24] For all-round trauma surgeons it is often difficult to get enough experience with pediatric trauma care.[25]

All known research about the effect of regionalization of pediatric trauma care was done in the United States of America.[16,18-22] Because of the differences between the American and the Dutch pediatric trauma population, it is doubtful whether the American results are applicable to the Dutch population. As far as we know, this is the first study about the effect of regionalization of trauma care in the pediatric population in Europe.

The aforementioned results of pediatric trauma care in Western societies lead to the hypothesis that children with major trauma in the Netherlands might have better

outcomes with regionalized trauma care. In order to confirm this hypothesis a surveillance based before-after study was performed. A database of all pediatric trauma patients discharged from the hospitals within the trauma care region Central Netherlands were studied before and after the regionalization of trauma care in 1999 and 2000. Study questions were: 1) did regionalization of trauma care reduce the in-hospital mortality rate of pediatric trauma patients in Central Netherlands? and 2) did referral behavior for pediatric trauma patients in Central Netherlands change after the regionalization of trauma care?

Methods

Study population

The study population includes all pediatric trauma patients up to 18 years of age that were discharged between January 1st 1996 and December 31st 1998, and between January 1st 2001 and December 31st 2006 from one of the hospitals within the trauma care region: Central Netherlands of the Dutch Medical Register. The trauma care region Central Netherlands includes eleven hospitals of which the university hospital is designated as level one trauma center, three hospitals are designated as level two trauma center, and the remaining seven hospitals are designated as level three. Patients with an International Classification of Diseases (ICD-9) diagnostic code between 800 and 905 or between 910 and 959.9, and with an E-code between E800 and E999 were included. Excluded were: E850-E879.9, E903.04-904.99, E929-E949.9, E959, E969, E977-E982.9, E989, and E999, because these E-codes are not directly trauma related. Patients who died before admission to the hospital were excluded.

Data collection and outcome measurement

The Dutch Medical Register is a continuous registration of all hospital admissions in The Netherlands. It includes patient demographics, date of admission and discharge, mortality, and diagnoses according to the ICD-9. Data for this study were extracted from this register, which has a 100% coverage in the study region. The outcome measures were: in-hospital mortality rate and the amount of multi-trauma patients (Injury Severity Score ≥ 16) that were directly admitted to a level one or level two trauma center. The Injury Severity Score (ISS) was calculated based on the ICD-9 diagnostic codes. Therefore a software program was used designed and validated by MacKenzie et al. of the John Hopkins University.[26]

Data analysis

The study population was divided into two groups based on the date of discharge: before (1996-1998) and after (2001-2006) regionalization of trauma care in the Netherlands. Differences in referral behavior and in-hospital mortality between these

two groups were analyzed with student t-tests. Results were given for the complete population and for children (aged 0-12) and adolescents (aged 13-18) separately. Standardized mortality ratios (SMR) were used to correct for the differences in ISS before and after regionalization. The population before regionalization was used as standard population. A p-value under 0.05 was considered to be statistically significant. The Statistical Package for the Social Sciences (SPSS) version 17.0 was used.

Results

In total 21 585 children were included. Mean age of the complete study population was 9.6 (SD 5.5), 62.4% was male, mean ISS was 4.3 (SD 4.4), and mean length of stay was 2.1 (SD 5.1). The mean ISS was significantly lower after regionalization of trauma care. The mean length of stay was significantly shorter after regionalization of trauma care. No clinically relevant differences in mean age and male-female ratio were found between the two periods. See table 1.

The in-hospital mortality rate for the complete population after regionalization is significantly lower than before regionalization of trauma care in the Netherlands. However, this effect is partly caused by the differences in mean ISS. After correction for the ISS, a significant decrease of the mortality rate was found for the adolescent group (aged 13-18) only. No significant change in mortality rate was found for children up to 12 years old. See table 2 for the mean in-hospital mortality rates, and table 3 for the SMR's for the two age categories. The referral behavior of the severely injured patients (ISS ≥ 16) did not significantly change after regionalization of trauma care in the Netherlands. Over sixty percent of the severely injured patients was referred to a level one or level two trauma center, before as well as after regionalization of trauma care. See table 4.

Table 1 Patient characteristics before (1996 - 1998) and after (2001 - 2006) regionalization of trauma care in the Netherlands in 1999 / 2000. * Significantly different from 1996-1998 (p = 0.000).

Patient characteristics	1996-1998	2001-2006
N	6 800	14 785
Mean age (years)	9.8 (SD 5.50)	9.6 (SD 5.45)
Mean male (%)	62.5	62.3
Mean ISS	4.6 (SD 5.10)	4.1 (SD 3.97)*
Mean length of stay (days)	3.1 (SD 6.36)	1.6 (SD 4.41)*

Table 2 Mean in-hospital mortality rates before (1996 -1998) and after (2001 - 2006) regionalization of trauma care in the Netherlands in 1999 / 2000. * Significantly different from 1996-1998 (p = 0.001).

Age categories	N	Mean mortality rate (%)	
		1996-1998	2001-2006
Age ≤ 18	21 585	0.49	0.21*
Age 0-12	13 739	0.21	0.13
Age 13-18	7 846	0.93	0.35*

Table 3 Standardized mortality ratios before (1996 - 1998) and after (2001 - 2006) regionalization of trauma care in the Netherlands in 1999 / 2000. Correction for differences in ISS between time periods.
* Significantly different from 1996 - 1998 (p < 0.050).

Age categories	N	Standardized mortality ratio	
		1996-1998	2001-2006
Age ≤ 18	21 585	1.00	0.74 (95% CI 0.47-1.00)
Age 0-12	13 739	1.00	0.97 (95% CI 0.42-1.52)
Age 13-18	7 846	1.00	0.64 (95% CI 0.34-0.93)*

Table 4 Amount of patients with ISS ≥ 16 referred to a level-one or two trauma center, or a level-three trauma center before (1996 - 1998) and after (2001 - 2006) regionalization of trauma care in the Netherlands in 1999 / 2000. No significant differences.

Age categories		Referral behavior of patients with ISS ≥ 16	
		1996-1998	2001-2006
Age ≤ 18 (n = 1096)	Level 1 or 2	60.8%	63.4%
	Level 3	39.2%	36.6%
Age 0-12 (n = 682)	Level 1 or 2	58.5%	61.6%
	Level 3	41.5%	38.4%
Age 13-18 (n = 414)	Level 1 or 2	64.5%	66.5%
	Level 3	35.5%	33.5%

Discussion

Analysis of the data extracted from the Dutch Medical Register showed that the in-hospital mortality rate of the adolescent trauma population of the trauma care region Central Netherlands decreased significantly since the regionalization of trauma care in 1999 / 2000. For children up to 12 years of age no significant change of the mortality rate was found. Furthermore, no significant change in referral behavior was found for both age categories.

So, this decrease in the in-hospital mortality for adolescents cannot be explained by a change in referral behavior. However, as mentioned in the introduction, multiple changes were made in pediatric trauma care over the past decades.[10-22] The introduction of triage systems and the quick transportation of injured children to the nearest trauma center are hypothesized to have improved the pediatric trauma care in our region. Another hypothesis for the reduction of the in-hospital mortality for adolescents in our population is improvement of the in-hospital pediatric trauma care, probably caused by a higher awareness. A possible explanation for the lack of change in referral behavior after regionalization, is that this change already had taken place far before the official designation of trauma centers in our region. Before regionalization, 36% of the severely injured children (ISS ≥ 16) were discharged from the university hospital already.

In comparison to other countries, the Dutch Medical Register showed us a remarkably low in-hospital mortality rate, with an overall mean of 0.3%. In Spain the pediatric in-hospital mortality rate reported for that same period was 0.5%,[27] in Canada between 0.5 and 0.9%,[28,29] in and in the United States between 0.9% and 3.2%.[16,30-33] Hackam has explained this difference in mortality rate between the US and other Western countries by the amount of firearm injuries in the United States.[34] Another explanation might be the one given by Mooney in a comment to the article of Densmore et al.: 'in some American states deaths at the scene had to be declared at the nearest hospital, and were therefore included in the in-hospital mortality rates'.[33] Twijnstra et al. described the in-hospital mortality rate for the adult population of the trauma care region Central Netherlands in 2010.[35] They also found a much lower in-hospital mortality rate in the Dutch adult population compared to other Western countries.

The subdivision into an adolescent and a child group showed an interesting difference between these two age categories. We found that the mortality rate for the adolescent group in the period before regionalization was much higher than for the younger children in that same period. In the Canadian register similar differences in mortality rates between young children and adolescents were found.[28] In our study the mortality rates of children and adolescents approached after regionalization.

These results are supported by the Canadian results of Diamond et al., who showed us that there were more preventable deaths among adolescent trauma patients than among trauma patients of younger age.[34]

Strengths and limitations

A major strength of this study was the large sample size of more than 20 000 patients. All pediatric patients of a complete trauma care region (eleven hospitals) were included. Because of the size and the completeness of the register, this sample is a good representation of the pediatric trauma population in the study region. Another strength is the long period over which the register was studied before as well as after regionalization of trauma care. As has been demonstrated earlier, a new trauma system needs time to settle in.

A limitation of the study is that diagnosis codes were taken from a linked administrative database, which may be prone to coding errors and variation.[36] However, a quality survey on our database conducted during the study period has shown a high accuracy of coded injury data: correctly coded in 91% of cases and in 9% incomplete.[37] This provides support for the validity of our data, although the possibility of underreporting of death in the Dutch Medical Registry has to be taken into account. Another limitation is that the outcome was only measured by mortality and referral behavior. Given the low mortality rate, a much more interesting outcome would have been quality of life or level of functioning,[38,39] but this type of information was not included in the registry.

We conclude that over the past decade, regionalization of trauma care has made an important contribution to the reduction of the burden of injury in adolescents in our region, but further research is needed to understand the etiology of this process.

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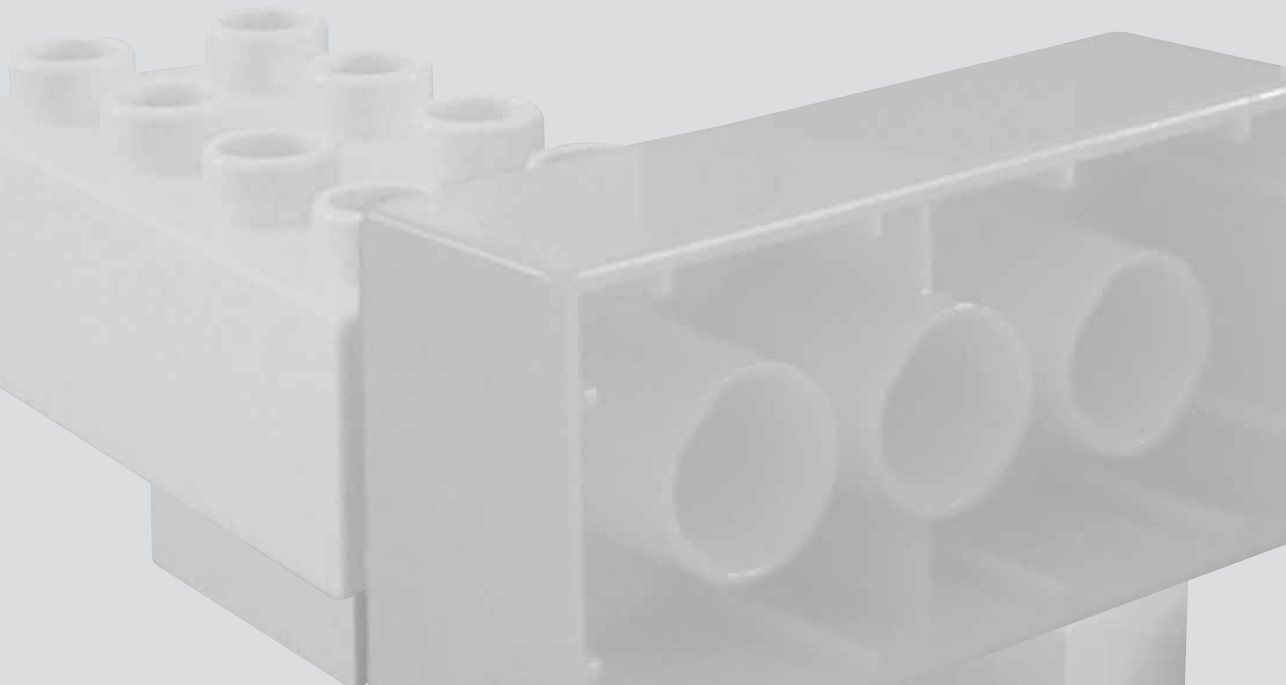
References

1. Polinder S, Haagsma JA, Toet H, Brugmans MJP, van Beeck EF, the EUROCOST and APOLLO reference group. Burden of injury in childhood and adolescence in 6 European countries. BMC Public Health 2010;10:45.
2. Polinder S, Meerding WJ, Toet H, Mulder S, Essink-Bot ML, van Beeck EF. Prevalence and prognostic factors of disability after childhood injury. Pediatrics 2005;116(6):810-817.
3. Evans SA, Airey MC, Chell SM, Connelly JB, Rigby AS, Tennant A. Disability in young adults following major trauma: 5 year follow up of survivors. BMC Public Health 2003;3:8.
4. Danseco ER, Miller TR, Spicer RS. Incidence and costs of 1987-1994 childhood injuries: demographic breakdown. Pediatrics 2000;105(2):1-8.
5. Hu X, Wesson DE, Logsetty S, Spence LJ. Functional limitations and recovery in children with severe trauma: a one-year follow-up. J Trauma 1994;37(2):209-213.
6. Cooper A, Barlow B, DiScala C, String D, Ray K, Mottley L. Efficacy of pediatric trauma care: results of a population-based study. J Pediatr Surg 1993;28(3):299-305.
7. Wesson DE, Williams JI, Spence LJ, Filler RM, Armstrong PF, Pearl RH. Functional outcome in pediatric trauma. J Trauma 1989;29(5):589-592.
8. Vademecum of Health Statistics of the Netherlands: 2003. Statistics Netherlands, Ministry of Health, Welfare and Sports, Voorburg/Heerlen, the Netherlands;2004.
9. O'Neale Roach J. Injuries kill over 20.000 children a year in developed countries. Biomedical Journal 2001;322:317.
10. Peden M, Oyegbite K, Ozanne-Smith J. World report child injury prevention. Geneva: World Health Organization;2008.
11. Moront ML, Gotschall CS, Eichelberger MR. Helicopter transport of injured children: system effectiveness and triage criteria. J Ped Surg 1996;8:1183-1188.
12. Schmidt U, Geerling J, Fuehler M, Hubrich V, Richter M, Krettek C. Die Praeklinische versorgung des pediatrischen traumapatienten: ein retrospectiver vergleich zwischen luft- und bodengebundener rettung. Unfallchirurg 2002;105(11):1000-1006.
13. Veen van M, Steyenberg EW, Ruige M, van Meurs AH, Roukema J, van der Lei J, Moll HA. Manchester triage system in paediatric emergency care: prospective observational study. BMJ 2008;337:a1501.
14. Engum SA, Mitchell MK, Scherer LR, Gomez G, Jacobson L, Solotkin K, Grosfeld JL. Prehospital triage in the injured pediatric patient. J Ped Surg 2000;35(1):82-87.
15. Jubelirer RA, Agarwal NN, Beyer FC, Ferraro PJ, Jacobelli MC, Pfeifer WF, Shah MA. Pediatric trauma triage: review of 1,307 cases. J Trauma 1990;30(12):1544-1547.
16. Nathens AB, Jurkovich GJ, Rivara FP, Maier RV. Effectiveness of state trauma systems in reducing injury-related mortality: a national evaluation. J Trauma 2000;48:25-31.
17. Mullins RJ. A historical perspective of trauma system development in the United States. J Trauma 1999;47(3 suppl):S8-S14.

18. Pracht EE, Tepas III JJ, Langland-Orban B, Simpson L, Pieper P, Flint LM. Do pediatric patients with trauma in Florida have reduced mortality rates when treated in designated trauma centers? J Ped Surg 2008; 43:212-221.
19. Potoka DA, Schall LC, Ford HR. Improved functional outcome for severely injured children treated at pediatric trauma centers. J Trauma 2001;51:824-834.
20. Potoka DA, Schall LC, Gardner MJ, Stafford PW, Peitzman AB, Ford HR. Impact of pediatric trauma centers on mortality in a statewide system. J Trauma 2000;49:237-245.
21. American academy of pediatrics, pediatric orthopaedic society of North America. Management of pediatric trauma. Pediatrics 2008;121:849-854.
22. Doolin EJ, Browne AM, DiScala C. Pediatric trauma center criteria: an outcome analysis. J Pediatr Surg 1999;34:885-890.
23. Kissoon N, Dreyer J, Walis M. Pediatric trauma: differences in pathophysiology, injury patterns and treatment compared with adult trauma. Can Med Assoc J 1990;142(1):27-34.
24. Browne GJ, Cocks AJ, McCaskill ME. Current trends in the management of major paediatric trauma. Emergency Medicine 2001;13:418-425.
25. Hamill J, Beasley SW. Training in paediatric trauma: the problem of safer societies. ANZ J Surg 2006;76:596-599.
26. MacKenzie EJ, Steinwachs DM, Shankar B. Classifying trauma severity based on hospital discharge diagnoses. Validation of an ICD-9CM to AIS-85 conversion table. Med Care 1989;27(4):412-422.
27. Navascues del Rio JA, Romero Ruiz RM, Soleto Martin J, Cerda Berrocal J, Barrientos Fernandez G, Sanchez Martin R, Molina Hernando E, De Tomas Palacios E, De Agustin Asensio JC, Luque Miraldea R, Aguilar Tremoya F, Vazquez Estevez J. First Spanish trauma registry: analysis of 1500 cases. Eur J Pediatr Surg 2000;10:310-318.
28. Diamond IR, Parkin PC, Wales PW, Bohn D, Kreller MA, Dykes EH, McLellan BA, Wesson DE. Pediatric blunt and penetrating trauma deaths in Ontario: a population-based study. J Ped Surg 2009;44:981-986.
29. Stewart TC, Grant K, Singh R, Girotti M. Pediatric trauma in Southwestern Ontario: linking data with injury prevention initiatives. J trauma 2004;57:787-794.
30. Courville XF, Koval KJ, Carney BT, Spratt KF. Early prediction of peosttraumatic in-hospital mortality in pediatric patients. J Pediatr Orthop 2009;29:439-444.
31. Burd RS, Jang TS, Nair SS. Evaluation of the relationship between mechanism of injury and outcome in pediatric trauma. J Trauma 2007;62:1004-1014.
32. Wang NE, Chan J, Mahlow P, Wise PH. Trauma center utilization for children in California 1998-2004: trends and areas for further analysis. Acad Emerg Med 2007;14(4):309-315.
33. Densmore JC, Lim HJ, Oldham KT, Guice KS. Outcomes and delivery of care in pediatric injury. J Ped Surg 2006;41:92-98.
34. Diamond IR, Parkin PC, Wales PW, Bohn D, Kreller MA, Dykes EH, McLellan BA, Wesson DE. Preventable pediatric trauma deaths in Ontario: a comparative population-based study. J Trauma 2009;66:1189-1195.

35. Twijnstra MJ, Moons KGM, Simmermacher RKJ, Leenen LP. Regional trauma system reduces mortality and changes admission rates: a before and after study. Ann Surg 2010;251:339-343.
36. Langley J, Stephenson S, Cryer C, Borman B. Traps for the unwary in estimating person based injury incidence using hospital discharge data. Inj Prev 2002;8:332-337.
37. Paas G, Veenhuizen K. Utrecht: Prismant; 2002. Reliability of the LMR database.
38. Janssens L, Gorter JW, Ketelaar M, Kramer WL, Holtslag HR. Long-term health condition in major pediatric trauma: a pilot study. Journal of Pediatric Surgery 2009;44(8):1591-1600.
39. Janssens L, Gorter JW, Ketelaar M, Kramer WL, Holtslag HR. Long-term health-related quality of life in major pediatric trauma: a pilot study. Eur J Trauma Emerg Surg 2009;35(4):371-377.



4

HEALTH-RELATED QUALITY OF LIFE MEASURES FOR LONG-TERM FOLLOW-UP IN CHILDREN AFTER MAJOR TRAUMA

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Abstract

Objective Our objective was to review measures of health-related quality of life (HRQL) for long-term follow-up in children after major trauma and to determine the measures that are suitable for a large age range, reliable and valid, and cover a substantial amount of the domains of functioning using the International Classification of Functioning, Disability, and Health (ICF) of the World Health Organization (WHO).
Methods The Medline and EMBASE databases were searched in all years up to October 2007, for generic HRQL measures suitable for children aged 5-18 years old and validated in English or Dutch. Measures were reviewed with respect to the age range for which the measure was suitable and reliability, validity, and the content related to the ICF.
Results The search resulted in 1 235 hits and 21 related articles. Seventy-nine papers met the inclusion criteria, describing in total 14 measures: Child Health and Illness Profile Adolescent and Child Edition (CHIP-AE / CE), Child Health Questionnaire Child and Parent Forms (CHQ-CF87 / PF50 / PF28), DISABKIDS, Functional Status II (FS II(R)), Health Utilities Index Mark 2 (HUI2), KIDSCREEN 52 / 27, KINDL, Pediatric Quality of Life Inventory (PedsQL), TNO-AZL Children's Quality of Life (TACQOL), and Youth Quality of Life Instrument-Research Version (YQOL-R). Measures that were suitable for a large age range were CHQ-PF50 / PF28, DISABKIDS, FS II(R), HUI2, KIDSCREEN, PedsQL, and TACQOL. All measures had moderate to good psychometric properties, except for CHQ-PF50 / PF28, KINDL, and TACQOL, which had either low internal consistency or bad test-retest reliability. The measures that covered more than six chapters of the ICF domains were CHIP-AE / CE, CHQ-CF87 / PF50, DISABKIDS, KIDSCREEN-52, PedsQL, and TACQOL.
Conclusions DISABKIDS, KIDSCREEN 52 and PedsQL are suitable for long-term follow-up measurement of HRQL in children after major trauma. They cover a large age range, have good psychometric properties, and cover the ICF substantially.

Introduction

Injuries are a leading cause of death in children of 1-18 years of age.[1,2] The survival rate of major traumatized children is about 80%.[2,3] Injuries can cause severe functional impairment and psychosocial problems in the short-term and long-term.[4-9] Despite the prominent role of major trauma in mortality and morbidity in children, relatively little research has been done in terms of quality of life of children after major trauma. Most studies focus on the consequences of brain injury,[10-12] whereas the quality of life in pediatric major trauma remains relatively unexplored. Van der Sluis and colleagues described the long-term outcome in pediatric polytrauma patients in 1997.[13] Nine years after trauma, the RAND-36 was administered to patients 18 years of age or older. The quality of life enjoyed by the patients did not differ from a healthy reference population. Holbrook et al. recently studied the quality of life in adolescents 3, 6, 12, 18 and 24 months after major trauma with the Quality of Well-being Scale.[14] Significant deficits in quality of well-being were found in adolescents after major trauma compared with US norms for healthy adolescents.

There are many terms used to describe quality of life in health care, for example: health-related quality of life (HRQL), well-being, health status, and functional status. In this review, the definition of HRQL as described by the World Health Organization (WHO) is adopted. The WHO defines HRQL as the individuals' perception of their position in life in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns.[15] To study HRQL in pediatric trauma patients, first a decision has to be made about what measure to use. Currently many HRQL measures for children are available. Some measures are disease specific, whereas others are generic. Unfortunately, no trauma-specific HRQL measure has been developed for children, leaving generic measures as first choice. Comparison of the available measures enables a well-considered decision.

The aim for this review is to provide an overview of the available measures of HRQL for long-term follow-up in children after major trauma so that measures can be selected that are suitable for a large age range, valid and reliable, and cover a substantial amount of the content of the International Classification of Functioning, Disability and Health (ICF) of the WHO.[16]

Methods

Literature search

Medline and EMBASE databases were searched in all years up to October 2007 for measures of HRQL in children. The following search was entered: [(child* OR pediatr* OR paediatr* OR adolesc*) AND (quality of life OR health status) AND (psychometr* OR validity OR reliability OR cronbach OR test-retest)]. In Medline the extension [Title/abstract] was added to all terms to specify the search. Inclusion criteria were: 1. validation study of a generic HRQL measure in children in a Western country, 2. the measure is suitable for children in the age range of 5-18 years, 3. the paper is written in English or Dutch, 4. the measure has an English or Dutch version, 5. the measure has both validity and reliability reported.

Measure comparison

The measures were reviewed on four levels: 1) age range, 2) reliability, 3) validity, and 4) the content related to the ICF. The underlying idea for the measure comparison on these four levels is as follows:

1) Age range

When a measure is suitable for a large age range, fewer measures are needed to study a cohort. Therefore, a better comparison can be made over time and between subjects of different ages. In this review, a large age range is defined as at least 10 years covered. Measures were selected that were suitable for children who were > 5 years old, because it is hypothesized that 5 years after trauma the most recovery that can be expected has taken place and that the child is in a relatively stable situation. Some measures have different versions for different age categories. When these versions were similar in content, the age ranges of these different versions were added. When they had a different amount of questions or a different scoring system, the versions were considered as separate measures and the age ranges were not added.

2) Reliability

On the second level, the internal consistency and the test-retest reliability of the HRQL measures were compared. In this review, a measure was considered reliable when it reached at least group comparison level for the internal consistency (Crohnbach's alpha > 0.70),[17] and had a substantial test-retest reliability (kappa, intraclass correlation coefficients (ICC), Spearman or Pearson correlation coefficient > 0.60).[18] A measure was found reliable when at least 80% of the measurements of reliability exceeded the set levels.

3) Validity

Comparison of the validity of a measure is a complicated matter, because there are many ways to describe it. Validity can be divided into content en construct validity. A method often used to describe content validity of an HRQL measure is the ability to differentiate between healthy subjects and children with a disease. Construct validity can be described, for example, by factor analysis, by the correlation of a measure with other instruments that aim to measure similar or different constructs, and by the correlation with preknown information or clinical symptoms. In this review, an attempt was made to give an overview of the content en construct validity for all included HRQL measures.

4) Content related to the ICF

The fourth and final level of comparison included the content of the questionnaires. This comparison was made in light of the ICF[16] (figure 1). It is a model in which health condition is defined by three domains: body functions & structures, activities, and participation. These domains are divided into chapters, as listed in table 5. To compare the content of the questionnaires, all items were placed in one of the ICF chapters. If an item encompassed different constructs, the item was placed in more than one chapter. For example, the fourth item of the Health Utilities Index Mark 2 (HUI2) 'Learns and remembers school work normally for age', encompassed

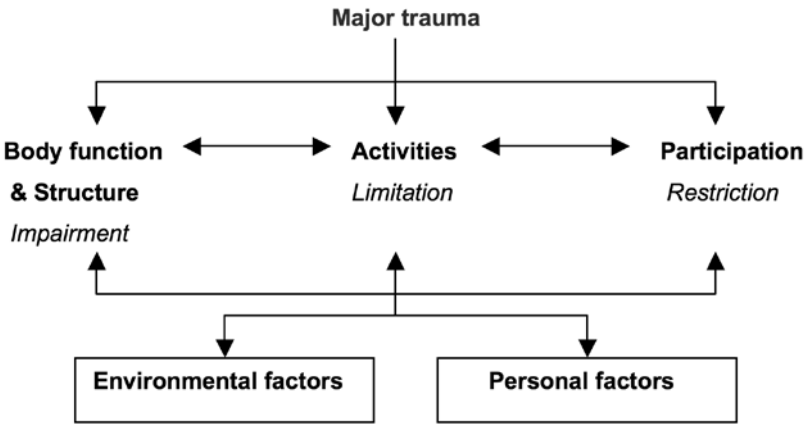

Figure 1 International Classification of Functioning, disability and health (ICF) of the World Health Organization (WHO).[12]

two constructs: 'learn' and 'remember'. These two constructs were placed in two different chapters, namely, the first chapter of activities and participation and the first chapter of body functions & structures, respectively. If the content of the item did not fit in one of the chapters, the item was placed in the category 'other'.

Placement of the items in the chapters of the ICF was done by three researchers independently. One of them (LJ) placed the items of all measures, whereas the other two (MK and MB) both placed the items of seven measures. So finally, all items were placed by two researchers. In case of disagreement, a discussion followed, led by a fourth independent person (JWG). This person finally decided in which ICF chapter the item was placed. The number of chapters covered by the items was used as a measure for covering the ICF. In this review, a measure was found to represent the ICF substantially when the items cover more than six chapters.

Results

The search in Medline and EMBASE databases rendered 1 235 hits and 21 related articles. Seventy-nine papers met the inclusion criteria, describing in total 14 measures. The number of references per measure varied between 1 and 26. The included measures are Child Health and Illness Profile Adolescent and Child Edition (CHIP-AE[19-21], CHIP-CE[22,23]), Child Health Questionnaire Child and Parent Form (CHQ-CF87[24-30], CHQ-PF50[26,27,30-53], CHQ-PF28[54-57]), DISABKIDS[58,59], Functional Status II (FS II(R))[60,61], HUI2[32,52,62-64], KIDSCREEN 52[65,66] and KIDSCREEN 27[67,68], KINDL[25,69-72], Pediatric Quality of Life Inventory 4.0 (PedsQL[10,73-91]), TNO AZL Child Quality Of Life questionnaire (TACQOL[92-95]), and Youth Quality of Life Instrument-Research Version (YQOL-R[96]).

Comparison of the age-range and other general characteristics

CHIP, CHQ, DISABKIDS, KIDSCREEN, PedsQL and TACQOL have different versions for different age categories. Besides language adaptations, the age-adapted versions of CHIP and CHQ also have different numbers of items and different scoring systems. Therefore, the child and adolescent edition of CHIP and the child and parent form of CHQ were considered as separate measures. The number of items and the scoring system of the different versions of DISABKIDS, KIDSCREEN, PedsQL and TACQOL are similar. Therefore, these versions were considered as one measure, and the age ranges were added.

The measures that are suitable for the largest age range are HUI2 and PedsQL. They are both validated for children between 2 and 18 years old. CHQ-PF50 / 28 (5-18

years), DISABKIDS (4-16 years), FS II(R) (0-12 years), KIDSCREEN 52 / 27 (8-18 years), and TACQOL (6-15) are also validated for an age range of 10 years or more. Measures suitable for an age range of less than 10 years are CHIP-AE / CE (11-17 / 6-11 years), YQOL-R (12-18 years), CHQ-CF (10-18 years), and KINDL (8-16 years). The large age range measures are all proxy-reported or clinician-administered, except for PedsQL, DISABKIDS, KIDSCREEN, and TACQOL, which also have a self-report version. The minimal age limit used for self-report measures varies between 8 and 11 years. The proxy-report measures and the clinician-administered measures are suitable for children of all ages.

The number of items varies enormously for each measure. HUI2 contains less then ten items, whereas CHIP-AE and TACQOL contain more than 100 items, resulting in large differences in the time needed to complete the questionnaire. Short measures take only 5 minutes or less, whereas the larger measures take 10-45 minutes to complete. Measures that take 20 minutes or more to complete were CHIP-AE / CE and CHQ-CF87 / PF50. Items are placed in a varying number of domains, with a median of 6 domains. PedsQL and YQOL-R have only 4 domains, whereas CHQ has 13 domains. General characteristics of all measures are summarized in table 1 and 2.

Comparison of reliability

Internal consistency for the total score is reported for FS II(R), KINDL, PedsQL and YQOL-R. In KINDL, PedsQL proxy-report version, and YQOL-R, all Cronbach alphas for the total score exceed the 0.70 level of group comparison. In PedsQL self-report version and in FS II(R), 95% and 63% of the alphas for the total score were > 0.70 respectively. Internal consistency for the domains is reported for all measures except for HUI2. In CHIP-AE / CE, DISABKIDS, FS II(R), KIDSCREEN 52 / 27, and YQOL-R, all alphas for the domains exceed the 0.70 level. Measures with nearly all alphas for the domains > 0.70 were CHQ-CF / PF50 (93% and 86%) and the proxy- and self-report version of PedsQL (95% and 84%). Measures with < 80% of the alphas for domains > 0.70 were TACQOL (69%), CHQ-PF28 (53%) and KINDL (33%).

ICC, Pearson correlation coefficients, and kappas were used to report test-retest reliability in the reviewed articles. Test-retest reliability for the total score is reported for FS II(R), HUI2, PedsQL, and YQOL-R. All measured coefficients for the total score exceeded the 0.60 level. Test-retest reliability for the domains is reported for all measures except for FS II(R), KIDSCREEN 52, KINDL, and PedsQL self-report version. All coefficients for the test-retest reliability of the domains exceeded the 0.60 level for CHIP-AE / CE, DISABKIDS, KIDSCREEN 27, PedsQL proxy-report version, and YQOL-R. HUI2 has 80% of its reported coefficients > 0.60. Measures with < 80% of the coefficients > 0.60 were TACQOL (73%), CHQ-PF50 (65%), CHQ-CF87 (60%), and CHQ-PF28 (50%). Reliability for all measures is summarized in table 3.

Table 1 General characteristics of HRQL measures in children: number and titles of the domains.

Measure	N and titles of the domains	
CHIP-AE	6	Discomfort, disorders, satisfaction with health, achievement, risks, resilience
CHIP-CE	5	Satisfaction, comfort, risk avoidance, resilience, achievement
CHQ-CF87 CHQ-PF50 CHQ-PF28	13	Physical functioning, role functioning: emotional/behavioral, role functioning: physical, bodily pain, general behavior, mental health, self-esteem, general health perceptions, parental impact: emotional, parental impact: time, family activities, family cohesion, change in health
DISABKIDS	6	Independence, physical limitation, emotion, social inclusion, social exclusion, treatment
FS II (R)	8	Communication, mobility, mood, energy, play, sleep, eating, toileting
HUI2	6	Sensation, mobility, emotion, cognition, self-care, pain
KIDSCR-52	10	Physical well-being, psychological well-being, moods & emotions, self-perception, autonomy, parent relation and home life, peers and social support, school environment, bullying, financial resources
KIDSCR-27	5	Physical well-being, psychological well-being, parent relations & autonomy, social support & peers, school environment
KINDL	6	Physical health, general health, family functioning, self-esteem, social functioning, school functioning
PedsQL4.0	4	Physical functioning, emotional functioning, social functioning, school functioning
TACQOL	7	Pain and symptoms, basic motor functioning, social functioning, school functioning
YQOL-R	4	Self, relationships, environment, general quality of life

Comparison of validity

Validity was assessed and reported differently in all studies, so a comparison was difficult to make. For most measures, content validity was assessed by the ability to differentiate between healthy subjects and children with a disease. All measures were able to do so in a variety of diseases, except for KINDL, which could not differentiate between healthy and chronically ill children. No information about content validity was reported for CHIP-CE and KIDSCREEN 52. Construct validity was assessed by factor analysis, by the correlation with other instruments that aim to measure similar or different constructs, and by the correlation with preknown information or

Table 2 General characteristics of HRQL measures in children: validated age-range, how to report, rating scale, number of items, time needed to complete the measure.

Measure	Age in years	Report	Rating scale	N items	Time in minutes
CHIP-AE	11-17	Self	3 to 5 point Likert scale	107	45
CHIP-CE	6-11	Proxy	3 to 5 point Likert scale	76	20
CHQ-CF87	10-18	Self	4 to 6 point Likert scale	87	20
CHQ-PF50	5-18	Proxy	4 to 6 point Likert scale	50	20
CHQ-PF28	5-18	Proxy	4 to 6 point Likert scale	28	5-10
DISABKIDS	4-16	Proxy or self	5 point Likert scale	37	10
FS II (R)	0-12	Proxy	3 point Likert scale	14	10
HUI2	2-18	Clinician or proxy	Ordinal classification system	6	< 5
KIDSCR-52	8-18	Proxy or self	5 point Likert scale	52	15-20
KIDSCR-27	8-18	Proxy or self	5 point Likert scale	27	10-15
KINDL	8-16	Self	5 point Likert scale	24	5-10
PedsQL4.0	2-18	Proxy or self	3 or 5 point Likert scale	23	5-10
TACQOL	6-15	Proxy or self	3 and 4 point Likert scale	108	10
YQOL-R	12-18	Self	11 point Likert scale	41	10-15

clinical symptoms. Factor analysis was performed for CHIP-AE / CE, CHQ-PF50, KIDSCREEN 27, KINDL, PedsQL, and TACQOL and revealed that most items of these measures load most highly on their conceptually derived scale. A summary of the information on content and construct validity for all measures is reported in table 4.

Covering the ICF

Measures that covered more than 6 chapters of the ICF domains were CHIP-AE / CE, CHQ-CF87 / PF50, DISABKIDS, KIDSCREEN 52, PedsQL, and TACQOL. CHQ-PF, HUI2, and KIDSCREEN-27 covered 6 chapters; YQOL-R covered 5 chapters; KINDL covered 4 chapters, and FS II(R) covered 3 chapters. CHIP-AE covered the ICF domain body functions & structures best, with all chapters represented in the measure. Only 1 to 4 of the chapters of body functions & structures were covered by the other measures. CHIP-AE / CE, CHQ-CF87, and TACQOL covered the ICF-domains activities and participation best, with 7 of 9 chapters represented in the measures. Measures with less than half of the chapters of activities and participation covered were CHQ-PF28, FS II(R), HUI2, KINDL, and YQOL-R. (table 5)

Table 3 Internal consistency and test-retest reliability for HRQL measures in children.

Measure	**Total, domain**	**Internal consistency**		**Test-retest**	
		Cronbach α	> 0.70	ICC,κ,Pearson	> 0.60
CHIP-AE	Domain	0.79 - 0.92	100%	0.74 - 0.93	100%
CHIP-CE	Domain	0.70 - 0.88	100%	0.63 - 0.85	100%
CHQ-CF87	Domain	0.54 - 0.97	93%	0.06 - 0.84	60%
CHQ-PF50	Domain	0.39 - 0.97	84%	-0.30 - 1.00	65%
CHQ-PF28	Domain	0.07 - 0.88	53%	0.14 - 0.75	50%
DISABKIDS	Domain	0.70 - 0.90	100%	0.71 - 0.83	100%
FS II(R)	Total	0.56 - 0.91	63%	0.60 - 0.92	100%
	Domain	0.83 - 0.93	100%		
HUI2	Total	0.90	100%		
	Domain	0.55 - 1.00	80%		
KIDSCR-52	Domain	0.76 - 0.90	100%		
KIDSCR-27	Domain	0.78 - 0.84	100%	0.61 - 0.74	100%
KINDL	Total	0.71 - 0.95	100%		
	Domain	-0.19 - 0.89	33%		
PedsQL4.0	Total	0.74 - 0.94	100%	0.78 - 0.88	100%
proxy-report	Domain	0.59 - 0.93	95%	0.75 - 0.91	100%
PedsQL4.0	Total	0.66 - 0.92	97%	0.86	100%
self-report	Domain	0.39 - 0.90	84%		
TACQOL	Domain	0.55 - 0.95	69%	0.30-0.91	73%
YQOL-R	Total	0.94 - 0.96	100%	0.78	100%
	Domain	0.77 - 0.99	100%	0.74 - 0.85	100%

Table 4 Content and construct validity for HRQL measures in children.

Measure	Content validity Differentiates health & disease	Construct validity Factor analysis, correlation with instruments, pre-known information, clinical symptoms, etc.
CHIP-AE	Healthy ≠ illness School population ≠ illness	Most items correlate most highly with the sub-domain in which they had originally been placed (factor analysis). Differentiates in predicted direction between four groups of teenagers known to differ in their current health status.
CHIP-CE	Healthy ≠ major chronic illness	Basic conceptual framework is supported by factor analysis. Emotional discomfort correlates (r 0.63) with Baltimore How I Feel scale. Self-esteem correlated with CHQ satisfaction (r 0.58). Limitation of activity correlates (r 0.53) with CHQ physical functioning scale.
CHQ-CF87	Healthy ≠ illness Norm ≠ diabetes Healthy ≠ chronic health condition	Presence of diabetes symptoms and concerns correlated with lower physical and psychosocial functioning of CHQ. In asthma 7 of 9 dimensions of the CHQ correlate with the Child Health Assessment Questionnaire. The CHQ correlated with the KINDL on the domains: physical, emotional, and self-esteem.
CHQ-PF50	Norm ≠ CP Norm ≠ diabetes Healthy ≠ chronic health condition	CHQ scales loaded highest on their hypothesized vector (factor analysis). Strong correlations between CHQ bodily pain and HUI2 / HUI3 pain scales (r 0.51-0.60), and between CHQ mental health and HUI2 / HUI3 emotion (r 0.53-0.64). CHQ is correlated with symptom severity in JCA and symptom activity in asthma.
CHQ-PF28	Healthy ≠ HIV Healthy ≠ chronic health condition	Severity of sickle cell disease correlates with mean physical summary score. All correlation coefficients between CHQ domains and the VAS rating of the child's health are positive and significant.
DISABKIDS	Healthy ≠ severe health condition	Differentiates between levels of severity of asthma and arthritis. Cor relations were highest with dimensions of HRQL measures evaluating similar concepts.
FS II(R)	Healthy ≠ medical problems / complaints	Moderate correlation with clinical rating. Negatively correlated with days hospitalized, days absent from school, and days in bed.
HUI2	Off treatment ≠ on treatment	HUI2 / HUI3 pain correlates with CHQ bodily pain (r 0.51-0.60). HUI2 mobility correlates with CHQ physical functioning (r 0.45-0.58). HUI2 / HUI3 emotion correlates with CHQ mental health (r 0.53-0.64). Important differences in HRQL scores between patients, parents, and physicians.
KIDSCR-52	?	Strong correlation with KIDSCREEN-27 (r 0.63-0.96). High correlation with KINDL for dimensions assessing similar constructs (r 0.51-0.68).
KIDSCR-27	Healthy ≠ physically ill Healthy ≠ mentally ill	Strong correlation with KIDSCREEN-52 (r 0.63-0.96). Moderate to high correlation with other HRQL measures assessing similar constructs (r 0.36-0.63). Correlation with psychosomatic complaints (r 0.52).
KINDL	Healthy ≠ DM Healthy = chronically ill	KINDL physical correlates with CHQ physical scales (r -.38-0.55). KINDL emotional and self-esteem correlates with CHQ mental health and self-esteem (r 0.41-0.62). Factor solution in line with the original subscales. Strong correlation with the Short Form-36 for mental health and physical functioning (r 0.53-0.86)
PedsQL4.0	Healthy ≠ chronic health condition (CP, ADHD, headache, asthma, DM, cancer, rheumatic disease) On ≠ off treatment	Most PedsQL items load most highly on their conceptually derived scale (factor analysis). Significant correlations in the expected direction with the PedsMIDAS total score (headache-specific measure of disability). Negatively correlated with the GMFCS score. Discriminates between children with extremity fractures and children with traumatic brain injury. Related to indicaters of morbidity and illness burden. Change over time as a result of clinical intervention.
TACQOL	Healthy ≠ chronic diseases, medical treatment	Almost all items (93%) loaded higher on their own factors than on other factors. Correlation between TACQOL and KINDL (r 0.24-0.60). Mean correlation between contextual similar domains of the EuroQol and the TACQOL was -0.55)
YQOL-R	Healthy ≠ chronic health condition	All scales correlate highly with the scales of the KINDL. Low correlation with two measures assessing different constructs: the Functional Disability Inventory and the Children's Depression Inventory.

Table 5 Number of items on the chapters of the ICF of pediatric health related quality of life measures.

		CHIP-AE	CHIP-CE	CHQ-PF87	CHQ-PF50	CHQ-PF28	DISABKIDS	FS II (R)	HUI2	KIDSCR-52	KIDSCR-27	KINDL	PedsQL	TACQOL	YQOL-R
Body functions & structures	BS 1 Structures of the nervous system and mental functions	17	10	16	7	4	8	11	2	22	10	12	8	20	13
	BS 2 The eye, ear and related structures, sensory functions and pain	10	5	3	2	1			2			1	1	5	
	BS 3 Voice and speech and the structures involved	3		1					1						
	BS 4 F&S of the cardiovascular, immunological, and respiratory systems	11	2												
	BS 5 F&S of the digestive, metabolic, and endocrine systems	7													
	BS 6 F&S of the genitourinary and reproductive systems	6													
	BS 7 Neuromusculoskeletal and movement-related F&S	6													
	BS 8 F&S of the skin and related structures	6	1												
Activities & participation	D 1 Learning and applying knowledge	1	4		2		1		1					4	2
	D 2 General tasks and demands	3	3				1			1					4
	D 3 Communication			1						1	1			3	
	D 4 Mobility	11	5	7	5	3	1		1	2	2		4	6	
	D 5 Self-care	30	3	1	1				1				1	4	
	D 6 Domestic life			1				1					1		
	D 7 Interpersonal interactions and relationships	25	27	18	8	4	9	1		16	8	6	3	9	14
	D 8 Major life areas	14	4	1	1	1	1			4	3	1	3	2	1
	D 9 Community, social, and civic life	4	2	4	3	2	2			3	1		1	3	
	Other	59	11	34	21	13	14	1	0	4	3	4	2	8	6

F&S = functions and structures

Discussion

The 14 measures that resulted from the literature search performed differently on all four aspects that were looked at in this review. Measures that performed best on one level were outperformed on other levels and vice versa. For the purpose of this review, a measure should meet the criteria on all four aspects to be found suitable in measuring HRQL in children after major trauma. Most measures met the first criterion 'suitable for an age range of at least 10 years'. Measures that did not meet this criterion were CHIP-AE / CE, CHQ-CF87, KINDL and YQOL-R. The second criterion was group comparison level for the internal consistency ($\alpha > 0.70$) and substantial test-retest reliability (kappa, ICC, Spearman or Pearson correlation coefficient > 0.60) in at least 80% of the measurements of reliability. Measures that did not meet this criterion were CHQ-CF87 / PF50 / PF28, FS II(R), KINDL, and TACQOL. The third aspect looked at was the content and construct validity of the measures, which was confirmed for all measures. The fourth and final criterion was that the items covered more than six chapters of the ICF domains. This criterion was met by all measures except for CHQ-PF28, FS II(R), HUI2, KIDSCREEN-27, KINDL, and YQOL-R. So the measures that met all four criteria were DISABKIDS, KIDSCREEN 52, and PedsQL4.0.

Two earlier reviews also came to a recommendation after comparing the general characteristics and psychometric properties of pediatric HRQL measures. Willis et al. assessed outcome measures in pediatric trauma populations.[97] They recommended PedsQL 4.0 for children > 2 years of age because it captured both functional and quality of life information, was quick to administer, covered a large age range, and had a self- and parent-proxy-report version. Eiser et al. reviewed generic and disease-specific measures of quality of life in 2001.[98] They recommended PedsQL for brief assessment during a regular clinic visit and CHQ where the goal is to improve family functioning or school integration. Other measures that performed well in current review: DISABKIDS and KIDSCREEN 52, were unfortunately not included in these two earlier reviews. In 2007, the European Consumer Safety Association (ECSA) developed guidelines for the conduction of follow-up studies measuring injury-related disability.[99] They chose EuroQol-5D (EQ-5D) in combination with HUI3 as the preferred common core to measure functional outcome after injury in patients aged 5 years or older. The ECSA assessed the content of the measures related to the ICF-domains. However, the psychometric properties of the measures were not considered. EQ-5D and the HUI3 were not included in this review because the measures were developed for adults and not sufficiently validated in children.

Strengths and limitations

The two largest biomedical databases (Medline and EMBASE) were searched for validation studies of HRQL measures for children. Despite the extensive search

strategy, some relevant related articles were not found initially. Perhaps the addition of more synonyms for quality of life could have overcome this limitation. Another option is to search more databases, for example, the psychological database PsycINFO. However, it seems that no measures were missed. The pediatric HRQL measures included in the most recent review articles corresponded mostly with the measures that were included in this review.[97,100-102] How Are You (HAY) was excluded because it also contained disease-specific questions. The Exeter HRQL and the Generic Child Questionnaire (GCQ) were excluded because psychometric properties were reported insufficiently. No measures were included that had not been reviewed previously.

The articles were screened for meeting the inclusion criteria. Because no trauma-specific HRQL measure is available for children, generic measures were selected. To make comparison of psychometric properties possible, only measures were included for which validity and reliability was reported. Results were limited to validation studies performed in Western countries, because culture is hypothesized to have a great impact on the psychometric properties of the measure. Only measures that have an English or Dutch version were included, because the English language is most used in Western society, and Dutch is the language of interest of the research group. Another reason was that for the comparison of the content of the measures the researcher should fully understand the items. Two French questionnaires, Vecú de Santé Perçué Adolescent (VSP-A) and Duke Health Profile (DUKE HP), were therefore excluded.

The number of available references for each measure is quite variable in this review. Some measures were assessed on the basis of only one reference, whereas other measures have 26 references for assessment. More references lead to a more reliable assessment of the psychometric properties of the measure. Unfortunately, internal consistency was not reported for HUI2, no test-retest was reported for KINDL, and no content validity was reported for KIDSCREEN 52. It is questionable whether the reported information on content validity, the ability to discriminate between health and disease, is really that interesting in a trauma population. It seems much more important for an HRQL measure to distinguish between subjects with injuries of different severity levels. Unfortunately, this information is lacking in current literature for all the included HRQL measures. In fact, PedsQL 4.0 is the only HRQL measure validated in children after trauma at all.[10] Comparison of general characteristics and covering the ICF-chapters of activities and participation are not influenced by the number of references.

Strength of this review is comparison of HRQL measures on four levels: age range, reliability, validity, and content related to the ICF. Earlier reviews on generic HRQL measures in children report general characteristics and psychometric properties.[97,98,100-104] The age range for which the measure is suitable, domain titles, number

of items, and time needed to complete the questionnaire is often described. Internal consistency of the measures is reported by Ravens-Sieberer et al., Willis et al., Rajmil et al., and Connolly et al., and the last two also report test-retest reliability.[97,101-103] Only Rajmil et al. report on the content of the measures.[102] They placed the dimensions of the questionnaires in one of three domains: physical, psychological, or social. No previous review compares HRQL measures for children on all four levels looked at in our review. An interesting concept that was considered as fifth level in this review was the responsiveness of the measure. Terwee et al. divided responsiveness of HRQL instruments into three categories: 1) the ability to detect change in general, 2) the ability to detect clinically important change, and 3) the ability to detect real changes in the concept being measured.[105] They also eliminated 31 measures of responsiveness after an extensive literature search.

All items of HRQL measures were placed into the chapters of the ICF domains. This provided a clear overview of the content of the measures related to the ICF. Most measures covered the chapters of activities and participation much better than the chapters of body functions & structures. This implies that in children, activities and participation are considered of more importance for HRQL than are body functions & structures. Sometimes placement of an item was difficult, because multiple interpretations of the item were possible. Especially when it came to cognitive functions, distinction between body functions and activities was often not very clear. Furthermore, many items could not be placed in one of the ICF chapters. The constructs measured by these items were often too broad to be placed in one chapter. Also items about personal or environmental factors, feelings, and emotions could not be placed in the chapters of the three ICF domains. The fact that many items could not be placed in the ICF implies that HRQL is a broader concept than health status as defined by the ICF.

Conclusions

Based on the results of this review DISABKIDS, KIDSCREEN 52, and PedsQL4.0 seem to be most suitable to measure HRQL of children over the long term after major trauma. They cover a large age range, have good psychometric properties, and cover the ICF content substantially.

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References

1. Vademecum of Health Statistics of the Netherlands: 2003. Statistics Netherlands, Ministry of Health, Welfare and Sports, Voorburg/Heerlen, the Netherlands;2004.
2. O'Neale Roach J. Injuries kill over 20.000 children a year in developed countries. Biomedical Journal 2001;322:317.
3. Suominem P, Kivioja A, Ohman J, Korpela R, Rintala R, Olkkola KT. Severe and fatal childhood trauma. Injury 1998;29(6):425-430.
4. Polinder S, Meerding WJ, Toet H, Mulder S, Essink-Bot ML, Beeck van EF. Prevalence and prognostic factors of disability after childhood injury. Pediatrics. 2005;116:810-817.
5. Schalamon J, Bismarck S, Schober PH, Hollwarth ME. Multiple trauma in pediatric patients. Pediatric surgical interventions 2003;19:417-423.
6. Evans SA, Airey MC, Chell SM, Connelly JB, Rigby AS, Tennant A. Disability in young adults following major trauma: 5 year follow up of survivors. BioMed central public health 2003;3:8.
7. Letts M, Davidson D, Lapner P. Multiple trauma in children: predicting outcome and long-term results. Canadian journal of surgery 2002;45(2):126-131.
8. Hu X, Wesson DE, Logsetty S, Spence LJ. Functional limitations and recovery in children with severe trauma: a one-year follow-up. The journal of trauma 1994;37(2):209-213.
9. Wesson DE, Williams JI, Spence LJ, Filler RM, Armstrong PF, Pearl RH. Functional outcome in pediatric trauma. The journal of trauma 1989;29(5):589-592.
10. McCarthy ML, MacKenzie EJ, Durbin DR, Aitken ME, Jaffe KM, Paidas CN, Slomine BS, Dorsch AM, Berk RA, Christensen JR, Ding R. The pediatric quality of life inventory: an evaluation of its reliability and validity for children with traumatic brain injury. Archives of physical medicine and rehabilitation. 2005;86:1901-1908.
11. Ravens-Sieberer U, Patrick PB, Benz B, Calaminus G, Flechtner H, Melchers P, Patrick P, Schafer B, Suhr L, Schrod L, Ure B, Willadino-Braga L. Quality of life in children with traumatic brain injury: basic issues, assessment, and recommendations. Restorative neurology and neuroscience. 2002;20:151-159.
12. Stacin T, Drotar D, Taylor HG, Yeates KO, Wade SL, Minich NM. Health-related quality of life of children and adolescents after traumatic brain injury. Pediatrics. 2002;109:E34.
13. Sluis van der CK, Kingma J, Eisma WH, Duis ten HJ. Pediatric polytrauma: short-term and long-term outcomes. The journal of trauma: injury, infection, and critical care. 1997;43:501-506.
14. Holbrook TL, Hoyt DB, Coimbra R, Potenza B, Size MJ, Sack MJ, Anderson JP. Trauma in adolescents causes long-term marked deficits in quality of life: adolescent children do not recover preinjury quality of life of function up to two years post-injury compared to national norms. The journal of trauma. 2007;62(3):577-583.
15. WHOQOL Group. The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization. Soc Sci Med. 1995;41:1403-1409.

16. World Health Organization. International classification of functioning, disability and health: ICF. World Health Organization, Geneva, Switserland;2001.
17. Bland JM, Altman DG. Crohnbach's α. Biomedical Journal. 1997;314:572.
18. Landis JR, Koch GG. The measurement of observer agreement for categorical data. Biometrics. 1977;33(1):159-174.
19. Rajmil L, Serra-Sutton V, Alonso J, Starfield B, Riley AW, Vazquez JR, & the research group for the Spanish version of the CHIP-AE. Quality of life research. 2003;12:303-313.
20. Starfield B, Riley AW, Green BF, Ensminger ME, Ryan SA, Kelleher K, Kim-Harris S, Johnston D, Vogel K. The adolescent child health and illness profile. A population-based measure of health. Medical care. 1995;33:210-217.
21. Starfield B, Berger M, Ensminger M, Riley A, Ryan S, Green B, McGauhey P, Skinner A, Kim S. Adolescent health status measurement: development of the child health and illness profile. Pediatrics. 1993;91:430-435P.
22. Riley AW, Forrest CB, Rebok GW, Starfield B, Green BF, Robertson JA, Friello P. The child report form of the CHIP-child edition, reliability and validity. Medical Care. 2004;42:221-231.
23. Riley AW, Forrest CB, Starfield B, Rebok GW, Robertson JA, Green BF. The parent report form of the CHIP-child edition: reliability and validity. Medical Care. 2004;42:210-220.
24. Raat H, Mangunkusumo RT, Landgraf JM, Kloek G, Brug J. Feasibility, reliability, and validity of adolescent health status measurement by the child health questionnaire child form (CHQ-CF): internet administration compared with the standard paper version. Quality of life research. 2007;16:675-685.
25. Helseth S, Lund T, Christophersen KA. Health-related quality of life in a Norwegian sample of healthy adolescents: some psychometric properties of CHQ-CF87-N in relation to KINDL-N. Journal of adolescent health. 2006;38:416-425.
26. Norrby U, Nordholm L, Andersson-gare B, Fasth A. Health-related quality of life in children diagnosed with asthma, diabetes, juvenile chronic arthritis or short stature. Acta pediatrica. 2006;95:450-456.
27. Norrby U, Nordholm L, Fasth A. Reliability of the Swedish version of child health questionnaire. Scandinavian journal of rheumatology. 2003;32:101-107.
28. Raat H, Landgraf JM, Bonsel GJ, Gemke RJ, Essink-Bot ML. Reliability and validity of the child health questionnaire-child form (CHQ-CF87) in a Dutch adolescent population. Quality of life research. 2002;11:575-581.
29. Waters EB, Salmon LA, Wake M, Wright M, Hesketh KD. The health and well-being of adolescents: a school based population study of the self-report child health questionnaire. The journal of adolescent health. 2001;29:140-149.
30. Wake M, Hesketh K, Cameron F. The child health questionnaire in children with diabetes: cross-sectional survey of parent and adolescent-reported functional health status. Diabetic medicine. 2000;17:700-707.
31. Rentz AM, Matza LS, Secnik K, Swensen A, Revicki DA. Psychometric validation of the child health questionnaire (CHQ) in a sample of children and adolescents with attention-deficit/hyperactivity disorder. Quality of life research. 2005;14:719-734.

32. Sung L, Greenberg ML, Doyle JJ, Young NL, Ingber S, Rubenstein J, Wong J, Samanta T, McLimont M, Feldman BM. Construct validation of the health ulitities index and the child health questionnaire in children undergoing cancer chemotherapy. British journal of cancer. 2003;88:1185-1190.
33. Wake M, Salmon L, Reddihough D. Health status of Australian children with mild to severe cerebral palsy: cross-sectional survey using the child health questionnaire. Developmental medicine and child neurology. 2003;45:194-199.
34. Warschburger P, Landgraf JM, Petermann F, Freidel K. Health-related quality of life in children assessed by their parents: evaluation of the psychometric properties of the CHQ-PF50 in two German clinical samples. Quality of life research. 2003;12:291-301.
35. Raat H, Bonsel GJ, Essink-Bot ML, Landgraf JM, Gemke RJBJ. Reliability and validity of comprehensive health status measures in children: the child health questionnaire in relation to the health utilities index. Journal of clinical epidemiology. 2002;55:67-76.
36. Andersson Gare BA, Ruperto N, Berg S, Hagelberg S, Jonsson NO, Magnusson B, Martinell J, Erling A, Landgraf JM. The Swedish version of the childhood health assessment questionnaire (CHAQ) and the child health questionnaire (CHQ). Clinical and experimental rheumatology. 2001;19:S146-150.
37. Foeldvari I, Ruperto N, Dressler F, Hafner R, Kuster RM, Michels H, Minden K, Schauer-Petrowskaja C, Bullinger M, Landgraf JM, Huppertz HI. The German version of the childhood health assessment questionnaire (CHAQ) and the child health questionnaire (CHQ). Clinical and experimental rheumatology. 2001;19:S71-75.
38. Hofer M, Ruperto N, Saurenmann R, Sauvain MJ, Huppertz HI, Landgraf JM, Prieur AM. The Swiss German and Swiss French versions of the childhood health assessment questionnaire (CHAQ) and the child health questionnaire (CHQ). Clinical and experimental rheumatology. 2001;19:S151-157.
39. Huemer C, Ruperto N, Huemer M, Sailer-Hoeck M, Kaulfersch W, Schwarz R, Rettenbacher A, Kenzian H, Artacker G, Pilz I, Bernecker M, Huppertz HI, Landgraf JM. The Austrian version of the childhood health assessment questionnaire (CHAQ) and the child health questionnaire (CHQ). Clinical and experimental rheumatology. 2001;19:S15-19.
40. Inocencio de J, Garcia-Consuegra J, Merino R, Calvo I, Garcia JJ, Ruperto N. The European Spanish version of the childhood health assessment questionnaire (CHAQ) and the child health questionnaire (CHQ). Clinical and experimental rheumatology. 2001;19:S141-145.
41. Joos R, Ruperto N, Wouters C, Boven K, Raat H, Landgraf JM, Veys EM. The Belgian-Flemish version of the childhood health assessment questionnaire (CHAQ) and the child health questionnaire (CHQ). Clinical and experimental rheumatology. 2001;19:S20-24.
42. Melo-Gomes JA, Ruperto N, Canhao H, Fonseca JE, Quintal A, Salgado M, Santos MJ. The Portugese version of the childhood health assessment questionnaire (CHAQ) and the child health questionnaire (CHQ). Clinical and experimental rheumatology. 2001;19:S126-130.
43. Nielsen S, Ruperto N, Herlin T, Pedersen FK. The Danish version of the childhood health assessment questionnaire (CHAQ) and the child health questionnaire (CHQ). Clinical and experimental rheumatology. 2001;19:S50-54.

44. Nugent J, Ruperto N, Grainger J, Machado C, Sawney S, Baildam E, Davidson J, Foster H, Hall A, Hollingworth P, Sills J, Venning H, Walsh JE, Landgraf JM, Roland M, Woo P, Murray KJ. The Brittish version of the childhood health assessment questionnaire (CHAQ) and the child health questionnaire (CHQ). Clinical and experimental rheumatology. 2001;19:S163-167.
45. Pelkonen P, Ruperto N, Honkanen V, Hannula S, Savolainen A, Lahdenne P. The Finnish version of the childhood health assessment questionnaire (CHAQ) and the child health questionnaire (CHQ). Clinical and experimental rheumatology. 2001;19:S55-59.
46. Pouchot J, Ruperto N, Lemelle I, Sommelet D, Grouteau E, David L, Duquesne A, Deslandre CJ, Kone Paut I, Pillet P, Goumy L, Barbier C, Guyot MH, Mazingue F, Gandon Laloum S, Fischbach M, Quartier P, Guyot C, Jean S, Gall le E, Plouvier E, Bost M, Lumley de L, LePlege A, Larbre JP, Guillemin F, Coste J, Landgraf JM, Prieur AM. The French version of the childhood health assessment questionnaire (CHAQ) and the child health questionnaire (CHQ). Clinical and experimental rheumatology. 2001;19:S60-65.
47. Pratsidou-Gertsi P, Vougiouka O, Tsitsami E, Ruperto N, Siamopoulou-Mavridou A, Dracou C, Daskas I, Trachana M, Aleleou V, Kanakoudi-Tsakalidou. The Greek version of the childhood health assessment questionnaire (CHAQ) and the child health questionnaire (CHQ). Clinical and experimental rheumatology. 2001;19:S76-80.
48. Ruperto N, Ravelli A, Pistorio A, Malattia C, Viola S, Cavuto S, Alessio M, Alpigiani MG, Buoncompagni A, Corona F, Cortis F, Falcini F, Gerloni V, Lepore L, Sardella ML, Strano CG, Zulian F, Gado-West L, Tortorelli A, Fantini F, Martini A. The Italian version of the childhood health assessment questionnaire (CHAQ) and the child health questionnaire (CHQ). Clinical and experimental rheumatology. 2001;19:S91-95.
49. Selvaag AM, Ruperto N, Asplin L, Rygg M, Landgraf JM, Forre O, Flato B. The Norwegian version of the childhood health assessment questionnaire (CHAQ) and the child health questionnaire (CHQ). Clinical and experimental rheumatology. 2001;19:S116-120.
50. Wulffraat N, Net van der JJ, Ruperto N, Kamphuis S, Prakken BJ, Cate ten R, Soesbergen van RM, Rossum van MA, Raat H, Landgraf JM, Kuis W, Pediatric rheumatology international trials organisation. The Dutch version of the childhood health assessment questionnaire (CHAQ) and the child health questionnaire (CHQ). Clinical and experimental rheumatology. 2001;19:S111-115.
51. Asmussen L, Olson LM, Grant EN, Landgraf JM, Fagan J, Weiss KB. Use of the child health questionnaire in a sample of moderate and low-income inner-city children with asthma. American journal of respiratory and critical care medicine. 2000;162:1215-1221.
52. Nixon-Speechley K, Maunsell E, Desmeules M, Schanzer D, Landgraf JM, Feeny DH, Barrera ME. Mutual concurrent validity of the child health questionnaire and the health utilities index: an exploratory analysis using survivors of childhood cancer. International journal of cancer. 1999;12:95-105.
53. Landgraf JM, Maunsell E, Nixon-Speechley K, Bullinger M, Campbell S, Abetz L, Ware JE. Canadian-French, German and UK versions of the child healh questionnaire: methodology and preliminary item scaling results. Quality of life research. 1998;7:433-445.

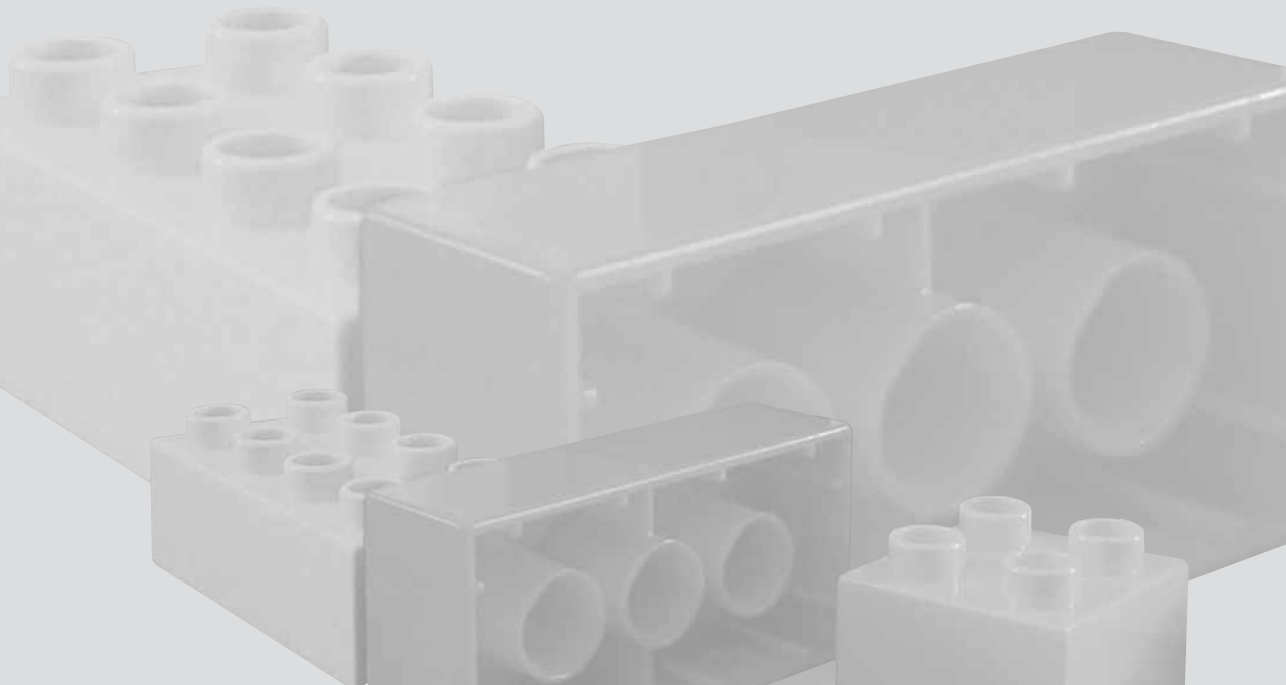
54. Raat H, Botterweck AM, Landgraf JM, Hoogeveen WC, Essink-Bot ML. Reliability and validity of the short form of the child health questionnaire for parents (CHQ-PF28) in large random school based and general population samples. Journal of epidemiology and community health. 2005;59:75-82.
55. Woods-Byrne M, Honig J. Psychometrics of child health questionnaire parent short form (CHQ-28) used to measure quality of life in HIV-infected children on complex anti-retroviral therapy. Quality of life research. 2005;14:1769-1774.
56. Georgalas C, Tolley N, Kanagalingam J. Measuring quality of life in children with adenotonsillar disease with the child health questionnaire: a first U.K. study. Laryngoscope. 2004;114:1849-1855.
57. Panepinto JA, O'Mahar KM, DeBaun MR, Rennie KM, Scott JP. Validity of the child health questionnaire for use in children with sickle cell disease. Journal of pediatric hematology and oncology. 2004;26:574-578.
58. Simeoni MC, Schmidt S, Muehlan H, Debensason D, Bullinger M; DISABKIDS group. Field testing of a European quality of life instrument for children and adolescents with chronic conditions: the 37-item DISABKIDS chronic generic module. Quality of life research. 2007;16(5):881-893.
59. Schmidt S, Debensason D, Muhlan H, Petersen C, Power M, Simeoni MC, Bullinger M; the European DISABKIDS group. The DISABKIDS generic quality of life instrument showed cross-cultural validity. Journal of clinical epidemiology. 2006;59(6):587-598.
60. Post MWM, Kuyvenhoven MM, Verheij TJM, Melker de RA, Hoes AW. De Nederlandse 'functional status II(R)': een vragenlijst voor het meten van de functionele gezondheidstoestand van kinderen. Nederlands tijdschrift voor geneeskunde. 1998;142:2675-2679.
61. Stein REK, Jessop DJ. Functional status II(R), a measure of child health status. Medical care. 1990;28(11):1041-1055.
62. Fu L, Talsma D, Baez F, Bonilla M, Moreno B, Ah-Chu M, Pena A, Furlong W, Barr RD. Measurement of health-related quality of life in survivors of cancer in childhood in Central America: feasibility, reliability, and validity. Journal of pediatric hematology and oncology. 2006;28:331-341.
63. Felder-Puig R, Frey E, Sonnleithner G, Feeny D, Gadner H, Barr RD, Furlong W, Topf R. German cross-cultural adaptation of the health utilities index and its application to a sample of childhood cancer survivors. European journal of pediatrics. 2000;159:283-288
64. Trudel JG, Rivard M, Dobkin PL, Leclerc JM, Robaey P. Psychometric properties of the health utilities index mark 2 system in pediatric oncology patients. Quality of life research. 1998;7:421-432.
65. Robitail S, Simeoni MC, Erhart M, Ravens-Sieberer U, Bruil J, Auquier P, and the European Kidscreen Group. Validation of the European proxy KIDSCREEN-52 pilot test health-related quality of life questionnaire: first results. Journal of adolescent health. 2006;39:596. e1-596.e10.
66. Ravens-Sieberer U, Gosch A, Rajmil L, Erhart M, Bruil J, Duer W, Auquier P, Power M, Abel T, Czemy L, Mazur J, Czimbalmos A, Tountas Y, Hagquist C, Kilroe J, Fuerth K, Robitail S, Simeoni M, Orbicini D, Rueden von U, Dimitrakaki C, Detmar S, Verrips E,

Mierzejewska E, Berra S, Tebe C, Bisegger C, Cloetta B, Atherton C. KIDSCREEN-52 quality-of-life measure for children and adolescents. Expert review of pharmacoeconomics and outcome research. 2005;5(3):353-364.

67. Ravens-Sieberer U, Auquier P, Erhart M, Gosch A, Rajmil L, Bruil J, Power M, Duer W, Cloetta B, Czemy L, Mazur J, Czimbalmos A, Tountas Y, Hagquist C, Kilroe J; the European KIDSCREEN group. The KIDSCREEN-27 quality of life measure for children and adolescents: psychometric results from a cross-cultural survey in 13 European countries. Quality of life research. 2007;16(8):1347-1356.
68. Robitail S, Ravens-Sieberer U, Simeoni MC, Rajmil L, Bruil J, Power M, Duer W, Cloetta B, Czemy L, Mazur J, Czimbalmos A, Tountas Y, Hagquist C, Kilroe J, Auquier P, and the KIDSCREEN group. Testing the structural and cross-cultural validity of the KIDSCREEN-27 quality of life questionnaire. Quality of life research. 2007;16:1335-1345.
69. Wee HL, Ravens-Sieberer U, Erhart M, Li SC. Factor structure of the Singapore English version of the KINDL children quality of life questionnaire. Health and quality of life outcomes. 2007;5:4.
70. Helseth S, Lund T. Assessing health-related quality of life in adolescents: some psychometric properties of the first Norwegian version of KINDL. Scandinavian journal of caring sciences. 2005;19:102-109.
71. Wee HL, Lee WWR, Ravens-Sieberer U, Erhart M, Li SC. Validation of the English version of the KINDL generic children's health-related quality of life instrument for an Asian population – results from a pilot test. Quality of life research. 2005;14:1193-1200.
72. Ravens-Sieberer U, Bullinger M. Assessing health-related quality of life in chronically ill children with the German KINDL: first psychometric and content analytical results. Quality of life research. 1998;7:399-407.
73. Laaksonen C, Aromaa M, Heinonen OJ, Suonimen S, Salantera S. Paediatric health-related quality of life instrument for primary school children: cross-cultural validation. Journal of advanced nursing. 2007;59(5):542-550.
74. Varni JW, Limbers CA, Burwinkle TM. How young can children reliably and validly self-report their health-related quality of life?: an analysis of 8,591 children across age subgroups with the PedsQL 4.0 generic core scales. Health and quality of life outcomes. 2007;5:1.
75. Varni JW, Limbers CA, Burwinkle TM. Parent proxy-report of their children's health-related quality of life: an analysis of 13,878 parents' reliability and validity across age subgroups using the PedsQL 4.0 generic core scales. Health and quality of life outcomes. 2007;5:2.
76. Connelly M, Rapoff MA. Assessing health-related quality of life in children with recurrent headache: reliability and validity of the PedsQL 4.0 in a pediatric headache sample. Journal of pediatric psychology. 2006;31(7):698-702.
77. Cremeens J, Eiser C, Blades M. Factors influencing agreement between child self-report and parent proxy-reports on the pediatric quality of life inventory 4.0 (PedsQL) generic core scales. Health and quality of life outcomes. 2006;2:58.

78. Reinfjell T, Diseth TH, Veenstra M, Vikan A. Measuring health-related quality of life in young adolescents: reliability and validity in the Norwegian version of the pediatric quality of life inventory 4.0 (PedsQL) generic core scales. Health and quality of life outcomes. 2006;4:61.
79. Varni JW, Burwinkle TM. The PedsQL as a patient-reported outcome in children and adolescents with attention-deficit/hyperactivity disorder: a population-based study. Health and quality of life outcomes. 2006;4:26.
80. Varni JW, Burwinkle TM, Berrin SJ, Sherman SA, Artavia K, Malcarne VL, Chambers HG. The PedsQL in pediatric cerebral palsy: reliability, validity, and sensitivity of the generic core scales and cerebral palsy module. Developmental medicine and child neurology. 2006;48:442-449.
81. Varni JW, Burwinkle TM, Seid M. The PedsQL 4.0 as a school population health measure: feasibility, reliability, and validity. Quality of life research. 2006;15:203-215.
82. Upton P, Eiser C, Cheung I, Hutchings HA, Jenney M, Maddocks A, Russell IT, Williams JG. Measurement properties of the UK-English version of the pediatric quality of life inventory 4.0 (PedsQL) generic core scales. Health and quality of life outcomes. 2005;3:22.
83. Upton P, Maddocks A, Eiser C, Barnes PM, Williams J. Development of a measure of the health-related quality of life of children in public care. Child: care, health and development. 2005;31:409-415.
84. Bastiaansen D, Koot HM, Bongers IL, Varni JW, Verhulst FC. Measuring quality of life in children referred for psychiatric problems: psychometric properties of the PedsQL 4.0 generic core scales. Quality of life research. 2004;13:489-495.
85. Felder-Puig R, Proksch K, Varni JW, Gadner H, Topf R. Validation of the German version of the pediatric quality of life inventory (PedsQL) in childhood cancer patients off treatment and children with epilepsy. Quality of life research. 2004;13:223-234.
86. Varni JW, Burwinkle TM, Rapoff MA, Kamps JL, Olson N. The PedsQL in pediatric asthma: reliability and validity of the pediatric quality of life inventory generic core scales and asthma module. Journal of behavioral medicine. 2004;27:297-318.
87. Eiser C, Vance YH, Horne B, Glaser A, Galvin H. The value of the PedsQLTM in assessing quality of life in survivors of childhood cancer. Child: care, health & development. 2003;29:95-102.
88. Varni JW, Burwinkle TM, Jacobs JR, Gottschalk M, Kaufman F, Jones KL. The PedsQL in type 1 and type 2 diabetes: reliability an validity of the pediatric quality of life inventory generic core scales and type 1 diabetes module. Diabetes care. 2003;26:631-637.
89. Varni JW, Burwinkle TM, Katz ER, Meeske K, Dickinson P. The PedsQL in pediatric cancer: reliability and validity of the pediatric quality of life inventory generic core scales, multi-dimensional fatigue scale, and cancer module. Cancer. 2002;94:2090-2106.
90. Varni JW, Seid M, Smith Knight T, Burwinkle T, Brown J, Szer IS. The PedsQL in pediatric rheumatology, reliability, validity, and responsiveness of the pediatric quality of life inventory generic core scales and rheumatology module. Arthritis and rheumatism. 2002;46(3):714-725.

91. Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the pediatric quality of life inventory version 4.0 generic core scales in healthy and patient populations. Medical care. 2001;39(8):800-812.
92. Stolk EA, Busschbach JJV, Vogels T. Performance of the EuroQol in children with imperforate anus. Quality of life research. 2000;9:29-38.
93. Verrips EGH, Vogels AG, Ouden den AL, Paneth N, Verloove-Vanhorrick SP. Measuring health-related quality of life in adolescents: agreement between raters and between methods of administration. Child: care, health and development. 2000;26: 457-469.
94. Verrips EGH, Vogels TGC, Koopman HM, Theunissen NCM, Kamphuis RP, Fekkes M, Wit JM, Verloove-Vanhorrick P. Measuring health-related quality of life in a child population. European journal of public health. 1999;9:188-193.
95. Vogels T, Verrips GH, Verloove-Vanhorrick SP, Fekkes M, Kemphuis RP, Koopman HM, Theunissen NL, Wit JM. Measuring health-related quality of life in children: the development of the TACQOL parent form. Quality of life research. 1998;7:457-465.
96. Patrick DL, Edwards TC, Topolski TD. Adolescent quality of life, part II: initial validation of a new instrument. Journal of adolescence. 2002;25(3):287-300.
97. Willis CD, Gabbe BJ, Butt W, Cameron PA. Assessing outcomes in paediatric trauma populations. Injury, international journal of the care of the injured. 2006;37:1185-1196.
98. Eiser C, Morse R. The measurement of quality of life in children: past and future perspectives. Developmental and behavioural pediatrics. 2001;22(4):248-256.
99. Van Beeck EF, Larsen CF, Lyons RA, Meerding WJ, Mulder S, Essink-Bot ML. Guidelines for the conduction of follow-up studies measuring injury-related disability. The journal of trauma: injury, infection, and critical care. 2007;62:534-550.
100. Raat H, Mohangoo AD, Grootenhuis MA. Pediatric health-related quality of life questionnaires in clinical trials. Current opinion in allergy and clinical immunology. 2006;6:180-185.
101. Ravens-Sieberer U, Erhart M, Wille N, Wetzel R, Nickel J, Bulliger M. Generic health-related quality of life assessment in children and adolescents. Pharmacoeconomics. 2006;24(12):1199-1220.
102. Rajmil L, Herdman M, Fernandez de Sanmamed MJ, Detmar S, Bruil J, Ravens-Sieberer U, Bullinger M, Simeoni MC, Auquier P. Generic health-related quality of life instruments in children and adolescents: a qualitative analysis of content. Journal of adolescent health. 2004;34:37-45.
103. Connolly MA, Johnson JA. Measuring quality of life in paediatric patients. Pharmacoeconomics. 1999;16(6):605-625.
104. Spieth LE, Harris CV. Assessment of health-related quality of life in children and adolescents: an integrative review. Journal of pediatric psychology. 1996;21(2):175-193.
105. Terwee CB, Dekker FW, Wiersinga WM, Prummel MF, Bossuyt PM. On assessing responsiveness of health-related quality of life instruments: guidelines for instrument evaluation. Quality of life research. 2003;12:349-362.



5

LONG-TERM HEALTH CONDITION IN MAJOR PEDIATRIC TRAUMA: A PILOT STUDY

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Abstract

Background Major trauma is the leading cause of death in children of developed countries. However, little is known about its long-term health consequences in survivors. Our aim was to describe the health condition in children at long-term after major trauma.

Methods Prospective cohort study of severely injured children (Injury Severity Score ≥ 16, age < 16) admitted to a Dutch level 1 trauma center in 1999 to 2000 (N = 40). About 7 years after trauma (median 7.3, range 6.3-8.2 years), survivors' health condition was assessed with the following: guides to the evaluation of permanent impairment of the American Medical Association (AMA guides), Glasgow Outcome Scales (GOS /GOSE), Vineland Adaptive Behavior Scales (VABS), Child Behavior Checklist (CBCL), and Strengths and Difficulties Questionnaire (SDQ).

Results Of 40 children, 28 were followed up. Most (n = 16; 57%) had no impairments (AMA-guides); minor to severe impairments were found in 12 of the respondents. About 80% (n = 22) had good recovery (GOS 5 and GOSE 7 / 8); the remaining had moderate disability (GOS 4 or GOSE 5 / 6). The mean scores on the VABS and the frequency of behavioral problems on the CBCL (24%) and the SDQ (20%) were comparable to healthy peers.

Conclusions This long-term follow-up study after major trauma revealed that most children had a health condition comparable to healthy peers; about 40% of the respondents was physically impaired or restricted in daily activities. Our experiences with different measures may be helpful to apply age-appropriate outcome measures for the clinical follow-up of children after major trauma and to design future longitudinal studies.

Introduction

In developed countries, injuries are the leading cause of death among children in the age range of 1 to 18 years old.[1,2] The survival rate of major trauma in children is about 80%.[3,4] Fortunately, most children recover fully from an accident, but there is a subgroup of patients that are left with physical disabilities or with cognitive or psychosocial problems.[5-10]

According to the International Classification of Functioning, Disability and Health (ICF) of The World Health Organization (WHO), health condition can be described by 3 domains: body function & structure, activities, and participation.[11] (figure 1). These 3 domains are interrelated and also influenced by personal and environmental factors. An example will clarify the use of the ICF model in describing a person's health condition. The health condition of a 15-year-old boy with a traumatic lower leg amputation can be described as follows: 1) On the domain of body function & structure, his amputation means not only the absence of his lower leg, including his ankle and foot, but also related impairments such as skin problems, phantom pain, muscle weakness, and others. 2) On the domain of activities, his amputation means that he has limitations in mobility-related activities but is able to walk with prosthesis or crutches. 3) On the domain of participation, his amputation means that he is restricted in his participation to play tennis at his tennis club at the same level.

The available literature about the health condition after pediatric trauma generally focuses on minor trauma or traumatic brain injury.[12-17] Major trauma is defined as life-threatening injury of 2 or more body regions or organ systems.[18] Literature about the health condition of children after major trauma is sparse, and the results are diverse.

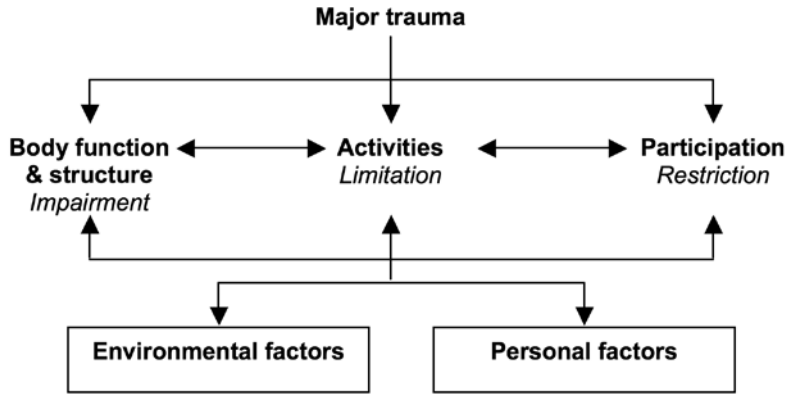


Figure 1 International Classification of Functioning, disability and health (ICF) of the World Health Organization.[13]

In children after major trauma, physical disabilities were found in 20% to 30% at discharge.[3,6] One year after major trauma, 20% to 55% of the children was found to have a physical disability.[4,8] At 2 to 9 years (mean 4.2 years) follow-up, physical disabilities are found in 10% to 30%, cognitive problems in 10% to 40%, and psychosocial problems in 20% to 50% of the children after major trauma.[4,6-8] Literature about the health condition of children after major trauma with a mean follow-up period of more than 5 years is missing. Furthermore, there is limited experience with measures of health condition in children after major trauma.

In summary, to understand better the problems after trauma, there is a need for large longitudinal studies that describe the long-term health condition at all levels of functioning in children after major trauma. The aim for this pilot study is to describe the health condition at each ICF level of functioning in a cohort of children 6 to 8 years after major trauma.

Methods

Study population

From January 1999 till December 2000, a consecutive cohort of patients with major trauma who were at the emergency department of the University Medical Center Utrecht (UMCU), The Netherlands, was defined.[19] The UMCU is a level 1 trauma hospital with a population of 1.1 million people in a densely populated region with high traffic intensity. Only children who survived the accident were part of the cohort. Included were children younger than 16 years at the time of the accident and who had an Injury Severity Score (ISS)[18] of at least 16. The injury severity is based on anatomical and physiologic disturbances in 6 body areas and rated on a 1 to 5 scale. The ISS is calculated by summing the squares of the 3 most severely injured body areas.

Procedure

Patients and their parents were asked by written invitation to participate in a follow-up examination 6 to 8 years after their trauma. If they did not respond, the investigator (LJ) contacted the patients and their parents by telephone. After obtaining written informed consent, respondents were sent the parent-report Child Behavior Checklist (CBCL) and the self-report Strength and Difficulties Questionnaire (SDQ). Respondents and their parents were asked to complete the questionnaires, and they were invited to visit the outpatient clinic. The investigator was trained to administer the guides to the evaluation of permanent impairment of the American Medical Association (AMA guides), the Vineland Adaptive Behavior Scales (VABS), the Glasgow Outcome Scale

(GOS), and the Glasgow Outcome Scale Extended (GOSE). During the outpatient visit, an open interview was undertaken about current complaints that could be related to the accident, followed by a physical examination according to the AMA guides. Subsequently, the VABS were administered to one of the parents. The completed CBCL and SDQ were taken in. The GOS / GOSE was scored afterward. The Medical Ethics Committee of the University Medical Center Utrecht approved the study protocol.

Outcome measurement

The AMA guides fifth edition was used as a measure for the ICF domain body function and structure.[20] The AMA guides express physical disorders into a percentage of permanent impairment for the whole person. Whole person impairment (WPI) of 0% means that the patient has no physical disorder. In this study, a percentage between 1 and 20 was defined as minor to moderate impairments. A percentage more than 20 was defined as severe impairments. McCarthy et al. validated the AMA guides in a group of 302 patients with a lower extremity fracture.[21] The percentage of permanent impairment, assessed with the AMA guides, was strongly related with direct observation of functioning ($r = 0.57$) and the assessment of patients themselves by the Sickness Impact Profile ($r = 0.55$).[22]

The WHO uses the same code in the ICF classification system for activities and participation because in practice it is difficult to distinguish between both domains. Activities and participation are subdivided into 9 chapters: 1) learning and applying knowledge, 2) general tasks and demands, 3) communication, 4) mobility, 5) self-care, 6) domestic life, 7) interpersonal interactions and relationships, 8) major life areas, and 9) community, social, and civic life. In current study, it is tried to cover all these chapters with the instruments used to measure activities and participation.

The GOS and the GOSE both measure the global concept recovery, including all chapters of activities and participation. The GOS describes the outcome on a 5-point scale ranging from 1: death to 5: good recovery. The GOSE describes the outcome on an 8-point scale ranging from 1: death to 8: full recovery without symptoms or signs. The extended version has less ceiling effect than the 5-point scale.[23] The GOSE also has better test-retest reliability than the GOS, respectively, $\kappa = 0.98$ and $\kappa = 0.92$.[24] The GOS is frequently used in major trauma populations, in contrast with the GOSE.[6,10,25,26] By way of illustration, the GOS / GOSE is added as appendix.

The VABS Survey Form measures on communication, daily skills, and socialization. It contains questions on all chapters of activities and participation, but chapters 1 and 3 to 7 are overrepresented. The VABS takes about 20 minutes to complete.[27]

The VABS is suitable for children in the age range of 0 to 18 years. A table with norm values is included for children younger than 19 years. These norm values are based on a healthy reference population from the United States. The measure is valid and has excellent reliability, with a Cronbach α of 0.99 and an intraclass correlation of 0.99 for the total score.[28]

The CBCL contains 113 closed questions on aberrant behavior and 7 open questions about sports, hobbies, friends, and school. It measures mainly on chapter 7 of the ICF domains activities and participation, but chapters 8 and 9 are represented in the questionnaire too. The questionnaire is validated for children aged 4 to 18 years but is analyzed for all children of the cohort. The questionnaire is administered by the parents and will take approximately 15 minutes to complete. Behavioral problems can be detected on 8 domains and on the total score. The domains are: 1) withdrawn, 2) somatic complaints, 3) anxious or depressed, 4) social problems, 5) thought problems, 6) attention problems, 7) delinquent behavior, and 8) aggressive behavior. Cutoff points are described for all domains and the total score separately. For example, a total score of more than 30 is defined as having behavioral problems. The CBCL has high test-retest reliability with an intraclass correlation of 0.95.[29,30] The outcome on the CBCL in the general Dutch population is described by Crijnen et al.[29]

The SDQ measures positive and negative attributes that can be allocated to 5 domains as follows: 1) emotional symptoms, 2) conduct problems, 3) hyperactivity / inattention, 4) peer problems, and 5) pro-social behavior. The SDQ measures on chapter 7 mainly, but chapters 1 and 2 are represented too. A total difficulty score can be calculated by summing the scores on the first 4 domains. A total score of more than 14 is defined as having mental problems. Cutoff values are also available for the domains separately. The SDQ contains 25 items and takes 5 to 10 minutes to complete. The self-report version of the SDQ is suitable for children aged 11 to 16 years, Children who were younger than 11 years were asked to complete the questionnaire with the help of one of their parents. The questionnaire was analyzed for all children of the cohort. The self-report version of the SDQ has satisfactory validity and reliability (Cronbach $\alpha > 0.70$, intraclass correlation 0.59-0.88).[31-33] Normative data in a United States population are described by Bourdon et al.[31]

Data analysis

Data were analyzed using descriptive statistics. The Statistical Package for the Social Sciences (SPSS) version 13.0 was used. A p-value of less than 0.05 was considered to be statistically significant. The VABS is only analyzed for the patients of the cohort who were younger than 19 years at follow-up.

Results

Forty severely injured (ISS ≥ 16) children younger than 16 years were referred to the emergency department of the University Medical Center Utrecht, the Netherlands, in the years 1999 and 2000. Of these patients, 12 were lost to follow-up as follows: 3 lived abroad, 4 addresses were untraceable, and 5 patients refused to participate. Reasons for refusal were 'participated in a lot of researches already', 'patient is finally going well and does not want to be reminded of the accident anymore', 'not interested', 'mother is sick and does not have time to participate', and 'patient is too busy with work and removal'. Three of the respondents did not fill in the CBCL and the SDQ. The AMA guide and the GOS / GOSE were analyzed for all respondents (n = 28), the VABS for all 19 respondents who were younger than 19 years, and the CBCL and the SDQ for 25 respondents.

Patient & injury characteristics

The patient and injury characteristics of the 28 respondents did not differ from the 12 children who were lost to follow-up. (table 1). The mean age of the 40 children at the time of the accident was 8.9 years (SD 4.6 years), and 25 (63%) were male. The mean follow-up period was 7.3 years (SD 0.7 years). Seventy percent of the injuries resulted from traffic accidents, 15% took place in or around home, and 5% resulted from sports. There were 83 injuries in total. The body region that was injured most frequently was the head (35%), followed by the thorax (18%), the lower extremity (17%), the abdomen (16%), the upper extremity (10%), and finally the spinal cord (5%). The mean ISS was 24.9 (SD = 11.1), the mean intensive care unit stay was 6.9 days (SD = 11.8 days), and the mean hospital stay was 21.5 days (SD 25.4 days). Most patients were discharged directly to their own homes (75%), a minority was referred to a rehabilitation center (18%), or to another hospital (8%).

Outcome on ICF-domain body function and structure

Measured by the AMA guides, the mean permanent impairment score was 12% (SD 20%) with a median score of 0% (range 0%-78%). Most respondents (57%, n = 16) were fully recovered (0% WPI). Minor to moderate impairments (1%-20% WPI) were found in 6 respondents, and severe impairments (> 20% WPI) were also found in 6 respondents. (figure 2). Causes of severe impairments were very divers and mostly caused by the sum of multiple impairments. In these 6 respondents with the worst outcome, the impairments were caused by spinal cord lesion, plexus brachialis lesion, ankylosis of a hand, knee flexion impairment, severe hearing problem, no light perception in one eye, emotional and behavioral problems, disturbance of short-term memory, and major scars.

Table 1 Patient & injury characteristics of 40 children (ISS ≥ 16, age < 16 years), that were admitted to the emergency department of the University Medical Center Utrecht, the Netherlands, in '99-'00.

Patient / injury characteristic		Included (n = 28)	Lost to follow-up (n = 12)	p-value
Mean age at time accident		8.2 years (SD 4.7)	10.2 years (SD 4.3)	0.19
Mean age at follow-up		15.1 years (SD 4.7)	18.0 years (SD 4.2)	0.08
Gender	Male	17 (61%)	8 (67%)	0.73
	Female	11 (39%)	4 (33%)	
Injury Severity Score		24.7 (SD 11.7)	25.3 (SD 10.0)	0.89
Cause of injury				0.80
	Traffic	19 (68%)	9 (75%)	
	Home	4 (14%)	2 (17%)	
	Sports	2 (7%)	0 (0%)	
	Other	3 (11%)	1 (8%)	
Body region				0.81
	Head	21 (36%)	8 (33%)	
	Thorax	10 (17%)	5 (21%)	
	Abdomen	10 (17%)	3 (13%)	
	Lower extremity	9 (15%)	5 (21%)	
	Upper extremity	5 (8%)	3 (13%)	
	Spinal cord	4 (7%)	0 (0%)	
Mean intensive care unit stay		8.1 days (SD 12.7)	4.1 days (SD 9.3)	0.33
Mean hospital stay		21.3 days (SD 24.8)	21.8 days (SD 28.0)	0.96
Destination after discharge				0.99
Home		21 (75%)	9 (75%)	
Rehabilitation center		5 (18%)	2 (17%)	
Another hospital		2 (7%)	1 (8%)	

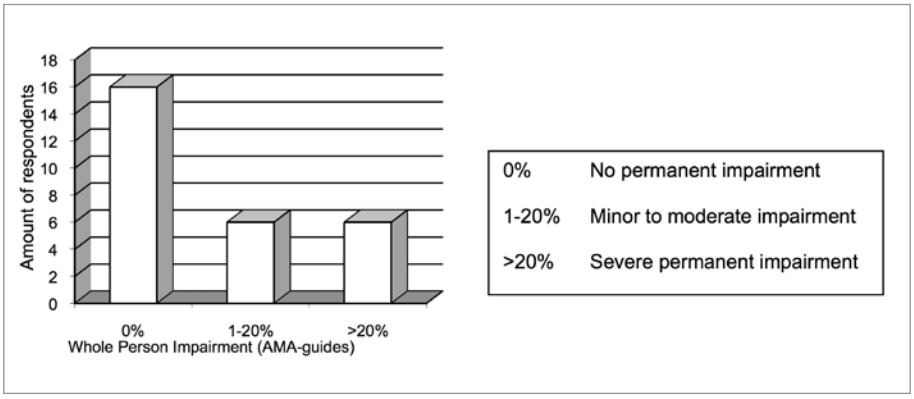


Figure 2 Permanent impairment measured with the AMA-guides of 28 respondents of a cohort of children 6 to 8 years after major trauma.

Outcome on ICF-domains activities and participation

On the GOS, most respondents (89%, n = 25) had a good recovery (GOS 5). Only 3 respondents had moderate disability (GOS 4). There were no respondents with a GOS less than 4. According to the GOSE, half of the respondents (50%, n = 14) were fully recovered (GOSE 8), 8 respondents (29%) had minor complaints (GOSE 7), and 6 respondents (21%) had moderate to severe posttraumatic signs (GOSE 6 or 5). There were no respondents with a GOSE score less than 5. (table 2). Altogether, there were 6 respondents with a low outcome score on the GOS (GOS ≤ 4) and the GOSE (GOSE ≤ 6). Four of these respondents also had a WPI more than 20% on the AMA guides. The other 2 respondents with a low outcome on the GOS / GOSE had a WPI just lower than 20%, namely 17% and 10%. Injuries to the head, the spinal cord, and the peripheral nervous system were overrepresented in these respondents with the lowest outcome on the GOS / GOSE.

The mean scores on the VABS domains of communication and daily skills of the major trauma cohort were comparable to the healthy United States reference population. On the socialization scale of the VABS, children after major trauma perform even better than healthy peers (2 years and 3 months ahead; SD 2 years). On the communication scale, 6 of the respondents lagged more than 2 years behind their peers. On the daily skills and socialization scales, only one of the respondents lagged more than 2 years behind their peers. (table 2). Altogether, there were 6 respondents who lagged more than 2 years behind their peers on at least one of the domains of the VABS. Not one of these respondents with the lowest outcome on the VABS also had a low score on the GOS / GOSE or had a WPI of more than 20%.

Most respondents (76%, n = 19) had no behavioral problems measured with the CBCL. Six respondents (24%) had a total score of more than 30 on the CBCL, which means that they have behavioral problems. These 6 respondents had problem scores on 1 to 4 domains of the CBCL. (table 2). There was only one respondent with a problem score on the CBCL who also had a low score on the GOS / GOSE and had a WPI of more than 20%.

According to the SDQ, most respondents (80%, n = 20) did not have major difficulties. Five respondents, however, had a total difficulty score of more than 14, which means that they have more difficulties than healthy peers. These 5 respondents had problem scores on 2 to 3 domains of the SDQ. (table 2). Three of the respondents who had a total score of more than 14 on the SDQ also had a total score of more than 30 on the CBCL. There was only one respondent with a problem score on the SDQ that also had a low score on the GOS / GOSE and had a WPI of more than 20%.

Table 2 Outcome characteristics on the ICF-domains of activities and participation of 28 respondents of a cohort of children 6 to 8 years after major trauma.

Activities and participation			
GOS	n = 28		
	Good recovery, GOS 5	25 (89%)	
	Moderate disability, GOS 4	3 (11%)	
GOSE	n = 28		
	Full recovery, GOSE 8	14 (50%)	
	Minor complaints, GOSE 7	8 (29%)	
	Post-traumatic signs, GOSE 6	5 (18%)	
	Activities at lower level, GOSE 5	1 (4%)	
VABS	n = 19 (aged under 19 years)		
	Mean VABS communication	0.4 years behind peer group as given in VABS (SD 3.3)	
	Mean VABS daily activities	0.5 years before peer group as given in VABS (SD 2.4)	
	Mean VABS socialization	2.2 years before peer group as given in VABS (SD 2.1)	
CBCL	n = 25	Mean (SD)	N problem score (%)*
	Behavioral problems, total score	19.5 (19.0)	6 (24%)
	Withdrawn	1.9 (2.5)	2 (8%)
	Somatic complaints	1.9 (2.2)	3 (12%)
	Anxious or depressed	2.7 (3.7)	4 (16%)
	Social problems	1.6 (2.2)	2 (8%)
	Thought problems	0.5 (0.9)	2 (8%)
	Attention problems	3.2 (3.1)	3 (12%)
	Delinquent behavior	1.2 (2.0)	3 (12%)
	Aggressive behavior	5.0 (5.0)	2 (8%)
SDQ	n = 25	Mean (SD)	N problem score (%)*
	Total difficulties score	10.3 (6.5)	5 (20%)
	Emotional symptoms	2.5 (2.3)	4 (16%)
	Conduct problems	1.8 (1.5)	3 (12%)
	Peer problems	2.3 (2.2)	7 (28%)
	Hyperactivity / inattention	3.7 (2.5)	3 (12%)
	Low score on pro-social behavior	8.4 (1.3)	0 (0%)

GOS Glasgow Outcome Scale; GOSE Glasgow Outcome Scale Extended; VABS Vineland Adaptive Behavior Scales; CBCL Child Behavior Checklist; SDQ Strengths and Difficulties Questionnaire

* A child has a problem score when it equals or exceeds the age-specific norm value (based on a healthy reference population described in the manual of the measures).

Discussion

This is a first descriptive study in which the health status was measured comprehensively in 28 children at least 6 years after their major trauma. About 40% of the participating children still had physical impairments. Half of these children with physical impairments were restricted in performing the activities of daily life. In daily functioning, children after major trauma had at least a similar level of communication, daily skills, and socialization compared to healthy peers. About 20% of the participants had a problem score on one of the behavioral questionnaires. Table 3 provides a summary of the results per respondent.

The results compared to the available literature

The injury characteristics of the cohort were comparable to other children after major trauma in the available literature. About 70% of the major traumas with ISS of 16 or greater were caused by traffic accidents. Other causes of major trauma were sports, falls from height, and accidents in or around the house.[3,4,6-8,10] The body part that was injured most frequently was the head, followed by the extremities, the thorax, and the abdomen.[3,4,6-10]

As measured by the GOS, 89% of the respondents had a good recovery, moderate and severe disability was found in 11% and 0% of the children after major trauma, respectively. The GOS was also used in a comparable research by Schalamon et al.[6] They found that 81% of the children had good recovery, 14% had moderate disability, and 5% had severe disability, 2 to 9 years (mean 4.2 years) after major trauma (ISS ≥ 16). The longer follow-up period in our study (mean 7.3 years) can probably explain the slightly better outcome. The extended version of the GOS (GOSE) was not used in children after major trauma before.

The scores on the VABS in the study population were better than expected. The mean score on the socialization scale was unexpectedly higher than the available norm values for the general United States population, which leads to the hypothesis that having a major trauma in childhood might improve socialization skills in the long-term. In 2005, 2 articles were published about the use of the VABS in children after traumatic brain injury.[34,35] In both studies, the children scored lower than the norm on all scales of the VABS within 5 years after the accident. The better score in current cohort could probably be explained by the longer follow-up period that was used, but it seems more likely that traumatic brain injury has a less favorable prognosis than injuries of other body regions. Unfortunately, the current cohort was too small to analyze the outcome for different injury groups separately.

Table 3 A summary of the results per respondent (n = 28).

Pat nr	Age (yrs)	Gender	ISS	Main injuries	BF&S	Activities and participation						
					%WPI	GOS	GOSE	VABSco[a]	VABSds[a]	VABSso[a]	CBCLtot[b]	SDQtot[c]
1	8	Male	19	##skull; cerebral contusion	0	5	8	+ 10.4	+ 2.3	+ 1.9	53 !	11
2	8	Female	66	#skull; liver rupture; hematothorax; #os pubis; epidural hematoma	0	5	8	- 0.7	- 0.2	+ 1.6	11	9
3	9	Female	25	#skull; spleen rupture; pneumothorax; subdural hematoma	0	5	8	+ 0.2	- 1.6	- 0.1	9	0
4	9	Female	38	##skull; cerebral contusion	14	5	7	- 0.7	- 1.4	+ 1.4	51 !	28 !
5	10	Male	17	Subdural/intracerebral/myelum C5 hematoma	0	5	8	- 0.5	- 1.42	- 0.5	15	5
6	10	Female	16	#humerus; #orbita; cerebral contusion	45	4	6	+ 2.2	- 1.0	+ 3.9	24	11
7	11	Male	18	Cerebral contusion	0	5	8	- 0.4	- 1.1	+ 5.5	15	8
8	12	Male	17	#cruris Gustillo III	0	5	7	+ 0.1	+ 2.1	+ 1.8	9	8
9	12	Male	29	Liver rupture	0	5	8	- 2.3	- 3.8	+ 3.5	7	5
10	12	Female	43	Bowel perforation; retroperitoneal hematoma; cerebral commotion	2	5	8	+ 1.3	+ 4.3	+ 5.1	17	3
11	13	Female	16	#cruris Gustillo I	0	5	8	- 0.3	+ 3.8	+ 5.5	5	7
12	13	Female	20	Intracerebral hematoma; cerebral commotion	0	5	8	- 2.3	- 1.3	+ 1.9	48 !	12
13	14	Male	17	Subdural hematoma	0	5	7	- 4.6	- 0.6	+ 3.2	17	13
14	14	Male	43	Cerebral contusion; liver contusion; kidney hematoma	5	5	7	- 5.0	+ 4.0	- 2.3		
15	15	Male	17	##skull; spleen rupture; cerebral contusion; n.abducens paresis	9	5	7	- 1.7	+ 3.3	+ 3.1	10	15 !
16	16	Female	20	Symphysiolysis; #acetabulum; #tibia; #sacrum	0	5	7	+ 2.9	+ 2.9	+ 2.9	51 !	13
17	17	Male	34	Subdural hematoma	0	5	8	- 2.3	+ 1.9	+ 1.9	5	8
18	17	Male	36	Spleen rupture; #olecranon; kidney hematoma; pneumothorax	0	5	8	- 3.8	- 2.0	+1.3	7	17 !
19	18	Male	18	#acetabulum; #antebrachi greenstick; kidney and lung contusion	0	5	8	+ 0.2	+ 0.2	- 0.1	6	4
20	19	Male	24	#skull; #tibia; pneumothorax; pneumopericard; #clavicula; #MC1	59	5	6				7	8
21	19	Female	16	##skull; epidural hematoma; 3rd degree burns, n.facialis paresis	29	5	7				62 !	22 !
22	20	Male	17	#mandibula; pneumothorax; cerebral contusion	10	5	6				9	10
23	20	Male	26	##femur; cerebral commotion	0	5	8					
24	21	Male	17	Lesion C4	17	5	6				2	9
25	21	Female	25	##skull; cerebral contusion; n.opticus lesion	24	5	7				6	11
26	21	Female	25	Intracerebral hematoma; hematothorax; #L4/5; spleen rupture	29	4	5					
27	22	Male	16	#skull; epidural hematoma	0	5	8				0	1
28	23	Male	17	Lesion L2; liver rupture; #WeberB; cerebral contusion	78	4	6				41 !	20 !

ISS Injury Severity Score; BF&S body function and structure; %WPI Percentage Whole Person Impairment; GOS Glasgow Outcome Scale; GOSE Glasgow Outcome Scale Extended; VABS Vineland Adaptive Behavior Scales; CBCL Child Behavior Checklist; SDQ Strengths and Difficulties Questionnaire
[a] The amount of years ahead (+) or behind (-) their peers on communication (co), daily skills (ds), and socialization (so). [b] Total score > 30 on the CBCL means behavioral problems. [c] Total score >14 on the SDQ means mental problems. # Fracture; ## Multiple fractures; ! Problem score.

The outcome on the CBCL and the SDQ can be interpreted by comparing them to a healthy reference population. Crijnen et al. described the outcome on the CBCL in a general population sample of Dutch children.[29] The mean scores on the 8 separate domains of the CBCL in the children of current cohort were comparable with the mean scores of the general population sample. The only exception was the mean score on somatic complaints, which was twice as high in the major trauma group (1.9 vs 0.9). For the SDQ, normative data are available for U.S. noninstitutionalized children.[31] The mean scores of current major trauma cohort on the 5 separate domains of the SDQ were all in the range of the low difficulties group, which means the lowest 80% of the US reference population.

The AMA guides were not used in children before, so no comparison with the literature is possible.

Strengths and limitations

The health condition of children long-term after major trauma is examined with the ICF model in mind. Using the ICF model is one of the strengths of this pilot study. The measures were chosen to cover together the 3 domains of the ICF model. So, the health condition of the children after major trauma was studied in its broadest view. Earlier studies mainly focused on the domain of activities, whereas the other ICF domains stayed relatively unexplored.[4-10] Another strength of this study is the long follow-up period. Previous studies show that children are still making progress between 5 and 9 years after major trauma.[4,6-8] So to asses a stable physical and mental condition, the follow-up period should be more than 5 years. Another assessment is recommended at an even longer follow-up period to ensure that a stable condition is reached.

A limitation of the study was the number of respondents. The study was designed as a pilot, a small group of children studied extensively to try out measures and to collect results that could found the start of a large multi-centered study. Patients were included for 2 years time from one trauma center in the Netherlands. Forty children met the inclusion criteria, and the response rate was 70%. A lot of effort was put into tracing all addresses, but probably because of the long follow-up period, 7 children were untraceable. Three of the respondents had not completed the CBCL and the SDQ, and the VABS could only be analyzed in children younger than 19 years at follow-up. Because of the small population, the ability to generalize the results is questionable. The 30% lost to follow-up might be a confounding variable. To draw conclusions on the outcome of the complete population of children after major trauma, a larger study is recommended.

Another limitation is that the CBCL and the SDQ are not validated for children older than 18.[23,29-31] The CBCL and the SDQ were analyzed for all respondents, irrespective of their age. Nine respondents were older than 18. The amount of behavioral problems in these older respondents was comparable to the rest of the cohort. Indicating that the outcome on the CBCL and the SDQ was not seriously affected by including the respondents who were older than 18 years.

Experiences with the measures

A number of measures were used in this pilot study, as one of the reasons to perform this study in the first place was to try out measures at different ICF levels in the major pediatric trauma population. The ICF domain 'body function & structure' was measured with the AMA guides. No difficulties were experienced in assessing the children according to the guides. Good discrimination could be made between respondents with different levels of functional impairment. However, when the respondents were limited in their body function by pain, this was not accounted for in the impairment score. Also, the guides were not always univocal in how to calculate the impairment score. Furthermore, it has to be taken into account that the percentages of WPI are based on the adult population and might not be directly applicable to children. For example, a scar can mean a lot more impairment to children than to adults. A validation study of the AMA guides in children is therefore recommended before using them at a larger scale.

The ICF domains activities and participation were measured with the GOS / GOSE, the VABS, the CBCL, and the SDQ. The GOS and the GOSE measure the same construct, but both have different advantages. With the GOSE, better distinction could be made between respondents than with the GOS, and the GOSE has less ceiling effect. An advantage of the GOS is that it is better known by scientists and is therefore frequently used in earlier studies. From this study, we learned that for discriminative purposes, the GOSE is preferred above the GOS in measuring the outcome in children after major trauma. A combination of the GOSE and the GOS is recommended if the outcome will be compared with earlier literature.

The CBCL and the SDQ both measure behavior of the person, but it is important to recognize that the questionnaires have a lot of dissimilarities. The CBCL has many items and takes quite a long time to complete (often > 15 minutes). Almost half of the items are about rare pathological behavior characteristics that are seldom affirmed. The CBCL is very sensitive in signaling behavioral problems but may be too detailed to be used as a screening tool in a population with an average amount of behavioral problems. The SDQ appears to be more suitable for that purpose. Respondents of all ages (8-23 years old) found it easy to complete, and it took usually less than 5 minutes.

Despite its relatively small amount of questions, the SDQ has a reported satisfactory reliability.[31-33]

The VABS compares the behavior of the respondents with age-appropriate behavior. Unfortunately, norm values are only available for children up to 18 years old, so only 19 respondents underwent the analysis. The questionnaire contains some out-of-date terminology such as guilders instead of euros and using a telephone kiosk instead of a mobile phone. However, no difficulties were experienced using the VABS in the major pediatric trauma population.

One of the greatest challenges of measuring long-term outcome in children after major trauma is that children are developing and will finally become adults. To compare short-term outcome with outcome on the long-term, ideally, the same measures are used at different time-points. A difficulty, however, is that outcome measures that are suitable for children are usually not suitable for adults and vice versa. Positive exceptions are the GOS and the GOSE, which are both validated in children and adults. The AMA guides have the potential of becoming a measure suitable for short and long-term outcome measurement, but first a validation study of the AMA guides in children should be performed.

Appendix A

Glasgow Outcome Scale and Glasgow Outcome Scale Extended

From 'Measurement in neurological rehabilitation' Derick T. Wade, Oxford.

Two versions: the 5-point and the 8-point version (GOS and GOSE)

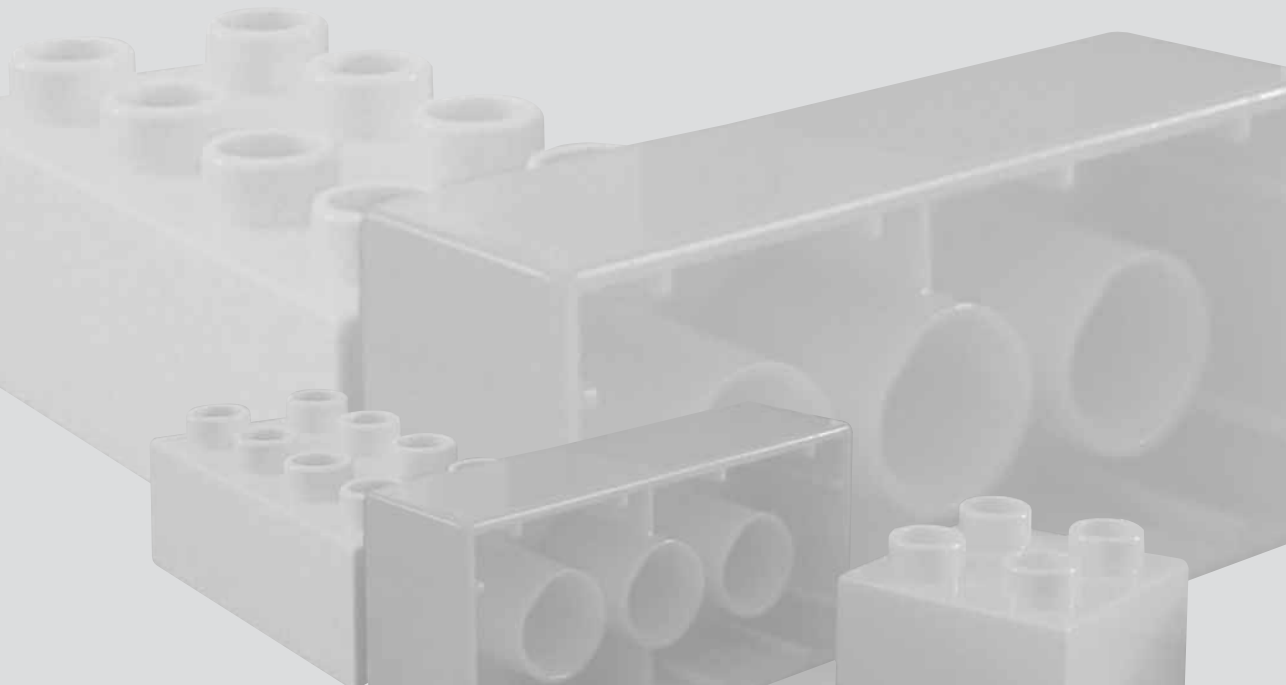
1	1	Death
2	2	Vegetative state Non-sentient, not obeying commands, no verbal response, no meaningful response, may have sleep-wake rhythm, may have spontaneous eye opening and ability to follow moving objects, may swallow food.
3		Severe disability; conscious but dependent.
	3	Communication is possible, minimally by emotional response, total or almost total dependency with regard to activities of daily life.
	4	Partial independence in activities of daily life, may require assistance for only one activity, such as dressing; many evident post-traumatic complaints and/or signs; resumption of former life and work possible.
4		Moderate disability; independent but disabled.
	5	Independent in activities of daily life, for instance can travel by public transport; not able to resume previous activities at work or socially; despite evident post-traumatic signs, resumption of activities at a lower level is often possible.
	6	Post-traumatic signs are present which, however, allow resumption of most former activities either full-time or part-time.
5		Good recovery.
	7	Capable of resuming normal occupational and social activities; there are minor physical or mental deficits or complaints.
	8	Full recovery without symptoms or signs.

References

1. Vademecum of Health Statistics of the Netherlands: 2003. Statistics Netherlands, Ministry of Health, Welfare and Sports, Voorburg/Heerlen, the Netherlands;2004.
2. O'Neale Roach J: Injuries kill over 20.000 children a year in developed countries. Biomedical Journal 2001;322:317.
3. Suominem P, Kivioja A, Ohman J, et al: Severe and fatal childhood trauma. Injury 1998;29(6):425-430.
4. Sluis van der CK, Kingma J, Eisma WH, et al: Pediatric polytrauma: short-term and long-term outcomes. J Trauma 1997;43(3):501-506.
5. Polinder S, Meerding WJ, Toet H, et al: Prevalence and prognostic factors of disability after childhood injury. Pediatrics 2005;116(6):810-817.
6. Schalamon J, Bismarck S, Schober PH, et al: Multiple trauma in pediatric patients. Pediatric Surgical Interventions 2003;19:417-423.
7. Evans SA, Airey MC, Chell SM, et al: Disability in young adults following major trauma: 5 year follow up of survivors. BMC Public Health 2003;3:8.
8. Letts M, Davidson D, Lapner P: Multiple trauma in children: predicting outcome and long-term results. Can J Surg 2002;45(2):126-131.
9. Hu X, Wesson DE, Logsetty S, et al: Functional limitations and recovery in children with severe trauma: a one-year follow-up. J Trauma 1994;37(2):209-213.
10. Wesson DE, Williams JI, Spence LJ, et al: Functional outcome in pediatric trauma. J Trauma 1989;29(5):589-592.
11. World Health Organization. International classification of functioning, disability and health: ICF. World Health Organization, Geneva, Switserland;2001.
12. Stylianos S, Ford HR: Outcomes in pediatric trauma care. Semin Pediatr Surg 2008;17:110-115.
13. Davey TM, Aitken LM, Kassulke D, et al: Long-term outcomes of seriously injured children: a study using the Child Health Questionnaire. J Paediatr Child Health 2005;41(5-6):278-283.
14. Sturms LM, Sluis van der CK, Stewart RE, et al: A prospective study on paediatric traffic injuries: health-related quality of life and post-traumatic stress. Clin Rehabil 2005;19(3):312-322.
15. Anderson VA, Catroppa C, Haritou F, et al: Identifying factors contributing to child and family outcome 30 months after traumatic brain injury in children. J Neurol Neurosurg Psychiatry 2005;76(3):401-408.
16. Catroppa C, Anderson VA, Morse SA, et al: Outcome and predictors of functional recovery 5 years following pediatric traumatic brain injury (TBI). J pediatr psychol 2008;[Epub ahead of print].
17. Johnson P, Thomas-Stonell N, Rumney P, et al: Long-term outcomes of pediatric acquired brain injury. Brain Cogn 2006;60(2):205-206.

18. Baker SP, O'Neill B, Haddon W, et al: The injury severity score: a method for describing patients with multiple injuries and evaluating emergency care. J Trauma 1974;14(3):187-196.
19. Holtslag HR, Beeck van EF, Lindeman E, et al: Determinants of long-term functional consequences after major trauma. J Trauma 2007;62(4):919-927.
20. American Medical Association. Guides to the evaluation of permanent impairment, fifth edition ed. Chicago:2001.
21. McCarthy ML, McAndrews MP, MacKenzie EJ, et al: Correlation between measures of impairment, according to the modified system of the American medical association, and function. J Bone Joint Surg 1998;80:1034-1042.
22. Spieler EA, Barth PS, Burton JF, et al: Recommendations to guide revision of the guides to the evaluation of permanent impairment. J Am Med Assoc 2000;283:519-523.
23. Hudak AM, Caecar RR, Frol AB, et al: Functional outcome scales in traumatic brain injury: a comparison of the Glasgow outcome scale (extended) and the functional status examination. J Neurotrauma 2005;22(11):1319-1326.
24. Wilson JTL, Edwards P, Fiddes H, et al: Reliability of postal questionnaires for the Glasgow outcome scale. J Neurotrauma 2002;19(9):999-1005.
25. Vles WJ, Steyerberg EW, Essink-Bot ML, et al: Prevalence and determinants of disabilities and return to work after major trauma. J Trauma 2005;58:126-135.
26. Sluis van der CK, Duis ten HJ, Geertzen JH: Multiple injuries: an overview of the outcome. J Trauma 1995;38:681-686.
27. Sparrow SS, Balla D, Cicchetti DV: Vineland Adaptive Behavior Scales (Survey ed.). Circle Pines, MN: American Guidance Service; 1984.
28. Bildt van A, Kraijer D, Sytema S, et al: The psychometric properties of the Vineland adaptive behavior scales in children and adolescents with mental retardation. J Autism Dev Disord 2005;35:53-62.
29. Crijnen AAM, Achenbach TM, Verhulst FC: Problems reported by parents of children in multiple cultures: the child behavior checklist syndrome constructs. Am J Psychiatry 1999;156:569-574.
30. Achenbach TM: Manual for the child behavior checklist / 4-18 and 1991 profile. Burlington, University of Vermont, department of psychiatry, 1991.
31. Bourdon KH, Goodman R, Rae DS, et al: The strengths and difficulties questionnaire: U.S. normative data and psychometric properties. J Am Acad Child Adolesc Psychiatry 2005;44(6):557-564.
32. Muris P, Meester C, Eijkelenboom A, et al: The self-report version of the strengths and difficulties questionnaire: its psychometric properties in 8- to 13-year-old non-clinical children. Br J Clin Psychol 2004;43:437-448.
33. Muris P, Meester C, Berg van der F: The strengths and difficulties questionnaire (SDQ), further evidence for its reliability and validity in a community sample of Dutch children and adolescents. Eur Child Adolesc Psychiatry 2003;12:1-8.

34. Barlow KM, Thomson E, Johnson D, et al: Late neurologic and cognitive sequelae of inflicted traumatic brain injury in infancy. Pediatrics 2005;116(2):e174-e185.
35. Poggi G, Liscio M, Adduci A, et al: Psychological and adjustment problems due to acquired brain lesions in childhood: a comparison between post-traumatic patients and brain tumor survivors. Brain Inj 2005; 19(10):777-785.



6

LONG-TERM HEALTH-RELATED QUALITY OF LIFE IN MAJOR PEDIATRIC TRAUMA: A PILOT STUDY

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Abstract

Background Major trauma is the leading cause of mortality and morbidity in children of developed countries. Little research has been done about the health-related quality of life (HRQL) in these children. The aim of the current research is to describe the HRQL of children in the long term after major trauma and to compare it with healthy peers.

Methods A prospective cohort study of severely injured children (ISS ≥ 16, age < 16 years) who survived the trauma and were admitted to the emergency department of a Dutch level 1 trauma center in 1999 and 2000 (n = 40) was conducted. Between 6 and 8 years after trauma (mean 7.3, SD 0.7 years), outcome was assessed by the Pediatric Quality of Life inventory (PedsQL 4.0), the EuroQol 5D (EQ-5D) and the EuroQol Visual Analogue Scale (EQ-VAS).

Results The mean age at the time of the accident was 8.9 years (SD 4.6 years), the mean ISS was 24.9 (SD 11.1), and 25 (63%) cases were male. Out of 40 patients 28 were followed up. The mean score on the PedsQL was 81.2 and this did not differ significantly from the norm value. On the EQ-5D, more health problems were reported than in a healthy reference population. The mean EQ-VAS score was 79.4 and was significantly lower than in healthy peers. The lowest scores on the PedsQL and the EQ-VAS were seen in teenagers and in respondents with spinal cord and/or severe cerebral injury.

Conclusions The results on HRQL in children in the long term after major trauma are inconclusive. Special attention should be given to teenagers with spinal cord or severe cerebral injury who reported the lowest HRQL.

Introduction

Major trauma is defined as life-threatening injury of two or more body regions or organ systems, with an Injury Severity Score (ISS) of 16 or more.[1] The survival rate of major trauma in children is about 80%.[2,3] In developed countries, injuries are the leading cause of death in children aged 1-18 years.[4,5] Injuries can cause severe functional impairment and psychosocial problems in the short term, as well as in the long term.[6-11] Despite this prominent role of major trauma in the mortality and morbidity in children, relatively little research has been done in terms of the health-related quality of life (HRQL) of children after major trauma. In this research, the definition of HRQL is adopted as described by the World Health Organization (WHO): HRQL is the individuals' perception of their position in life in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns.[12]

There are many validated quality of life measures available for children. Recently, three review articles were written about quality of life measures for the use in pediatric trauma populations.[13-15] Two of these reviews came to a recommendation. Both concluded that the Pediatric Quality of Life Inventory (PedsQL) was one of the most suitable quality of life measures in children after major trauma, because it was quick to administer, had self and parent proxy report versions, covered a large age range (2-18 years), and had good psychometric properties.[13,15] In 2007, the European Consumer Safety Association (ECSA) developed guidelines for the conduction of follow-up studies measuring injury-related disability.[16] They chose the EuroQol-5D (EQ-5D) as the preferred measure of quality of life after injury in patients aged 5 years or older.

Van der Sluis et al. described the quality of life in children (age ≤ 15 years, n = 74) nine years after major trauma (ISS ≥ 16) with the RAND-36 survey.[3] The quality of life enjoyed by the patients did not differ from a healthy reference population. Winthrop et al. and Holbrook et al. measured lower quality of life in children within 2 years after trauma compared to healthy peers.[17,18] Winthrop et al. used the Child Health Questionnaire (CHQ) in pediatric trauma patients (ISS ≥ 9) at baseline and at 1 and 6 months post-trauma. Holbrook et al. used the Quality of Well-Being Scale in adolescents at 3, 6, 12, 18, and 24 months after trauma (mean ISS 10.8, SD 7.4). More research was done about the quality of life after minor injuries.[6,19-22] In these studies, a lower quality of life was also found in children within 2 years after trauma compared to healthy reference groups.

Only Van der Sluis et al. used a follow-up period of more than two years post-trauma.[3] However, they measured the quality of life in patients that were already in adulthood at the time of the measurement. Therefore, it is still not known how children after major trauma rate their quality of life. Especially in children, it is important to use a long follow-up period when studying the outcome, because they are still growing

and developing. Some children are just becoming aware of their problems when they start living on their own. Another shortcoming in current literature is that only Van der Sluis et al. studied major trauma according to the definition of Baker et al.[1,3]

Overall, it can be concluded that there is a need for large longitudinal studies that describe the long-term HRQL in children after major trauma. The aim for this pilot study is to measure HRQL in children in the long term after major trauma with the PedsQL and the EQ-5D and to compare it with the available norm values for the Dutch population.

Methods

Study population

During a two-year period (January 1999 till December 2000), data on all severely injured patients that were admitted to the Emergency Department of the University Medical Center Utrecht (UMCU) were collected. The UMCU is a level 1 trauma hospital with a population of 1.1 million people in a densely populated region with high traffic intensity. A consecutive cohort was defined that included all patients who were aged less than 16 years with an ISS of at least 16. The patients that survived the accident and their parents were asked by written invitation to participate in a follow-up examination 6-8 years after their trauma. If there was no response, the investigator (LJ) contacted them by telephone. After obtaining informed consent, the patients were sent the Pediatric Quality of Life inventory (PedsQL) and the EuroQol 5D (EQ-5D) with an extra question about cognition plus the Visual Analogue Scale for health state (EQ-VAS), which they were asked to complete and return. Parents were allowed to help when their children were less than 12 years of age. The Medical Ethics Committee of the UMCU approved the study protocol.

Outcome measurement

The PedsQL 4.0 generic core measures quality of life on four domains: physical functioning, emotional functioning, social functioning, and school functioning. The PedsQL has 23 questions and takes about 5-10 minutes to complete. The answers are rated in a five-point Likert scale: never a problem, almost never a problem, sometimes a problem, often a problem, and almost always a problem. Each answer represents a score of 100, 75, 50, 25, or 0, respectively, so that higher scores indicate better HRQL. The total score is the mean score of all item scores. The domain scores are the mean of the item scores for that domain. The self-report version is suitable for children in the age range of 8-18 years. The parent proxy report version is suitable for children in the age range of 2-18 years. The reliability and the content and construct validity of the PedsQL 4.0 was repeatedly confirmed.[23-29] The outcome on the PedsQL in a healthy Dutch child population was described by Bastiaansen et al. in 2004.[28]

The EQ-5D defines HRQL along five dimensions: mobility, self care, daily activities, pain or discomfort, and anxiety or depression. Recently, a sixth dimension is added to the questionnaire: cognition. Each dimension has three levels: no problem, moderate problem, and severe problem. The EuroQol also contains a Visual Analogue Scale (EQ-VAS) for health state. The questionnaire takes 2-5 minutes to complete. The EQ-5D has been designed and well validated in adults[30], but is also validated for child populations.[31-34] For the EQ-VAS scores, pediatric norm values were described by Stolk et al.[34] They reported the mean EQ-VAS score for 33 children (5-15 years old) of the general population as a reference group for their study about the quality of life in children with imperforate anus. Unfortunately, the norm values for the five dimensions of the EQ-5D were only described for adult populations. In 1993, Essink-Bot et al. validated the Dutch version of the EQ-5D in 857 randomly selected adult respondents.[35] Norm scores were described in seven age categories, ranging from 18-29 to 80+. The youngest category (aged 18-29 years) of this adult population was used as the norm value in the current study.

Data analysis

Data were analyzed using descriptive statistics. The Statistical Package for the Social Sciences (SPSS) version 15.0 was used. A p-value under 0.05 was considered to be statistically significant.

Results

Forty severely injured (ISS ≥ 16) children under 16 years of age were referred to the emergency department of the UMCU in the years 1999 and 2000. Of these patients, 12 were lost to follow-up: three lived abroad, four addresses were untraceable, and five patients refused to cooperate. The mean follow-up period was 7.3 (SD 0.7 years). At follow-up, the respondents were aged between 8 and 23 years. The patient and injury characteristics of the 28 respondents did not differ from the 12 children that were lost to follow-up. (table 1). Four of the respondents did not fill in both questionnaires completely. The PedsQL was analyzed for 25 respondents, the EQ-5D for 26 respondents, and the EQ-VAS for 27 respondents.

Health related quality of life

The outcomes on the PedsQL and the EQ-VAS both have a negatively skewed distribution (Skewness –1.50 and –1.10 respectively). (figure 1). On the PedsQL, 92% of the respondents reported a total score within 2 SD from the mean, whereas two of the respondents reported a much lower score of 35 and 51. On the EQ-VAS, the skewness is less obvious but still clearly present. All but one of the respondents scored within 2 SD from the mean, the one respondent that stood out had an EQ-VAS score

Table 1 Patient and injury characteristics of 40 children (ISS ≥ 16, age < 16 years) that were admitted to the emergency department of the University Medical Center Utrecht, The Netherlands, in 1999-2000.

Patient and injury characteristic	All children (n = 40)	Included (n = 28)	Lost to follow-up (n = 12)	p-value*
Mean age (years) at time accident	8.9 (SD 4.6)	8.2 years (SD 4.7)	10.2 years (SD 4.3)	0.19
Mean age (years) at follow-up	16.0 (SD 4.7)	15.1 years (SD 4.7)	18.0 years (SD 4.2)	0.08
Gender		17 (61%)	8 (67%)	0.73
Male	25 (63%)	11 (39%)	4 (33%)	
Female	15 (37%)			
Injury Severity Score (ISS)	24.9 (SD 11.1)	24.7 (SD 11.7)	25.3 (SD 10.0)	0.89
Cause of injury				0.80
Traffic	28 (70%)	19 (68%)	9 (75%)	
Home	6 (15%)	4 (14%)	2 (17%)	
Sports	2 (5%)	2 (7%)	0 (0%)	
Other	4 (10%)	3 (11%)	1 (8%)	
Body region				
Head	29 (35%)	21 (36%)	8 (34%)	
Thorax	15 (18%)	10 (17%)	5 (21%)	
Abdomen	13 (16%)	10 (17%)	3 (12%)	
Lower extremity	14 (17%)	9 (15%)	5 (21%)	
Upper extremity	8 (10%)	5 (8%)	3 (12%)	
Spinal cord	4 (5%)	4 (7%)	0 (0%)	
Mean intensive care unit stay (days)	6.9 (SD 11.8)	8.1 days (SD 12.7)	4.1 days (SD 9.3)	0.33
Mean hospital stay (days)	21.5 (SD 25.4)	21.3 days (SD 24.8)	21.8 days (SD 28.0)	0.96
Destination after discharge				0.99
Home	30 (75%)	21 (75%)	9 (75%)	
Rehabilitation center	7 (18%)	5 (18%)	2 (17%)	
Another hospital	37%)	2 (7%)	1 (8%)	

* Difference between included patients and those lost to follow-up

of 42. Because of the skewed distributions of the outcome on the PedsQL and the EQ-VAS, the median is believed to be a better representative of the group than the mean. The median is much higher than the mean for the PedsQL total score, for all PedsQL domains and for the EQ-VAS score. (table 2).

On the EQ-5D, 13 respondents report one or more health problems. Four respondents (15%) reported problems with mobility. Problems with self-care were not reported. Five respondents (19%) reported problems with usual activities. Pain or discomfort

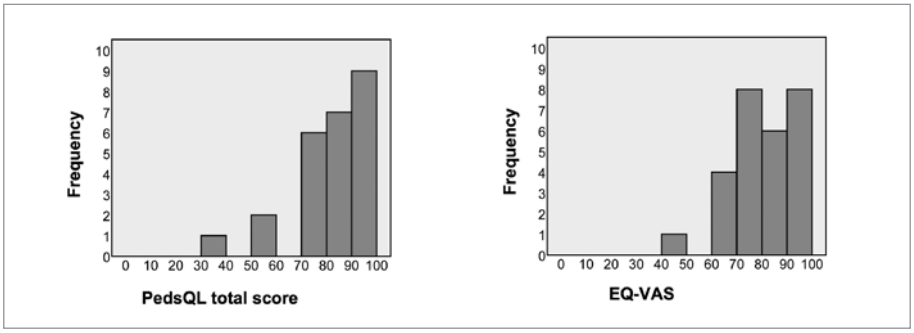


Figure 1 Negatively skewed distributions of the Pediatric Quality of Life inventory (PedsQL) total score (skewness –1.50) and the EuroQol Visual Analogue Scale (EQ-VAS) (skewness –1.10) in children in the long term after major trauma.

Table 2 The mean, median, and norm values of the Pediatric Quality of Life inventory (PedsQL) and the EuroQol Visual Analogue Scale (EQ-VAS) in children in the long term after major trauma, including the p-value of the Student's t-test between the current mean and norm value.

Measure	Mean (SD)	Median (range;25th;75th)	Norm value mean (SD)	p-value
PedsQL (n = 25)				
Total score	81.2 (15.3)	85.0 (35-97;74.0;92.0)	84.2 (10.4)[28]	> 0.10
Physical functioning	83.9 (19.8)	91.0 (9-100;75.0;97.0)	88.8 (9.7)	> 0.10
Emotional functioning	80.4 (17.5)	85.0 (45-100;62.5;95.0)	78.0 (17.3)	> 0.10
Social functioning	83.5 (19.2)	90.0 (35-100;75.0;97.5)	86.0 (13.4)	> 0.10
School functioning	76.0 (19.0)	85.0 (40-100;65.0;92.5)	81.4 (13.0)	0.05 < p < 0.10
EQ-VAS (n = 27)				
VAS health status	79.4 (12.1)	80 (42-95;74.0;91.0)	90.7 (11.3)[34]	< 0.01

was reported by nine respondents (35%), anxiety or depression by seven respondents (27%), and problems with cognition were reported by six respondents (23%).

The outcome compared to norm values

To conclude whether the quality of life of children in the long term after major trauma is lower than in healthy peers, current cohort is compared to the Dutch general child population group described by Bastiaansen et al.[28] The PedsQL scores of children in the long term after major trauma were not significantly different from the general population. The outcome on the EQ-5D is compared to the youngest age-category (18-29 years old) of the Dutch general population group described by Essink-Bot et al. in 1993.[35] On all dimensions except self-care, more problems were reported by the children in the long term after major trauma than by the healthy adults aged 18-29 years. The EQ-VAS score of children in the long term after major trauma was significantly lower than the EQ-VAS measured in the healthy child reference group of Stolk et al.[34]

Respondents with the lowest outcome scores

As mentioned before, there were three respondents in the current cohort with an outcome score on the PedsQL or the EQ-VAS of more than 2 SD below the mean of all respondents. On the PedsQL there were two respondents that stood out negatively, whereas on the EQ-VAS, there was one. Without these respondents, the mean scores on the PedsQL would have been 84.5 instead of 81.2, and the mean EQ-VAS would have been 81.8 instead of 79.4. All three respondents with the lowest outcome scores were teenagers at the time of the accident. In the other respondents, the amount of teenagers was about 30%. Severe cerebral injuries and spinal cord lesions were over-represented in the respondents with the lowest outcome scores. All three respondents with the lowest outcome had a cerebral contusion, compared to about 50% in the other respondents. A cerebral bleeding was reported for two out of three respondents of the lowest outcome group, compared to about 30% in all other respondents. Spinal cord lesions were reported for two out of three respondents of the lowest outcome score group, compared to 8% in all other respondents.

Discussion

The HRQL of children 6-8 years after major trauma did not significantly differ from healthy peers when measured with the PedsQL. The EQ-VAS scores were significantly lower compared to a healthy reference population. The distributions of the outcome scores of the PedsQL and the EQ-VAS were negatively skewed, which means that there were a few respondents with a much lower outcome score than the rest of the cohort. In these respondents severe cerebral injuries, spinal cord injuries, and respondents of older age were over-represented.

The outcome compared to the available literature

The injury characteristics of the cohort were comparable to other children after major trauma in the available literature. About 70% of the major traumas with ISS ≥ 16 were caused by traffic accidents. Other causes of major trauma were sporting activities, falls from height, and accidents in or around the house.[2,3,7-9,11] The body part that was injured most frequently was the head, followed by the extremities, the thorax, and the abdomen.[2,3,7-11] Males were over-represented in major trauma child populations, with 56-82% of the children with major trauma being male.[2,8,9] The mean intensive care unit stay varied from 4 to 9 days and the mean hospital stay from 13 to 26 days.[2,7-9]

The markedly skewed distribution of HRQL as measured in current research has not been described before. Earlier studies about children's HRQL after major trauma did not mention anything about the distribution of the outcome.[3,17,18] Van der Sluis et al. did report a skewed distribution on the somatic sections of the Functional Independence Measure in children after major trauma. The maximum score on self-care, sphincter control, mobility, and locomotion was reported by 86% of the respondents, and, just like in current study, cerebral and spinal cord injuries were over-represented in the group with lower scores.[3]

Strengths and limitations

A strength of this study is the long-term follow-up. Previous studies show that children are still making progress between 5 and 9 years after major trauma.[3,7-9] So, to asses a stable physical and mental condition, the follow-up period should be at least 5 years. To be sure that a stable condition is reached, another assessment is recommended at an even longer follow-up period.

Another strength is the use of the reliable and well-validated PedsQL. The self-report version of the PedsQL was chosen mainly based on the first three words of the WHO definition of HRQL: "the individuals' perception…". Even though parents usually proclaim to know their child well, large differences are found between self-report and parent proxy report HRQL on the PedsQL, with low intra-class correlation coefficients ranging from 0.02 to 0.23.[26] Besides, it is documented that the parents' HRQL influences how they rate their child's HRQL.[26] According to Varni et al., parent proxy reporting should only be the primary outcome measure when the child is too young or ill or otherwise unable to self-report.[24,25] The minimum age at which children are believed to reliably report their own HRQL is observed to be as low as 5 years.[24-26]

A limitation of this study is the number of respondents. The study was designed as a pilot: a small group of children studied extensively to try out measures and to collect results that could fuel the start of a large multi-centered study. To obtain as many questionnaires as possible, respondents were telephoned repeatedly and one of the

respondents was visited at home. A lot of effort was put into tracing all addresses, but probably because of the long follow-up period, seven children were untraceable. The groups were too small to statistically analyze the differences between respondents that stood out negatively and other respondents. Therefore, it is recommended to design a large longitudinal study in children after major trauma. This can only be possible in a network of multiple trauma centers with a good research infrastructure and follow-up protocol.

Another limitation is the age range for which the measures are suitable. The PedsQL is validated for children aged up to 18 years, but in the current cohort, about 30% of the patients were older than 18 years at follow-up. The validity of the proxy report version of the EQ-5D in children is confirmed for children aged up to 18 years, but the only validation study for the self-report version of the EQ-5D denies its validity in adolescents aged 10-18 years old.[31,33,35] Essink-Bot et al. found much lower EQ-5D norm values for the young adults aged 18-29 years than the norm values that were found by Stolk et al. for children aged 5-15 years old.[34,35] Also for the EQ-VAS, lower norm values are described for older respondents. So, if the respondents that were over 18 years of age at follow-up were excluded, the mean score on the EQ-5D and the EQ-VAS would probably have been higher.

PedsQL or EQ-5D?

No problems were reported in completing both questionnaires and evaluating the VAS score. Respondents who had already finished school did complete the PedsQL school functioning domain. They chose the best answer to fit their current situation. The advantage of the EQ-5D compared to the PedsQL is that it can be used in adults as well as children, so a better comparison can be made over a long follow-up period. However, it is recommended to further validate the self-report version of the EQ-5D in children and to produce norm values for children before using the EQ-5D in a large multicenter study. So, based on current information on both HRQL questionnaires, the PedsQL is recommended.

Conclusions

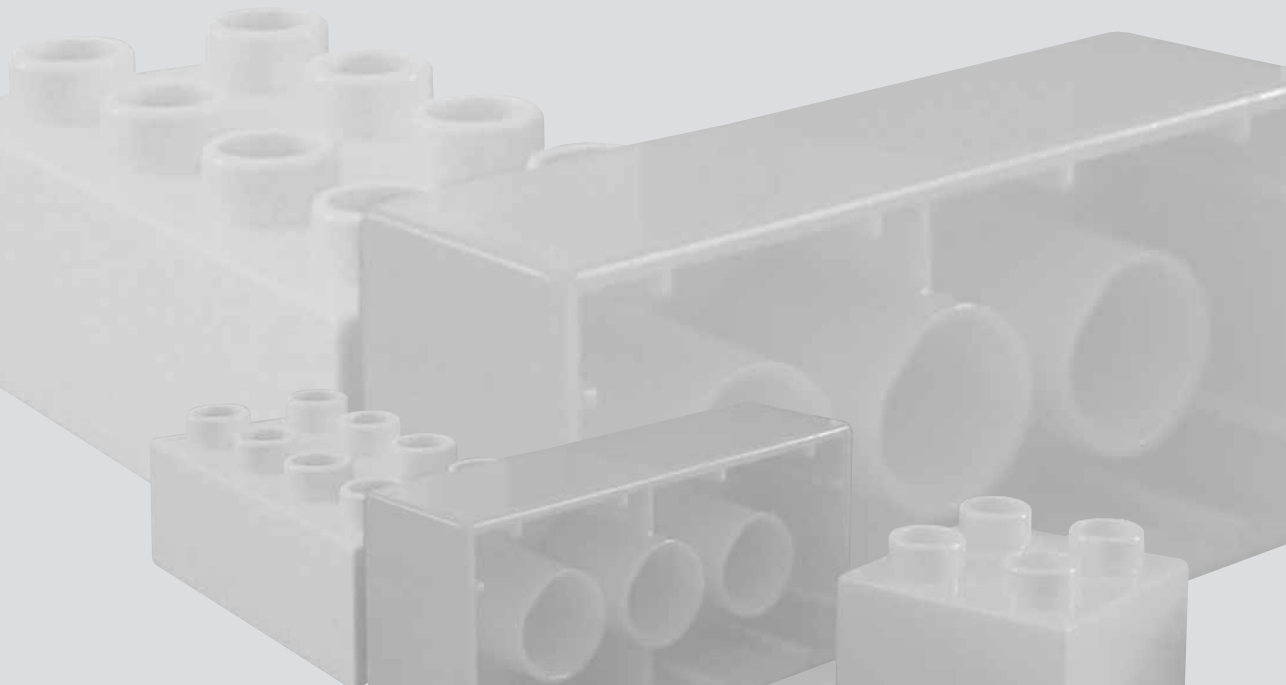
The EQ-VAS score of children 6-8 years after major trauma is significantly lower than in healthy peers. The HRQL measured by the PedsQL is not significantly different from healthy peers. A trend was recognized towards lower HRQL in teenagers with spinal cord or severe cerebral injury. To draw firm conclusions about the effect of age and injury on HRQL in children in the long term after major trauma, a large longitudinal study is required.

References

1. Baker SP, O'Neill B, Haddon W, Long WB. The injury severity score: a method for describing patients with multiple injuries and evaluating emergency care. The Journal of Trauma 1974;14(3):187-196.
2. Suominen P, Kivioja A, Ohman J, Korpela R, Rintala R, Olkkola KT. Severe and fatal childhood trauma. Injury 1998;29(6):425-430.
3. Van der Sluis CK, Kingma J, Eisma WH, Duis ten HJ. Pediatric polytrauma: short-term and long-term outcomes. The Journal of Trauma 1997;43(3):501-506.
4. Vademecum of Health Statistics of the Netherlands: 2003. Statistics Netherlands, Ministry of Health, Welfare and Sports, Voorburg/Heerlen, the Netherlands;2004.
5. Roach OJ. Injuries kill over 20.000 children a year in developed countries. Biomedical Journal 2001;322:317.
6. Polinder S, Meerding WJ, Toet H, Mulder S, Essink-Bot ML, Beeck van EF. Prevalence and prognostic factors of disability after childhood injury. Pediatrics 2005;116(6):810-817.
7. Schalamon J, Bismarck S, Schober PH, Hollwarth ME. Multiple trauma in pediatric patients. Pediatric surgical Interventions 2003;19:417-423.
8. Evans SA, Airey MC, Chell SM, Connelly JB, Rigby AS, Tennant A. Disability in young adults following major trauma: 5 year follow up of survivors. BMC public health 2003;3:8.
9. Letts M, Davidson D, Lapner P. Multiple trauma in children: predicting outcome and long-term results. Canadian Journal of Surgery 2002;45(2):126-131.
10. Hu X, Wesson DE, Logsetty S, Spence LJ. Functional limitations and recovery in children with severe trauma: a one-year follow-up. The Journal of Trauma 1994;37(2):209-213.
11. Wesson DE, Williams JI, Spence LJ, Filler RM, Armstrong PF, Pearl RH. Functional outcome in pediatric trauma. The Journal of Trauma 1989;29(5):589-592.
12. World Health Organization. International classification of functioning, disability and health: ICF. World Health Organization, Geneva, Switserland;2001.
13. Janssens L, Gorter JW, Ketelaar M, Kramer WL, Holtslag HR. Health related quality of life measures for long-term follow-up in children after major trauma. Quality of Life Research 2008;17(5):701-713.
14. McCarthy ML. Measuring children's health-related quality of life after trauma. The Journal of Trauma 2007;63:S122-S129.
15. Willis CD, Gabbe BJ, Butt W, Cameron PA. Assessing outcomes in paediatric trauma populations. Injury 2006;37:1185-1196.
16. Beeck van EF, Larsen CF, Lyons RA, Meerding WJ, Mulder S, Essink-Bot ML. Guidelines for the conduction of follow-up studies measuring injury-related disability. The Journal of Trauma 2007;62:534-550.
17. Holbrook TL, Hoyt DB, Coimbra R, Potenza B, Sise MJ, Sack DI, Anderson JP. Trauma in adolescents causes long-term marked deficits in quality of life: adolescent children do not recover preinjury quality of life or function up to two years postinjury compared to national norms. The Journal of Trauma 2007;62:577-583.

18. Winthrop AL, Brasel KJ, Stahovic L, Paulson J, Schneeberger B, Kuhn EM. Quality of life and functional outcome after pediatric trauma. The Journal of Trauma 2005;58:468-474.
19. Davey TM, Aitken LM, Kassulke D, Bellamy N, Ambrose J, Gee T, Clark M. Long-term outcomes of seriously injured children: a study using the Child Health Questionnaire. Journal of Paediatrics and Child Health 2005;41(5-6):278-283.
20. Sturms LM, Sluis van der CK, Stewart RE, Groothoff JW, Duis ten HJ, Eisma WH. A prospective study on pediatric traffic injuries: health-related quality of life and post-traumatic stress. Clinical Rehabilitation 2005;19:312-322.
21. Sturms LM, Sluis van der CK, Groothoff JW, Duis ten HJ, Eisma WH. Young traffic victims' long-term health-related quality of life: child self-reports and parental reports. Archives of Physical Medicine and Rehabilitation 2003;84:431-436.
22. Sturms LM, Sluis van der CK, Groothoff JW, Eisma WH, Duis ten HJ. The health-related quality of life of pediatric traffic victims. The Journal of Trauma 2002;52:88-94.
23. McCarthy ML, MacKenzie EJ, Durbin DR, Aitken ME, Jaffe KM, Paidas CN, Slomine BS, Dorsch AM, Berk RA, Christensen JR, Ding R, CHAT Study Group. The pediatric quality of life inventory: an evaluation of its reliability and validity for children with traumatic brain injury. Archives of Physical and Rehabilitation Medicine 2005;86:1901-1908.
24. Varni JW, Limbers CA, Burwinkle TM. How young can children reliably and validly self-report their health-related quality of life?: an analysis of 8,591 children across age subgroups with the PedsQL 4.0 generic core scales. Health and Quality of Life Outcomes 2007;5:1.
25. Varni JW, Limbers CA, Burwinkle TM. Parent proxy-report of their children's health-related quality of life: an analysis of 13,878 parents' reliability and validity across age subgroups using the PedsQL 4.0 generic core scales. Health and Quality of Life Outcomes 2007;5:2.
26. Cremeens J, Eiser C, Blades M. Factors influencing agreement between child self-report and parent proxy-reports on the pediatric quality of life inventory 4.0 (PedsQL) generic core scales. Health and Quality of Life Outcomes 2006;2:58.
27. Varni JW, Burwinkle TM, Seid M. The PedsQL 4.0 as a school population health measure: feasibility, reliability, and validity. Quality of Life Research 2006;15:203-215.
28. Bastiaansen D, Koot HM, Bongers IL, Varni JW, Verhulst FC. Measuring quality of life in children referred for psychiatric problems: psychometric properties of the PedsQL 4.0 generic core scales. Quality of Life Research 2004;13:489-495.
29. Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the pediatric quality of life inventory version 4.0 generic core scales in healthy and patient populations. Medical Care 2001;39(8):800-812.
30. Brooks R. EuroQol: the current state of play. Health Policy 1996;37:53-72.
31. Sach TH, Barton GR. Interpreting parental proxy reports of (health-related) quality of life for children with unilateral cochlear implants. International Journal of Pediatric Otorhinolaryngology 2007;71:435-445.

32. Matza LS, Secnik K, Mannix S, Sallee FR. Parent-proxy EQ-5D ratings of children with attention-deficit hyperactivity disorder in the US and the UK. Pharmacoeconomics 2005;23(8):777-790.
33. Vitale MG, Levy DE, Johnson MG, Gelijns AC, Moskowitz AJ, Roye BP, Verdisco L, Roye DP. Assessment of quality of life in adolescent patients with orthopaedic problems: are adult measures appropriate? Journal of Pediatric Orthopedics 2001;21:622-628.
34. Stolk EA, Busschbach JJV, Vogels T. Performance of the EuroQol in children with imperforate anus. Quality of Life Research 2000;9:29-38.
35. Essink-Bot ML, Stouthard ME, Bonsel GJ. Generalizability of valuations on health states collected with the EuroQolc-questionnaire. Health Economics 1993;2(3):237-246.



7

GENERAL DISCUSSION

General discussion

As mentioned in the introductory chapter this thesis had two main aims. The first aim was to describe trends in pediatric trauma in the Netherlands, and to describe changes in mortality and referral behavior after regionalization of trauma care (chapter 2 and 3). The second aim was to describe the health condition and health-related quality of life long-term after major pediatric trauma, and to select the best suitable measures to do so (chapter 4, 5 and 6). The conclusions and suggestions for future research will be discussed separately for both aims.

Trends in pediatric trauma and changes after regionalization of trauma care

The conclusions drawn from the trend study (chapter 2) and the surveillance based before-after study (chapter 3) were supplementary. The incidence of fall, sport, and bicycle accidents in the pediatric population in Central Netherlands has increased since 2001. Prevention activities should be focused on children from 0 to 9 for fall injuries, boys from 10 to 18 for sport injuries, and children from 5 to 18 for bicycle injuries. Regionalization of trauma care in the Netherlands reduced the in-hospital mortality rate for adolescents. Further research is needed to understand the etiology of this process.

The burden of pediatric trauma in the Netherlands changed from mortality towards morbidity. So, more children suffered moderate to severe trauma, but less children died because of their injuries. Explanations for this trend could lie in prevention, pre-hospital and hospital care. Traffic was the major cause of traumatic death in children. Improvements on car safety, like airbags and safety belts for all passengers, non-blocking break systems, and a third stop lamp, could have lowered the injury severity. Perhaps, these prevention activities caused part of the mortality decrease. However, after correction for the severity of injury the decrease in the mortality rate persisted. So, the decrease was (also) caused by the improvement of pre-hospital and hospital care. With the results of this thesis no definite distinction could be made between the effects of the regionalization of trauma care, the implementation of pre-hospital or in-hospital triage systems, and the effect of increased awareness in trauma care. Most likely it is a combination of these factors that caused the change from mortality towards morbidity.

In the last 15 years the Dutch government took a lot of effort in preventing traffic accidents by campaigns, improvement of dangerous traffic situations, and enforcement of traffic legislation.[1] According to the results of the trend analyses, prevention activities should be extended towards fall and sport injuries. Males in their second decade of life and their trainers should be educated about strategies to prevent sport injuries.[2]

In toddlers a lot of fall injuries could be prevented, if the use of stair gates was better promoted in homes with toddlers.[3,4] Furthermore, the legislation on playground equipment should be complemented with a maximum height of 1.5m and the obligation to use a soft ground surface, to prevent severe injury.[5,6]

Distinction between age-categories and gender revealed a lot of differences in mortality, morbidity, referral behavior of major injury, and mechanism of injury. It is well known that boys are much more likely to sustain injury than girls, and that these differences increase in adolescence. In children under 10 the male-female ratio was 1.3:1, whereas in adolescents it was 2.9:1. It is probably the level of testosterone that initiates more risky behavior in adolescent males. The distinction between age categories was also seen in the effect of regionalization of trauma care. The mortality rate in children up to 12 years of age did not change, whereas in adolescents the mortality rate decreased substantially. A Canadian study has already shown that there were more preventable deaths among adolescent trauma patients than among patients of younger age.[7] However, the etiology of the process of regionalization in our region is unclear, because there was no significant change in the amount of adolescents with major trauma referred to a level-1 or level-2 trauma center.

Without changes in referral behavior, then what did cause the reduced mortality rate in adolescents? Regionalization is more than just a change in the referring behavior of the severely wounded. To get designated as a level one or level two trauma center, a hospital has to meet specific criteria established by the American College of Surgeons (ACS). Usually, it takes a lot of effort to adapt the current trauma care to meet the ACS criteria. Some hospitals have to attract extra specialists or have to extent the availability of operating rooms with a complete operating team to a 24/7 coverage. The willingness of a hospital to make all these adaptations and additional costs shows their concern for providing good trauma care. These adaptations to meet the ACS criteria could have caused the reduced mortality rate in adolescents.
However, the increased awareness for trauma care in trauma centers could have caused the effect too.

Should the Netherlands have a pediatric trauma center? Based on the situation in the USA and Australia, centralization of pediatric trauma care can be advocated. Mortality rates were reduced and the functional outcome was improved.[8-11] In trauma care region Central Netherlands a similar drop in the mortality rate was found in the adolescent trauma population after regionalization of trauma care. Predicting the effect of a pediatric trauma center in the Netherlands seems hardly possible, so many factors are involved. According to the results of trauma care region Central Netherlands there should be enough pediatric trauma patients to meet the admission volume performance requirements of a level 1 pediatric trauma center. Because of the higher

volume, the personnel of the pediatric trauma center will become more experienced in the acute care of pediatric trauma patients, which will probably increase the quality of care. However, long distances to the pediatric trauma center can cause unacceptable response times. In those far away regions, a child in need of acute trauma care might therefore be better off in a nearby adult trauma center, or other transportation means like helicopter transport are needed more frequently. For all-round trauma surgeons in other centers, it will become very difficult to get enough experience with pediatric trauma, which might affect their quality of care.[12] Furthermore, there will be a lot of political and financial pros and cons of the establishment of a pediatric trauma center in the Netherlands, but that is outside the scope of this thesis.

There are still some important etiological questions unanswered, that could give direction to future research. First of all, why is still more than 30% of the children with major trauma treated at a level 3 trauma center more than 5 years after the regionalization of trauma care? Secondly, why did the referral behavior of children with major trauma not change? Finally, what did cause the decrease of the mortality-rate in adolescents and how can we further reduce it? The first questions could easily be answered by an interview with the ambulance and emergency care personnel, and a research of their triage protocols. It is probably a bigger challenge to get the answer to that final question.

Health condition and health-related quality of life long-term after major pediatric trauma

The conclusion of the systematic review (chapter 4) was that the DISABKIDS, the KID-SCREEN-52, and the PedsQL4.0 are the most suitable measures for health-related quality of life (HRQL) in children long-term after major trauma. They are suitable for a large age-range, have good psychometric properties, and cover the content of the ICF substantially. The long-term health condition (chapter 5) and the HRQL (chapter 6) were measured in a pilot study of children with major trauma. It was concluded that the majority of the children had a health condition comparable to healthy peers, but about 40% was physically impaired or restricted in daily activities long-term after major trauma. The results on HRQL in children long-term after major trauma were inconclusive.

A trauma-specific measure for HRQL in children has not been developed yet, therefore generic measures were used in this thesis. Three generic HRQL measures were found suitable, however a more trauma-specific measure could be developed with even better validity. Injuries in the pediatric trauma population mostly affected the extremities or the head/neck. Most health problems in the long-term were caused by cerebral, spinal cord and extremity injuries. The most reported problems were: problems with learning, concentration and behavior, mobility problems and pain.

The ideal trauma-related HRQL measure for children should cover all chapters of the International Classification of Functioning, Disability and Health, but with a focus on function and related activities of the nervous system and the extremities. Furthermore, it should be ideal when the same measure could be used in children as well as in young adults. This should be taken into account with the formulation of the questions. It would be worthwhile to invest in the development and validation of a trauma-specific HRQL measure for children, but until that time the generic measures are sufficient.

One of the conclusions of the pilot study was that 7 years after major trauma still 40% of the children was physically impaired or restricted in their daily activities. The results of the major trauma population were compared with healthy peers. Some differences in the health condition were identified between cases and the norm population. But it should be taken into account that it is difficult to distinguish between developmental changes normal for a child and the effect of major trauma on his or her development. Parents will always blame the history of cerebral trauma for the learning disabilities of their child, but it is impossible to know how the child would have developed without that cerebral trauma. Furthermore, it could be possible that the child had a greater risk for major trauma in the first place, because it was born with a low intelligence. Other possible effect modifiers are for example social economic status or comorbidities. These effect modifiers could not be ruled out with the small pilot study presented in this thesis. Future research should focus on the long-term functional outcome after major pediatric trauma and the possible effect modifiers involved. This could be done with a large longitudinal study with at least 10 years follow-up.

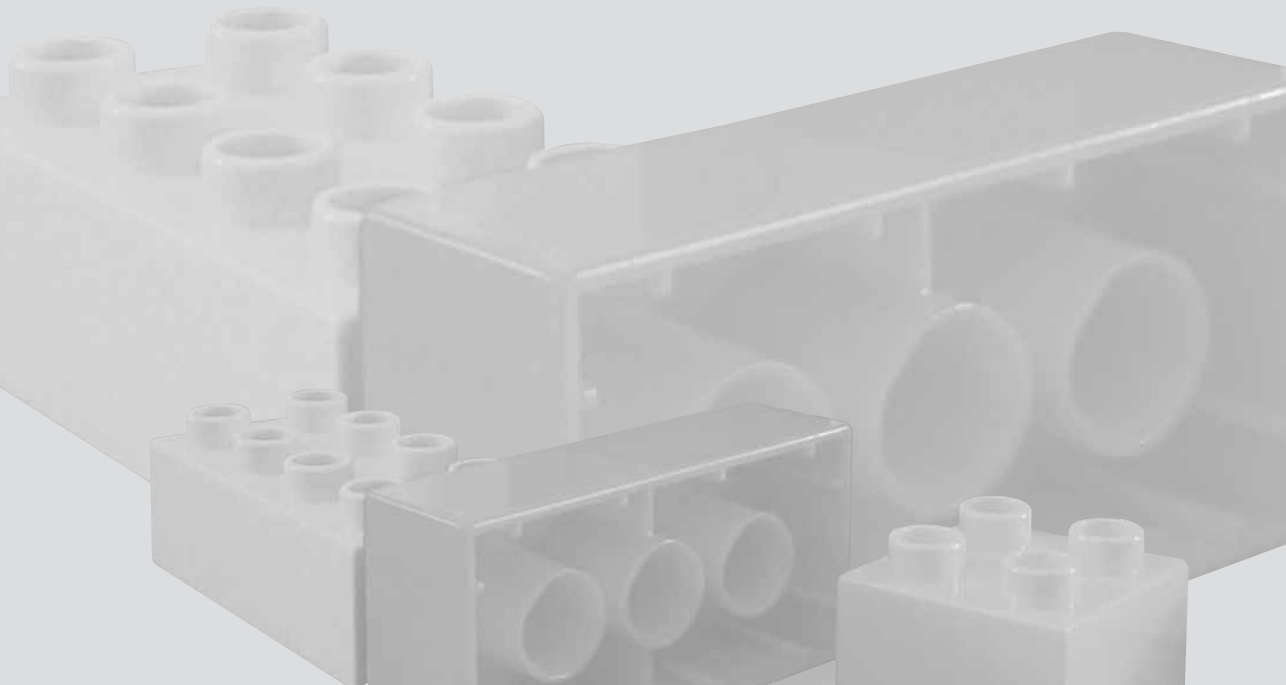
During the development from child to adulthood an increasing amount of functions are required from the human body. Therefore, it is not surprising that even long-term after major trauma still ‘new’ health problems arise. For example, a non-functional left foot is not a big impairment for a little baby, but it will become a problem when the child should learn to walk. A frequently heard problem was that children and their parents did not know where to go to with their ‘new’ health problems and questions long-term after the accident. Usually, the rehabilitation program stopped years ago and patients were hesitant to call their former specialists. The general practitioner was often not consulted, because it was assumed that he or she had not enough expertise on the issue, or just because they had not thought of the possibility. To my opinion the general practitioner or the rehabilitation specialist could both provide in this need. A more intense co-operation between the rehabilitation specialist and the general practitioner at the end of a rehabilitation process, could improve the long-term care after major pediatric trauma. An interview among children long-term after major trauma and their parents could improve the understanding of their needs of care.

General conclusions

The burden of pediatric trauma in the Netherlands changed from mortality towards morbidity. The mortality rate decreased, whereas the incidence of fall, sport and bicycle accidents increased since 2001. In the long-term four out of ten children that suffered major trauma experienced disabilities. Future research should focus on the etiology of regionalization, further improvements of pediatric trauma care, and long-term functional outcome in children with major trauma.

References

1. Lanting LC, Hoeymans N (eindred.). Let op letsels. Preventie van ongevallen, geweld en suïcide.
2. Abernethy L, Bleakley C. Strategies to prevent injury in adolescent sport: a systemic review. Br J Sports Med 2007;41:627-638.
3. Beirens TMJ, Brug J, van Beeck EF, Dekker R, Juttmann RE, Raat H. Presence and use of stair gates in homes with toddlers (11-18 months old). Accident Analysis and Prevention 2007;39:964-968.
4. Khambalia A, Joshi P, Brussoni M, Raina P, Morrongiello B, MacArthur C. Risk factors for unintentional injuries due to falls in children aged 0-6 years: a systemic review. Injury Prevention 2006;12:378-385.
5. Sherker S, Ozanne-Smith J, Rechnitzer G, Grzebieta R. Out on a limb: risk factors for arm fracture in playground equipment falls. Injury Prevention 2005;11:120-124.
6. Laforest S, Robitaille Y, Lesage D, Dorval D. Surface characteristics, equipment height, and the occurrence and severity of playground injuries. Injury Prevention 2001;7:35-40.
7. Diamond IR, Parkin PC, Wales PW, Bohn D, Kreller MA, Dykes EH, McLellan BA, Wesson DE. Preventable pediatric trauma deaths in Ontario: a comparative population-based study. J Trauma 2009;66:1189-1195.
8. Potoka DA, Schall LC, Ford HR. Improved functional outcome for severely injured children treated at pediatric trauma centers. J Trauma 2001;51:824-834.
9. Potoka DA, Schall LC, Gardner MJ, Stafford PW, Peitzman AB, Ford HR. Impact of pediatric trauma centers on mortality in a statewide system. J Trauma 2000;49:237-245.
10. American academy of pediatrics, pediatric orthopaedic society of North America. Management of pediatric trauma. Pediatrics 2008;121:849-854.
11. Doolin EJ, Browne AM, DiScala C. Pediatric trauma center criteria: an outcome analysis. J Pediatr Surg 1999;34:885-890.
12. Hamill J, Beasley SW. Training in paediatric trauma: the problem of safer societies. ANZ J Surg 2006;76:596-599.



SUMMARY

Summary

The first objective of this thesis is to describe trends in pediatric trauma in the Netherlands, and to describe changes in mortality rates and referral behavior after regionalization of trauma care. The second objective of this thesis is to describe the health condition and the health-related quality of life long-term after major pediatric trauma, with additionally the objective to select the most suitable measures to do so.

Chapter 1 provides a brief introduction to the topic of the thesis. It starts with an introduction to the changes in pediatric trauma care in the last decades, followed by an explanation of the concept functional outcome, and the use of classifications in trauma care research. At the end of the introductory chapter aims and outline of the thesis are provided.

In **chapter 2** trends in moderate to severe pediatric trauma in the Netherlands are described from 1996 to 2009. Based on these trends target groups for prevention activities were selected. Included were all children discharged from trauma care region Central Netherlands with moderate to severe trauma. Selection was made based on an Injury Severity Score of at least 4, trauma-related International Classification of Diseases (ICD-9) diagnostic codes, and External Causes of Injury and Poisoning codes (E-codes). The mean age and the mean injury severity decreased significantly between 1996 and 2009. The incidence rate of moderate to severe trauma increased since 2001 with 1.1% annually (95% CI 0.7-1.5). This trend was caused by an increase of fall, sport, and bicycle injuries. Prevention activities should be focused on children from 0 to 9 for fall accidents, boys from 10 to 18 for sport injuries, and children from 5 to 18 for bicycle injuries.

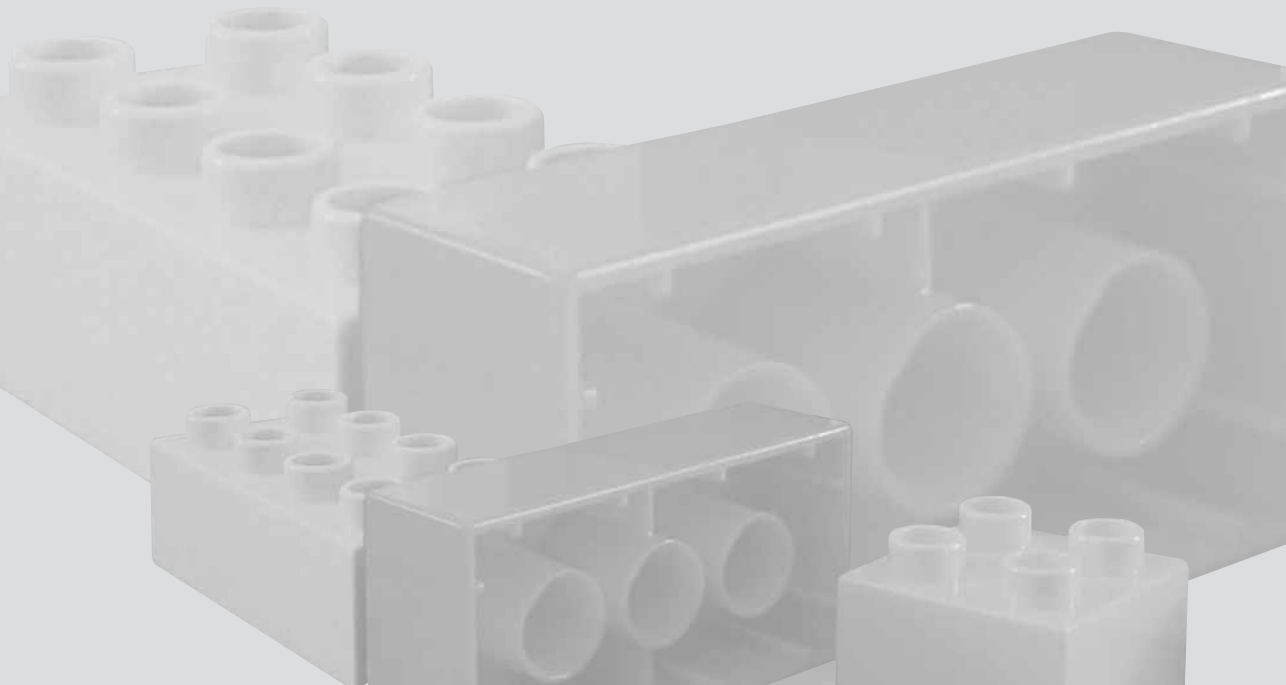
The effects of regionalization of trauma care in the region Central Netherlands are presented in **chapter 3**. The Dutch system of trauma care was regionalized in 1999 / 2000, which means that specialized trauma centers were designated for the care of the severely injured. Referral behavior of children with major trauma and the in-hospital mortality rates were compared before (1996-1998) and after (2001-2006) regionalization. Children that were discharged in the study period with a trauma-related ICD-9 diagnostic code and a trauma-related E-code were included. It was concluded that the mortality rates for adolescents were reduced after regionalization. No changes in referral behavior were found. Further research is needed to understand the etiology of this process.

In **chapter 4** a systematic review of health-related quality of life measures for long-term follow-up in children after major trauma is presented. The Medline and

EMBASE databases were searched for generic health-related quality of life measures for children. Seventy-nine papers met the inclusion criteria and fourteen measures were described. The objective was to determine the measures that are suitable for a large age range, that are reliable and valid, and that cover a substantial amount of the domains of functioning of the International Classification of Functioning, Disability and Health. It was concluded that the DISABKIDS, the KIDSCREEN-52, and the Pediatric Quality of Life Inventory (PedsQL) were suitable for the long-term follow-up measurement of health-related quality of life in children after major trauma.

The results of a pilot study among forty severely injured children are presented **chapter 5** and **chapter 6**. About seven years after the accident the health condition was measured by: the guides to the evaluation of permanent impairment of the American Medical Association, the Glasgow Outcome Scales, the Vineland Adaptive Behavior Scales, the Child Behavior Checklist, and the Strengths and Difficulties Questionnaire. Health-related quality of life was measured by: the PedsQL, the EuroQol 5D, and the EuroQol Visual Analogue Scale (EQ-VAS). It was concluded that 40% of the children long-term after major trauma were physically impaired or restricted in daily activities. Most children however, had a health condition comparable to healthy peers. The outcome on the health-related quality of life was inconclusive. The mean score on the PedsQL did not differ from the norm value, on the EQ-5D more health problems were reported than in a healthy reference population, and the mean EQ-VAS score was lower than in healthy peers. The lowest quality of life was measured in teenagers with spinal cord and/or severe cerebral injury.

In **chapter 7** the conclusions of the thesis as a whole are discussed and ideas for future research are provided.



NEDERLANDSE SAMENVATTING

Nederlandse samenvatting

Het eerste doel van dit proefschrift is om trends te beschrijven voor ongevallen bij kinderen in Nederland en om de veranderingen te beschrijven in mortaliteit en het verwijsgedrag van matig en ernstig gewonde kinderen na regionalisatie van de traumazorg. Het tweede doel is om de gezondheidsstatus en de gezondheid gerelateerde kwaliteit van leven te meten in kinderen lang nadat zij een ernstig ongeval hebben meegemaakt. Daarnaast had dit proefschrift tot doel om daarvoor de meest geschikte meetinstrumenten te selecteren.

Hoofdstuk 1 geeft een korte introductie op het onderwerp van dit proefschrift. Het begint met een inleiding over de veranderingen in de traumazorg van de laatste decennia, gevolgd door een uitleg van het concept functionele uitkomst en het gebruik van classificaties in het onderzoek op het gebied van traumazorg. Aan het eind van het inleidende hoofdstuk worden de doelen en een kort overzicht van het proefschrift gegeven.

In **hoofdstuk 2** worden trends beschreven van 1996 tot 2009 voor matig tot ernstig gewonde kinderen in Nederland. Gebaseerd op deze trends worden doelgroepen voor preventieactiviteiten geselecteerd. Alle kinderen met een matig tot ernstig letsel die werden ontslagen vanuit traumazorgregio Midden Nederland werden geïncludeerd. Er werd geselecteerd op basis van een Injury Severity Score (ISS) van minimaal 4, een trauma gerelateerde diagnosecode volgens de International Classification of Diseases (ICD-9) en op basis van de External Causes of Injury and Poisoning code (E-code). De gemiddelde leeftijd en de gemiddelde letselernst namen significant af tussen 1996 en 2009. De incidentie van matig tot ernstige letsels bij kinderen nam jaarlijks toe met 1,1% (95% CI 0,7-1,5) sinds 2001. Deze trend werd veroorzaakt door een toename van het aantal val-, sport- en fietsongevallen. Preventie-activiteiten zouden zich moeten richten op kinderen van 0 tot 9 voor val-ongevallen, jongens van 10 tot 18 voor sportongevallen en kinderen van 5 tot 18 voor fietsongevallen.

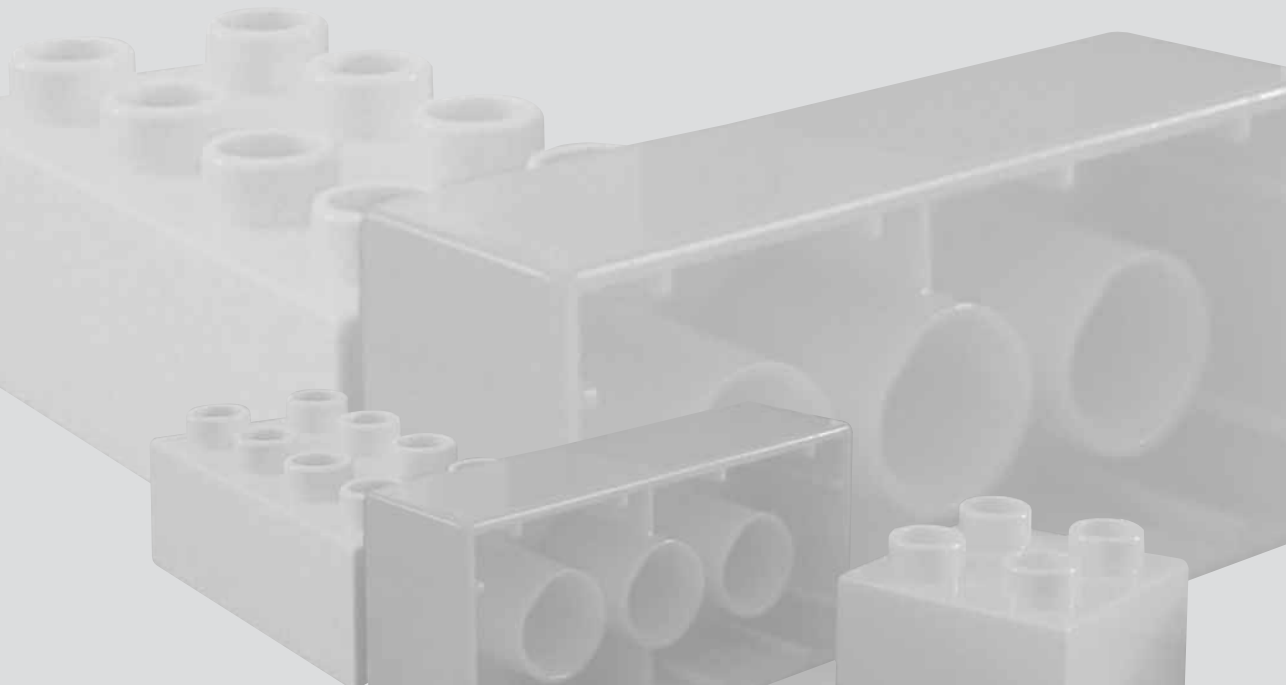
De effecten van regionalisatie van de traumazorg in de regio Midden Nederland worden gepresenteerd in **hoofdstuk 3**. De Nederlandse traumazorg werd geregionaliseerd in 1999 / 2000, wat betekend dat er gespecialiseerde traumacentra werden aangewezen voor de zorg van ernstige gewonden. Het verwijsgedrag van kinderen met een ernstig letsel en de ziekenhuismortaliteit werden vergeleken vóór (1996-1998) en na (2001-2006) de regionalisatie. Kinderen die werden ontslagen gedurende de studieperiode met een trauma gerelateerde ICD-9 diagnose code en een trauma gerelateerde E-code werden geïncludeerd. Er werd geconcludeerd dat de ziekenhuis mortaliteit voor adolescenten was afgenomen na de regionalisatie. Er werden geen

verschillen gevonden in het verwijsgedrag. Nader onderzoek is nodig om de etiologie van dit proces te begrijpen.

In **hoofdstuk 4** wordt een systematische review gepresenteerd van meetinstrumenten voor gezondheid gerelateerde kwaliteit van leven op de lange termijn voor kinderen na een ernstig ongeval. In de databases van Medline en EMBASE werd gezocht naar generieke meetinstrumenten voor gezondheid gerelateerde kwaliteit van leven. Negenenzeventig artikelen voldeden aan de inclusiecriteria en zij beschreven veertien meetinstrumenten. Het doel was om te bepalen welke meetinstrumenten geschikt waren voor een brede leeftijdscategorie, betrouwbaar en valide waren en een substantieel deel bestreken van de functioneringsdomeinen van de International Classification of Functioning, Disability and Health. Er werd geconcludeerd dat de DISABKIDS, de KIDSCREEN-52, en de Pediatric Quality of Life Inventory (PedsQL) geschikt waren voor het meten van gezondheid gerelateerde kwaliteit van leven op de lange termijn bij kinderen na een ernstig ongeval.

De resultaten van een pilot studie onder veertig kinderen na een ernstig ongeval worden gepresenteerd in **hoofdstuk 5** en **hoofdstuk 6**. Circa 7 jaar na het ongeval werd de gezondheidsstatus gemeten met: de Guides to the evaluation of permanent impairment van de American Medical Association, de Glasgow Outcome Scales, de Vineland Adaptive Behavior Scales, de Child Behavior Checklist en de Strengths and Difficulties Questionnaire. Gezondheid gerelateerde kwaliteit van leven werd gemeten met: de PedsQL, de EuroQol 5D (EQ-5D) en de EuroQol Visual Analogue Scale (EQ-VAS). Er werd geconcludeerd dat 40% van de kinderen met een ernstig ongeval op de lange termijn fysieke beperkingen heeft of wordt belemmerd in de dagelijkse activiteiten. Echter, de meeste kinderen hadden een gezondheidsstatus die vergelijkbaar was met gezonde leeftijdsgenoten. De uitkomst op het gebied van gezondheid gerelateerde kwaliteit van leven was niet eenduidig. De gemiddelde score op de PedsQL verschilde niet van de normpopulatie, er werden meer gezondheidsproblemen gerapporteerd op de EQ-5D dan in een gezonde referentiegroep en de EQ-VAS score was lager dan in gezonde leeftijdsgenoten. De laagste kwaliteit van leven werd gemeten in tieners met een letsel aan het ruggenmerg en/of die een ernstig hersenletsel hadden.

In **hoofdstuk 7** worden de conclusies van het gehele proefschrift bediscussieerd en worden er ideeën voor toekomstig onderzoek aangedragen.



DANKWOORD

Dankwoord

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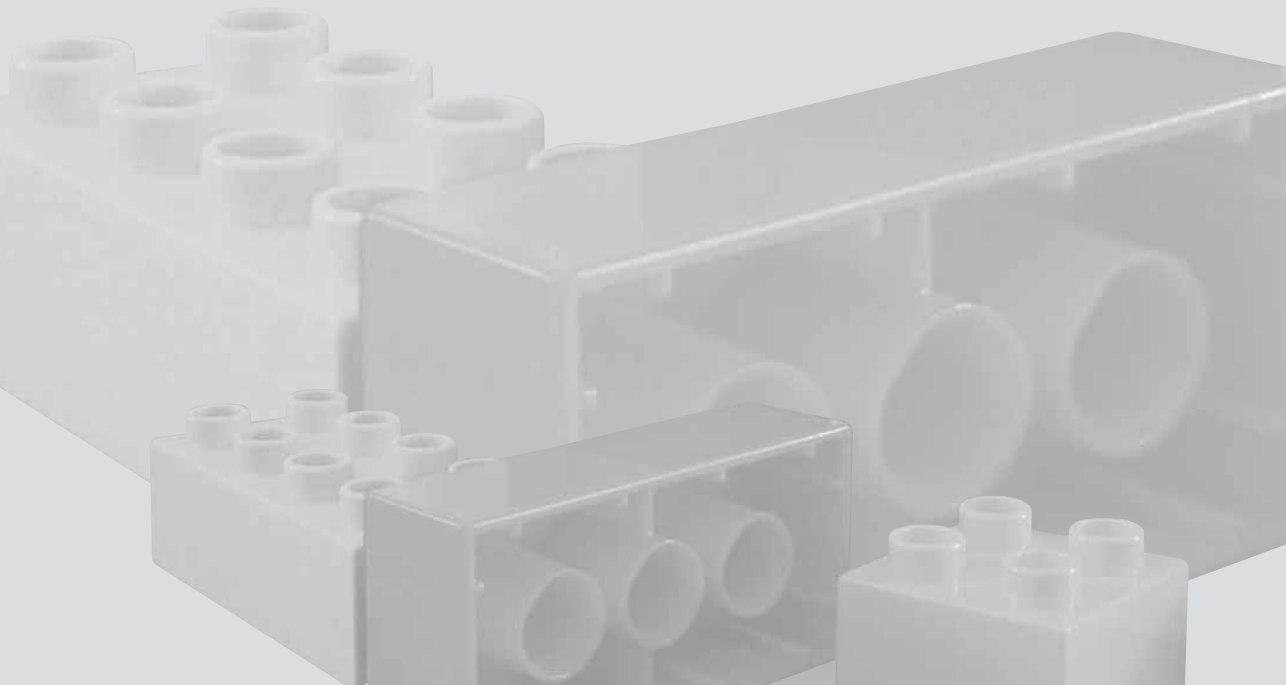
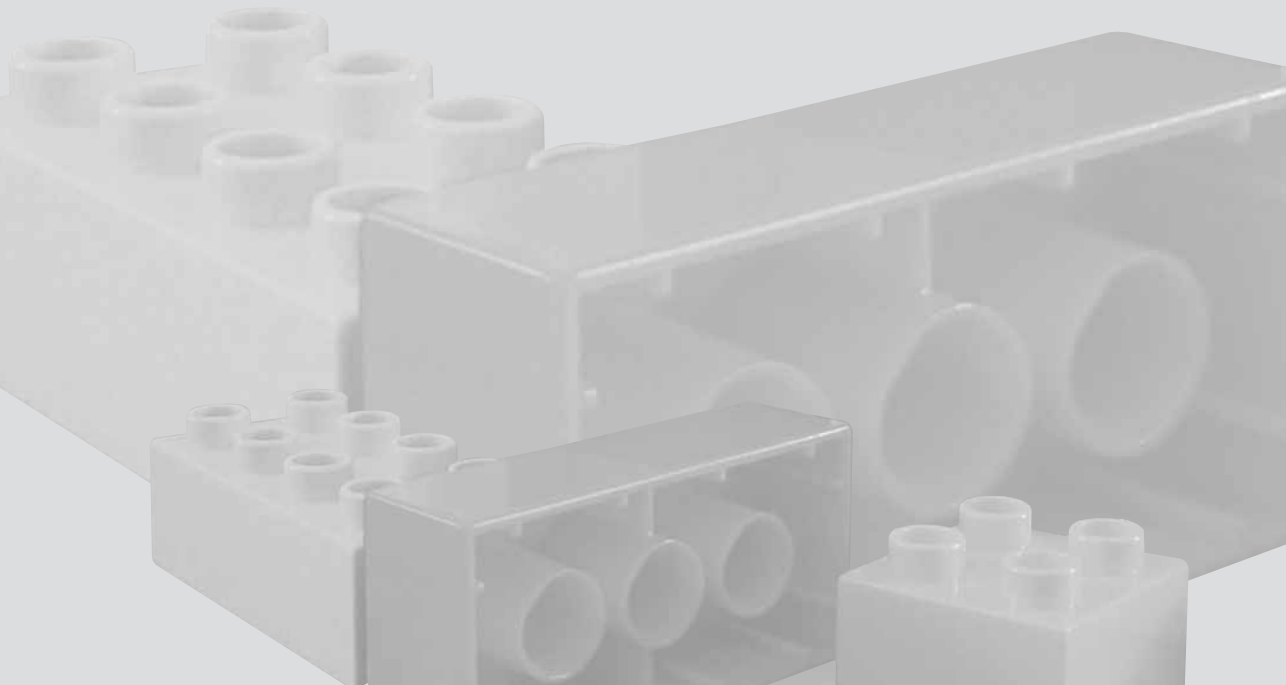


CURRICULUM VITAE

Erica Louise (Loes) Janssens werd geboren op 26 januari 1981 te Breda. In 1999 behaalde zij haar atheneumdiploma aan de Nassau Scholengemeenschap te Breda. Zij studeerde Voeding en Gezondheid aan de Wageningen Universiteit, met gezondheidsleer als specialisatie. In september 2003 werd dit met goed gevolg afgerond, wat haar de titel ingenieur opleverde. Vervolgens werd zij geselecteerd voor een verkorte opleiding geneeskunde te Utrecht, genaamd 'Selective Utrecht Medical Master' of kortweg SUMMA. Dit is een vierjarige opleiding tot basisarts en onderzoeker. Reeds in het eerste jaar van haar geneeskundeopleiding startte zij met het onderzoek wat uiteindelijk heeft geresulteerd in dit proefschrift. Na het behalen van de artsenbul in januari 2008 werkte zij eerst een jaar als poortarts op de spoedeisende hulp van het Mesos Medisch Centrum te Utrecht. Vervolgens heeft zij een half jaar gewerkt als arts-assistent chirurgie in het Sint Franciscus Gasthuis te Rotterdam en een half jaar als arts-assistent psychiatrie op de gesloten afdeling van het Regionaal Psychiatrisch Centrum te Woerden. In september 2010 startte zij met de opleiding tot huisarts, die zij begin 2013 hoopt te kunnen afronden.



LIST OF ABBREVIATIONS

List of abbreviations

ACS	American College of Surgeons
AIS	Abbreviated Injury Scale
AMA	American Medical Association
CBCL	Child Behavior Checklist
CHIP-AE / CE	Child Health and Illness Profile Adolescent and Child Edition
CHQ-CF / PF	Child Health Questionnaire Child and Parent Forms
CI	Confidence Interval
DUKE HP	Duke Health Profile
ECSA	European Consumer Safety Association
E-codes	External Causes of Injury and Poisoning codes
EQ-5D	EuroQol-5D
EQ-VAS	EuroQol Visual Analogue Scale
FS II(R)	Functional Status II (Revised)
GCQ	Generic Child Questionnaire
GOS	Glasgow Outcome Scales
GOSE	Glasgow Outcome Scales Extended
HAY	How Are You
HRQL	Health-Related Quality of Life

HUI2	Health Utilities Index Mark 2
ICC	Intraclass Correlation Coefficients
ICD-9	International Classification of Diseases diagnostic code
ICF	International Classification of Functioning, Disability, and Health
ISS	Injury Severity Score
PedsQL	Pediatric Quality of Life Inventory
SD	Standard Deviation
SDQ	Strengths and Difficulties Questionnaire
SMR	Standardized Mortality Ratio
SPSS	Statistical Package for the Social Sciences
TACQOL	TNO-AZL Children's Quality of Life
UMCU	University Medical Center Utrecht
VABS	Vineland Adaptive Behavior Scales
VSP-A	Vecú de Santé Perçué Adolescent
WHO	World Health Organization
WKZ	Wilhelmina Kinderziekenhuis
WPI	Whole Person Impairment
YQOL-R	Youth Quality of Life Instrument-Research Version