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ADULT AND PEDIATRIC TRAUMA

OUTCOMES AND HEALTH-RELATED QUALITY OF LIFE

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To Mark,
Jonathan, David, Mikael, Hanna
and my parents Ewa and Sven

"Have a heart that never hardens, and a temper that never tires, and a touch that never hurts."

Charles Dickens

ABSTRACT

Background: Trauma is the number one killer of children and young adults and the most common cause for hospital admissions for these age-groups in Sweden. Trauma is also one of the most common causes for hospital care and early death for older people. In the last decades trauma care has advanced and improved short-term survival of injured but knowledge of the long-term outcome is limited.

The overall aim of this thesis is to investigate long-term outcome and health-related quality of life after injuries in different age groups and to identify factors associated with outcome.

Methods: The thesis is based on four studies. In the first study patients with major trauma were contacted 5 years after injury and HRQL was measures using the SF-36 questionnaire and compared to an age and sex-matched reference group. In the second study data was collected on children with injuries to describe demographic and injury characteristics and outcome. The sample in the second study was the source for the third and fourth study. The third study measured HRQL using the PedsQL 4.0 in a cohort of children 6 years after injury and determined the relationship within subgroups in the cohort. The fourth study measured child HRQL in a sample of children after injury and their parent´s and determined the relationship within scoring results and the impact of parent´s reported mental health status.

Results: The adult major trauma patients (n=205) reported significantly lower HRQL scores in all eight domains compared to the reference group. A large number of patients suffered from physical (68%) and psychological disabilities (41%) and nearly half reported the need for better follow-up after discharge from hospital. The severity of the injury did not anticipate a lower health-related quality of life. In the pediatric group (n=432) the median injury severity score was 4 (IQR 1-9), 50% sustained head injuries and the most severe head injuries were seen in the youngest age group. Mortality rate was low (1%), 19% stayed in a PICU and the median length of hospital stay was two days. In the follow-up study (n=204) the youngest children had the lowest PedsQL scores. Children who suffered from extremity injuries had lower scores in the school functioning compared to children with head injuries. The levels of agreement between child self-report and parent proxy report of PedsQL 4.0 scales were excellent (ICC≥0.80) for all scales with the exception of children´s self-reported emotional functioning. Multiple regression analyses showed that poor parental mental health status contributed to worse child self-report and parent proxy report of children´s HRQL.

Conclusion: Adult major trauma patients have significant disabilities 5 years after injury. Improved follow-up by trauma specialist teams are needed. Children´s HRQL 6 years after trauma seems to in parity or better than healthy peers. Parent´s mental health status can possibly impact on children´s HRQL long after an injury. Further studies are recommended to evaluate the PedsQL 4.0versions for self-report in pediatric trauma population.

KEY WORDS**: TRAUMA, INJURY, HEALTH-RELATED QUALITY OF LIFE, FOLLOW-UP, PEDIATRIC, ADOLESCENTS, SF-36, PEDSQL 4,0**

LIST OF PUBLICATIONS

This thesis is based on the following papers which will be referred to by their Roman numerals:

I. Sluys K, Häggmark T, Iselius L. Outcome and quality of life 5 years after major trauma. *J Trauma.* 2005;59:223−232.

II. Sluys K, Lannge M, Iselius L, Eriksson LE. Outcomes in pediatric trauma care in the Stockholm region. *Eur J Trauma Emerg Surg.* 2010:36:308−317.

III. Sluys K, Lannge M, Iselius L, Eriksson LE. Health-related quality of life of children and adolescents 6 years after pediatric trauma. *Submitted*

IV. Sluys K, Lannge M, Iselius L, Eriksson LE. Health-related quality of life 6 years after pediatric trauma: Impact of parental mental health on child-parent reports. *Manuscript*

CONTENTS

LIST OF ABBREVIATIONS

AIS	Abbreviated Injury Scale
EU-27	European Union 27 member countries
EQ-5D	EuroQol Group – 5D (Health-related quality of life measure)
GCS	Glasgow Coma Score
HQOL	Health-Related Quality of Life
ISS	Injury Severity Score Scale
ICD-9	International classification of disease, 9^{th} revision
ICD-10	International classification of disease, 10^{th} revision
ICC	Intra-class Correlation Coefficient
ICU	Intensive care unit
MAIS	Maximum Abbreviated Injury Scale
MH	SF-36 mental health domain
NISS	New Injury Severity Scale
PedsQL	Pediatric Quality of Life Inventory 4.0 Generic Core Scale
PICU	Pediatric intensive care unit
PTSD	Post-traumatic stress disorder
QOL	Quality of Life
SF-36	Short-form Health Survey
UK	United Kingdom
US	United States of America
WHO	World Health Organization

1 INTRODUCTION

Trauma is the number one cause of death of children and young adults and the most common cause of acute care hospital admissions for these age groups in Sweden. Trauma is also one of the most common causes of acute hospital care and early death among older people. Besides the human loss and disabilities resulting from trauma, injuries place a substantial economic burden on society. The impact of injury has been investigated epidemiologically with focus on the significance of primary and secondary injury prevention. Research in tertiary prevention has studied the immediate consequences of the injury and factors related to survival rates. In the last decade long-term outcome studies have received more attention than before. These studies are necessary to reduce long-term mortality and morbidity and to improve outcome for injured patients. There is also a need for more information about the consequences of injury in order to give sufficient prognostic information to patients, their families, insurance companies, and government agencies. The studies in this thesis were designed to eliminate some of the deficiencies in our knowledge about the consequences of trauma.

2 BACKGROUND

2.1 TRAUMA IN A PUBLIC HEALTH PERSPECTIVE

Trauma is one of the leading public health problems and the most common avoidable cause of death among children and adults up to age 45 years. The World Health Organization (WHO) reports that more than five million people die from injuries annually, accounting for nine percent of global mortality. [1,2] For every death, several thousand injured people seek medical attention. Survivors incur temporary or permanent impairments and disabilities resulting in human suffering, major social consequences and economic costs for the individual, families and society. Although the main causes and effects of trauma differ depending on population, season and geographical location, the damage is a major contributor to the total burden of ill-health in regions throughout the world. [1,2]

The most common cause of death from trauma worldwide is traffic accidents, and more than 90 percent of the deaths occur in low and middle income countries. According to a report from WHO 1.3 million people are killed on the roads annually, and another 50 million are injured. [3] Traffic-related deaths are predicted to rise by 66 percent over the next 20 years. But there are big differences between rich and poor countries; a reduction of 28 percent is expected in rich countries while an increase of 92 percent is expected in China and 147 percent in India. The United Nations and the WHO have declared 2011-2020 a decade of action for road safety, with focus on increasing road safety around the world. [3]

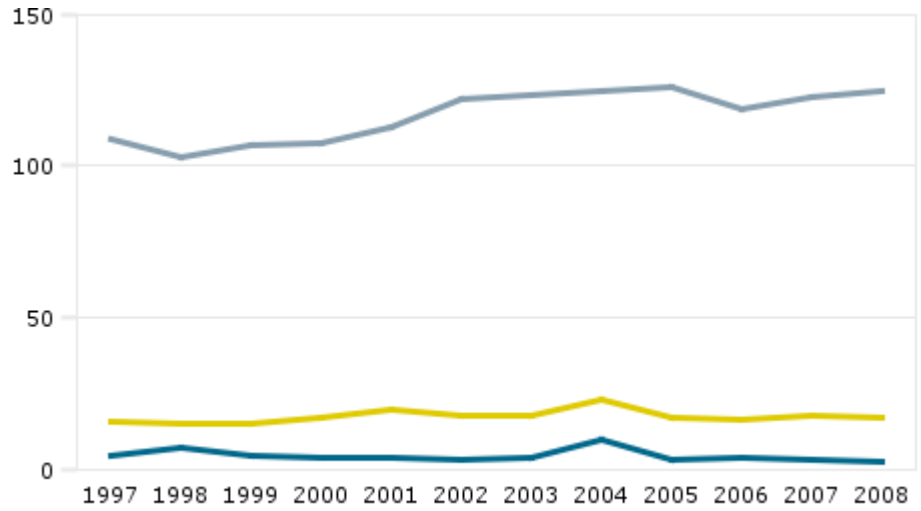
Injury prevalence in the European Union

In the EU's 27 member countries, more than 250,000 people are killed by trauma annually, which means about 700 deaths per day. [4,5] Two-thirds of the people killed are between 15 and 24 years old. When all age groups are combined, injuries are the fourth leading cause of death in the EU; only cardiovascular diseases, tumors and diseases of the respiratory system claim more lives. The rate of deaths from injuries varies widely among the member countries and it is estimated that more than 100,000 lives per year could be saved if all countries reached the same levels as the Netherlands and the UK, which are the countries with the lowest number of deaths related to injuries in the EU. [4,5] Looking at the entire population, the most

common causes of trauma-related death in the EU are self-inflicted injuries (24%), traffic accidents (21%) and falls (21%). Among young children, drowning is the leading cause of death; among adolescents and young adults it is traffic-related injuries, and among older adults the main cause is falls. [4,5]

Injury prevalence in Sweden

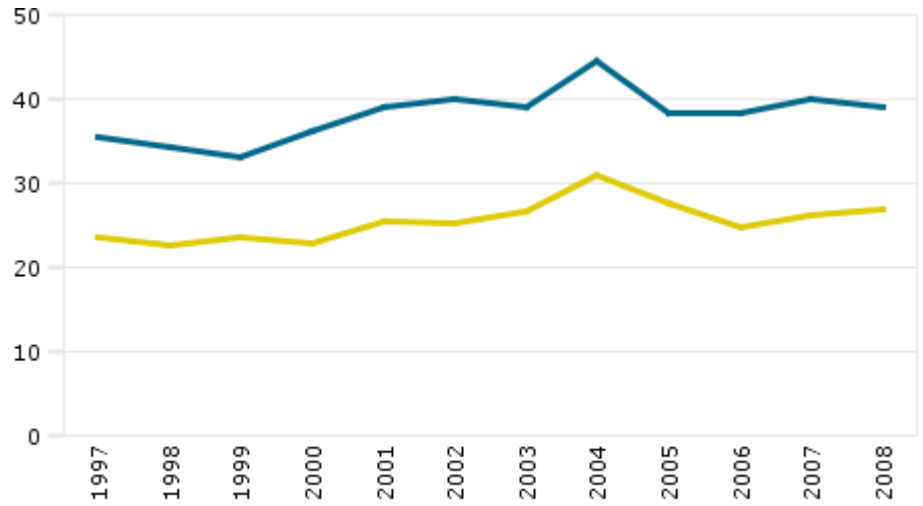
Injury is the most common cause of death in children and young adults and the fourth leading cause of death across all age groups in Sweden. [6,7] Each year close to 5000 people die as a result of an injury event, 150,000 are discharged from acute care hospitals after treatment for injuries, and approximately 600,000 are treated in emergency departments and discharged within 24 hours. [7] People aged 65 years and older account for two thirds of all deaths and for half of all those who need hospitalization due to injury events. A contributing factor is often an already established underlying medical condition. [6,8] (Figure 1) The most common causes of death are self-inflicted injury (38%), falls (29%) and traffic accidents (27%). Deaths from assault (2%) have decreased in recent years. The most common injuries in all age groups are intracranial injuries, including fractures of the skull and lower extremities. [6] Figure 2 display injury mortality rates per 100,000 by sex in Sweden.



Blue line=0-17 years; Yellow line=18-64 years; Grey line=65+

Source: National Swedish Board of Health and Welfare (DOR)

Figure 1. Injury mortality rates (per 100, 000 population) by age in Sweden, 1997 to 2008



Men=blue line; Women=yellow line

Source: National Swedish Board of Health and Welfare (DOR)

Figure 2. Injury mortality rates (per 100,000 population) by sex in Sweden, 1997 to 2008

Since the early 1990s the injury death rates for children and adolescents have fallen to less than half and Sweden is considered one of the safest countries in Europe. [9] The highest rates of death caused by unintentional injury are seen in males aged 15−19 years followed by females aged 15−19 years and males aged 1−4 years. Deaths caused by intentional injury are most common in males aged 15−19 years followed by females 15−19 years and female infants <1 year. [9] (Table 1) Traffic injury events are the most common cause of death, especially among males aged 15−19 years. Suicide rates are high in males and females aged 15−19 years. [9] (Table 2)

Table 1. Injury mortality rates per 100,000 by age and sex in Sweden and EU-27, 2010

Unintentional death, age	<1 yr	1–4 yr	5–9 yr	10–14 yr	15–19 yr
Males, Sweden	1.71	1.76	1.53	1.58	11.14
EU-27	11.03	5.48	3.79	5.84	25.07
Females, Sweden	0.00	0.00	1.21	1.25	3.60
EU-27	8.42	5.05	2.28	3.08	7.13
Intentional deaths, age	**<1**	**1–4**	**5–9**	**10–14**	**15–19**
Males, Sweden	0.00	0.44	0.38	0.79	10.21
EU-27	1.30	0.71	0.17	0.89	10.75
Females, Sweden	1.80	0.47	0.00	1.67	4.58
EU-27	1.42	0.33	0.20	0.59	3.11

Source: Child Safety Country Profile 2012 Sweden, European Child Safety Alliance.

Table 2. Injury related mortality rate per 100,000 by cause in children 0−19 years in Sweden (2008−2010).

Injury mechanism	Age years males/females				
	<1	1–4	5–9	10–14	15–19
Pedestrian	1.15/0.00	0.45/0.16	0.13/0.00	0.00/0.14	0.30/0.43
Motor vehicle	0.00/0.63	0.30/0.00	0.52/0.54	0.51/0.14	7.23/2.58
Motorcycle drivers	0.00/0.00	0.00/0.00	0.26/0.00	0.37/0.00	1.43/0.43
Cyclists	0.00/0.00	0.15/0.00	0.00/0.00	0.13/0.14	0.10/0.22
Drowning	0.00/0.00	0.90/0.32	0.65/0.00	0.38/0.14	0.92/0.11
Falls	0.00/0.00	0.15/0.00	0.00/0.00	0.26/0.00	0.20/0.32
Fires, burns and scalds	0.00/1.24	0.30/0.16	0.27/0.56	0.00/0.66	0.00/0.00
Poisoning	0.00/0.00	0.00/0.00	0.00/0.00	0.12/0.00	1.63/0.97
Choking/strangulation	0.60/1.25	0.15/0.00	0.00/0.00	0.00/0.00	0.31/0.00
Suicide/self-inflicted	0.00/0.00	0.00/0.00	0.00/0.00	0.52/1.20	10.19/5.39
Homicide	0.00/1.23	0.75/0.32	0.26/0.14	0.13/0.28	0.51/0.86

Source: Child Safety Country Profile 2012 Sweden, European Child Safety Alliance.

Injury prevention and risk factors

Injuries can be prevented or controlled. Haddon [10] describes three phases representing stages in a time continuum that begins before injury and ends with the outcome. These phases are known as the pre-event, the event, and the post-event phase. [10] The classical model for injury prevention is based on Haddon's three phases and includes: 1) primary prevention aimed to prevent new injuries; 2) secondary prevention aimed to reduce the severity of injuries; 3) tertiary prevention aimed to decrease the frequency and severity of disability after an injury. [10] Risk is the probability of an adverse health outcome, or a factor that raises this probability. Research has identified a number of risks that raise the probability of injuries: chronic diseases; alcohol; medicinal or recreational drugs; external environmental factors; and socio-demographic factors such as age, sex, ethnicity, education and economy. [11] In Sweden, a registry case/control study investigating differences in socio-economic background in children and adolescents with injuries admitted to acute care hospital and comparing these with a control group found a significantly increased risk of injuries in households with single parents, households receiving social assistance, parents with lower education, and mothers with lower education. The risk of suicide and self-inflicted injuries was twice as high for those in households receiving social assistance or with single parents compared to other peers. [11,12]

Some of the legislative preventive measures that have clear-cut beneficial effects include regulations concerning child passenger restraints, seatbelts, bicycle and motorcycle helmets, smoke alarms, hot water temperature, child-proof packaging, and isolation fencing around swimming pools. A recent report, "The Child Safety Country Profile 2012" [13] for Sweden, suggests that recommended safety equipment is both reasonably available and affordable for families in the lower socio-economic strata in Sweden.

2.2 INJURY DEFINTION AND CLASSIFICATIONS

Defining the concept of injury presents challenges and complexities and there is no consensus definition. Unlike most diseases, injuries must be defined simultaneously by the causative event and the resulting pathology. [14] One of the most frequently cited

definitions of injury is that used by Baker and O'Neill in the "Injury Fact Book" [15] where injury is described as physical damage to the human body produced by the transfer of external energy that exceeds body tissue resistance. The energy can be kinetic, thermal, chemical, electrical, or radiant. Damage can also occur from a lack of vital energy such as oxygen. The interval of time over which the energy transfer or the deprivation of physiological essentials occurs is known as exposure, and can be acute or chronic. [15,16]

The concept of injury mechanisms is used to describe the physical impact of energies on the body's various tissues. [16] The injury mechanism can be a vehicle crash in which kinetic energy is transmitted through the car body to the passenger compartment and human tissue. Events that cause damage can be divided into unintentional or intentional. [16] Injuries can also be divided into blunt or penetrating injury. [16] A gunshot wound is a penetrating injury and can be caused by an unintentional or intentional event. Another example of blunt injuries are fractures sustained from a bicycle crash. Injury severity varies depending on several factors including the type of energy transmitted; for example, the extent of a burn depends on the temperature and exposure time and a gunshot wound on the projectile mass and velocity. [16]

Trauma is a Greek word for wound and is used to describe physical and/or mental injury and/or emotional stress. [17] The concept of trauma is expressed in such terms as injury, shock, accident, accidental injury, causative and fatality. [18] The term major trauma is used to define severe tissue damage with a real or potentially life-threatening condition that requires immediate acute care resources for optimal care of the injured. [19] The World Health Organization (WHO) uses the terms trauma and injury interchangeably. [20]

2.3 TRAUMA MANAGEMENT

The history of trauma care is linked to wars and wounds. One of the most famous figures in this field is Florence Nightingale who in 1854 organised care for battlefield wounded and was determined to achieve the best for the patients even under very difficult conditions. Her work proved an inspiration to the founder of the Red Cross Movement. [21] Another world-famous person in trauma care is Jean Henri Dunant,

Nobel Peace Prize laureate, who established the International Red Cross 1863 to aid the wounded on the battlefield and to care for them later until they recovered. The Red Cross is also active in peacetime to alleviate the hardships caused by natural catastrophes [22]. After World War I the first civilian trauma system was developed in Austria and the first regional trauma system was started in Germany during the 1970s.[23]

Trauma management consists of a chain where each link is vitally important for the patient's survival. This management system continues to evolve at every stage, starting at the point of injury and continuing through recovery. [24] The focus is on how the human system responds to injury and factors that can improve outcome for patients and their families. This includes stabilization in the field, resuscitation, intensive care, intermediate acute care, acute care, rehabilitation and prevention. In the pre-hospital phase the patient is triaged, treatment is initiated to secure vital functions, and the patient is rapidly transported to a trauma team within an acute care hospital. [25] In the resuscitation phase the focus is on identifying and correcting any immediately life-threatening conditions. [26,27] The abbreviation <C>ABCDE is used for prioritizing care. [28] (Table 3) The members of the trauma team work in parallel and anticipate problems, rather than reacting once they develop. [19,27,29]

Table 3. The primary goal in the resuscitating phase

<C>	Catastrophic Haemorrhage Control
A	Airway (and cervical spine control where appropriate)
B	Breathing and Ventilation (with oxygen where available)
C	Circulation and Haemorrhage Control
D	Disability or Neurological Deficit
E	Exposure/ Environment/ Extremity

In the intensive care phase the focus is on continued stabilization, ongoing assessment and evaluation, and support for the human system's response to trauma. [29,30] Early detection of life-threatening complications is essential as the patient's condition may deteriorate and fail to achieve balance, owing, for example, to infections or injuries that were overlooked in the initial assessment phase. [31] Many trauma patients do not need intensive care and are transported directly from the resuscitation

area to intermediate care or an acute care unit where the focus of care is similar to that in the intensive care phase. [29,30]

Rehabilitation starts directly after resuscitation and continues through recovery. The goal of the rehabilitation phase is to minimize complications and improve overall functioning and adaptation. [32] Patients with major trauma have a wide range of needs including physical, psychological, functional, social, and economical. The patient's needs are met by a multidisciplinary team consisting of rehabilitation specialists in medicine and nursing, psychologists, occupational therapists, physiotherapists, speech and language therapists and social workers. [33]

Trauma nurses have traditionally recognized the effects of stress and adaptability in the recovery trajectory and these variables have become more valued by the multidisciplinary team as essential in the patient's recovery. Trauma nursing is person-centered care that focuses on patients' conditions as well as the effects of illness on the lives of the patients and their families. [18] (Table 4)

Table 4. Five areas in trauma nursing

▪	Support of vital functions
▪	Support of physiological adaptation
▪	Promotion of security and safety
▪	Psychological adaptation and social support
▪	Support of existential needs

Psychological reactions to trauma

Traumatic events trigger a stress reaction causing a cascade of biochemical agents to be released in a person's body to get ready for a fight-or-flight response. A variety of physiological, psychological and behavioral responses follow during the body's and mind's normal reactions in the effort to regain equilibrium. [34,35] Most psychological reactions after trauma are normal and should be expected and included in care plans. Expert psychiatric help is needed for patients with risk of suicide, pre-injury mental illness, psychotic illness, and who risk psychiatric complications owing to head injuries. [36] The widely respected early intervention program "Psychological first aid" [37] should be implemented in trauma care and include: comforting and protecting; counteracting helplessness; reuniting patients with family or friends; re-establishing

order; supporting expression of feelings; providing accurate information; doing psychological triage. [38,39]

2.4 TRAUMA OUTCOME

Outcome of trauma has been defined and measured in different ways but has most commonly been considered in terms of survival or death [40,41], the extent of functional recovery and disability [42], and the length of stay in hospital [43,44]. Outcome has also been integrated into the evaluation of trauma management performance [45,46,47] and comparisons between hospitals [48]. As outcome measures progressed, injury scoring systems were developed as tools for analysis and comparison of individual patients and groups. Injury scoring systems can also be used for triaging patients, allocating and evaluating medical resources, and assessing quality of medical care (audit). [49] A variety of scoring systems have been developed, each with its own problems and limitations. It is essential that injury scoring systems are accurate, valid, reproducible and free from observer bias. [49] The systems are based on: 1) anatomical data, 2) physiological data or 3) a combination of these data. For the purpose of this thesis three anatomical injury scoring systems will be described.

Abbreviated injury score (AIS)

The Abbreviated Injury Scale (AIS) was developed by the American Medical Association, the Association for the Advancement of Automotive Medicine and the Society of Automotive Engineers in the US. [50] The AIS system was originally intended for use on blunt injuries caused by motor vehicle traffic events, but its scope is expanding to include other injuries and it now classifies more than 2000 injuries in nine body regions. [51] AIS is a consensus-derived, anatomically based system, grading injuries according to body regions such as face and thorax, type of anatomic structure such as vessels and nerves, specific nature of injury such as contusion and bleeding, and location of injury such as mandible and lung. Each injury is assigned a seven–digit number where the last post-decimal digit defines the severity in an ordinal scale from 1 (minor) to 6 (unsurvivable). Injuries graded ≤ 3 are usually considered not life-threatening, AIS 4 injuries are considered life-threatening but survivable, AIS 5 are considered life-threatening and probably not survivable, and AIS 6 injuries are non-survivable. AIS is used to describe injuries and to rank them by severity. The

Maximum AIS (MAIS), which is the highest AIS grade in a patient with multiple injuries, has been used to describe the overall severity of traffic-related injuries. [52] The AIS system has limitations, particularly with respect to multiple injuries, as it is not possible to apply linear mathematical calculations to the scores to obtain an overall severity score. [53] The studies (paper I–IV) included in this thesis use the revised AIS-90, which takes age into consideration as an important variable in relation to injury severity. [54]

Injury Severity Score (ISS)

The AIS system forms the foundation for the Injury Severity Score (ISS). [55] This system was developed in an attempt to assess the overall severity of multiple injuries and provide a method for comparing mortality in groups of injured patients. The ISS score is defined as the sum of squares of the highest AIS scores in the three most severely injured body regions. Six body regions are defined and only one injury per body region is allowed. The ISS score ranges on an ordinal scale from 1 to 75, where 75 is unsurvivable. If any one of the body regions is rated at AIS-6 the ISS is automatically defined as 75. Several studies have confirmed that ISS relates to mortality and length of hospital stay, and that the correlation grows stronger with increasing age of the patient hospital stay and increases with age. [43,56] The ISS has several limitations; one is its inability to account for multiple injuries to the same body region. The system also limits the total number of contributing injuries to three body regions. Another limitation is that ISS weighs injuries equally in all body regions, not taking into consideration the increased risk of mortality for example in traumatic brain injuries (TBI). In a study by Copes et al. [57] the mortality rates were found to peak at ISS 16 and ISS 25. A possible explanation for this finding is that an increase in ISS does not strictly reflect an increase in severity and risk of mortality. For example, the mortality rate for an ISS of 16 from an isolated AIS 4 injury is higher than the mortality rate for two AIS 3 injuries amounting to ISS 18. Lastly, many of the integer values from 1 to 75 cannot occur, while other ISS values can be reached through several different combinations of AIS scores, for example a score of 75 can be the result of either three AIS 5 injuries ($5^2+5^2+5^2$) or with at least one AIS 6 injury. These limitations reduce the predictive value of the ISS. [58]

New Injury Severity Scores (NISS)

NISS is based on the same system as ISS but differs in that the three highest AIS scores in any body region are squared and summed to calculate a NISS score 1−75. [58] This significant modification of the ISS avoids many of its previously acknowledged limitations. NISS has been reported to be superior to the ISS in terms of mortality prediction, as multiple injuries to one body region are given their full weight. [59,60,61] For example, a patient with bilateral closed femur shaft fractures can exsanguinate into the thighs and is obviously more seriously injured than a patient with a single fracture, but both would have an ISS of 9. In NISS both fractures count giving a score of 18. Similarly, patients with closed head injuries are also underscored by ISS. At present, it is unlikely that NISS will replace ISS completely because of the role ISS plays in Trauma and Injury Severity scores (TRISS) methodology.

Most injury scoring systems include only the physical aspects of injury and how serious the injury is. However, it is also important to take into consideration the emotional, psychological, functional ability and economic consequences, and the ongoing impact to the injured person, their family and the health care system. Table 5 gives examples of several dimensions of severity that have been identified and listed in the manual for AIS-2005. [51]

Table 5. Examples of dimensions of severity

▪ Threat to life
▪ Mortality: theoretical, expected, actual
▪ Amount of energy dissipated/absorbed
▪ Hospitalization and need for intensive care
▪ Length of hospital stay
▪ Treatment cost
▪ Treatment complexity
▪ Length of treatment
▪ Temporary and permanent disability
▪ Permanent impairment
▪ Quality of life

Source: AIS-2005. Association for the Advancement of Automotive Medicine.

2.5 CONCEPT OF HEALTH-RELATED QUALITY OF LIFE

2.5

Health is a complex concept with many components, traditionally assessed through classical health indicators derived from the bio-medical model. The model is based on

the assumption that diseases are generated by agents which cause changes in the human body's structure and function. [62] The damaged structure can be repaired or replaced; the disease is treated from a medical point of view but not necessarily from the patient's subjective experience of illness, which is a broader view of health than physical causes and psychological consequences. [62] In 1948 the WHO defined health by a social model as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". [63] This definition expanded on earlier views of health, and included not only somatic indicators, but also a person's perception of physical and psychological well-being in everyday life, and how social relations are managed. [64,65]

Quality of life (QOL) is a broad multidimensional concept that includes subjective evaluations of different aspects of life. The WHO Quality of Life group (WHOQOL) defines quality of life (QOL) as "an individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". [66] Health is one of several important domains of overall quality of life; other domains are for example housing, education, work and community. Key aspects include culture, values, and spirituality. Several disciplines have conducted research in the field, including the medical discipline. The definitions of QOL in the health context are mostly unclear or absent despite the concept having been a category in Index Medicus since 1966. [67] Some definitions of QOL in health have a holistic emphasis on the physical, emotional, and social well-being of patients after health care treatments [68] while others define the QOL concept as the impact of a person's health on his or her ability to lead a fulfilling life [69].

The development of health-related quality of life (HRQL) evolved in the 1980s to include those aspects of overall quality of life that can be clearly shown to affect health. [70,71,72] HRQL can be explained as a multi-dimensional concept that encompasses the physical, emotional, and social components associated with an illness or treatment. [73] Several large surveys with empirical data from children and adults support the conceptualizing HRQL dimensions of physical, emotional, and social function and well-being. [73,74] Determinants include social support, socioeconomic status and health risks and conditions. On a community level examples of determinants are resources, conditions, policies, and practices that influence a population's health

perceptions and functional status. [75] HRQL has become important in health surveillance and is considered a valid indicator of service needs and intervention outcomes [76] and for health care policy making [77]. Self-assessed HRQOL status has also proved to be a stronger predictor of mortality and morbidity than objective measures of health. [77,78]

2.6 HEALTH-RELATED QUALITY OF LIFE AFTER TRAUMA

Trauma care has improved substantially in the last two decades and this has led to higher survival rates. [79,80] The currently held view is that traditional outcome measures, such as survival rates and presence of functional disabilities, are inadequate and do not capture the range of ways in which a patient may be affected by injury and sequelae. HRQL assessment has emerged as an important health outcome measure after trauma, to evaluate adults' and children's health, and the effectiveness of different therapeutic interventions. [81,82,83] In the last two decades there has been a major increase in the development and utilization of multidimensional HRQL assessment instruments that are generic or disease-specific. [84,85] Because injury characteristics are heterogeneous, generic instruments are preferred and enable comparisons across multiple groups. [85] Measures obtained using disease-specific instruments can complement generic measures focusing on specific aspects of health with respect to particular diseases or organ systems. [85,86] Numerous instruments are available for measuring the HRQL in children and adults after trauma. It has been recommended that, in particular, three features should be considered. First, HQOL instrument need to be multidimensional, a feature that distinguishes them from other health outcome measures. Second, the instruments need to measure aspects of life that are meaningful to adult trauma patients and to pediatric trauma patients and their families. Finally, HRQL instruments need to take the patient's perspective when measuring the impact of injury on physical, emotional, and social well-being. [83] In this thesis the SF-36® Health Survey and the Pediatric Quality of Life Inventory™ Version 4.0 Generic Core Scales were used as HRQL measures. Both instruments cover the essential domains of HRQL and are suitable for long-term follow-up measurement of HRQL in adult and pediatric trauma patients, respectively.

The measures have good psychometric properties and are widely used around the world. The SF-36 [82,87] and the PedsQL 4.0 [83,88–91] are recommended as generic instruments in follow-up studies after trauma.

HRQL in children after trauma

Measurement of HRQL in children has proved challenging, and one challenge is the source from which the information is obtained. [92] The gold standard for measuring children's HRQL is self-report, as children have a unique awareness of their own health and earlier research has revealed that children as young as 5 years can self-report their HRQL. [66,92,93] However, few self-report HRQL measures have been developed for young children and as a result, parent proxy reports have been the source of children's HRQL. [93–96] It is well documented in the literature that there are discrepancies between the child's self-report and the parent's proxy report, where lower agreement has been found in subjective HRQL domains such as emotional and social functioning and higher in objective domains such as physical functioning. [97–99] There are situations where a child is unable to provide a self-report and parents' proxy report is the only source of information. Most authors agree that it is important to include the parents' proxy reports as a complement to children's self-reports as a secondary outcome measure. [99,100]

Relatively little is known about the impact that injuries have on children, and their families. Most studies of HRQL of children after injury have been carried out within two years after injury using a variety of HRQL measures and relying on parents' proxy reports. These studies have focused on different age ranges and injuries and have revealed rapid recovery during the first year after moderate to severe injuries, followed by a plateau phase during which any remaining disabilities remain more or less unchanged. [101−108] The few existing long-term follow-up studies have found that children continue to recover 5 to 10 years after moderate to severe injuries and a majority of them report HRQL scores similar to those of healthy peers. [109−112]

HRQL in adults after trauma

A majority of major adult trauma patients (ISS ≥16) sustain injuries involving many body systems. These patients are most often cared for in intensive care units (ICU) sustaining multiple complications including psychological complications. Longer stay in ICU are associated with significant loss of muscle mass, and some cognitive deficits

depending on a several factors, for example head injuries and medical treatments. Most follow-up studies have explored outcome up to a year after injury investigating morbidity, functional outcome, return to work, and health-related quality of life (HRQL). [113−118] The few long-term follow-up studies over 3 years that exist comes mainly from Europe and Canada.[119−125] These studies has been carried out with different methods and measurements, interestingly most studies on moderate to severe injuries up to one year or over three years or more shows decreased HRQL with physical and psychological disabilities and about 70 percent returning to work. A recent database search found 41 research reports published in English or German in peer-reviewed journals between 1995 and 2009 focusing on heterogeneous injuries using self-reported HRQL measures in longitudinal studies, in line with the EuroSafe guidance. [126] Of the 41 studies, fifteen were from Europe: U.K. (7), the Netherlands (5), Norway (2), and Spain (1). Most of these studies had been carried out 6, 12, or 24 months after injury and reported high prevalence of various problems within the first year post-injury. Predictive variables identified as being associated with HRQL scores were injury severity, type of injury, sex, mental health status and comorbidity. Variables that predicted long-term disability were length of stay in hospital, injury type and/or injury mechanism, and injury severity. The most commonly used HRQL measures were SF-36 and EQ-5D. [127]

3 AIMS

The overall aim of the thesis is to investigate long-term outcome and health-related quality of life after injuries in different age groups and to identify factors associated with outcome.

Specific aims of the papers included in the thesis:

I. To assess outcome and quality of life 5 years after major trauma in a population treated at a regional trauma center in Stockholm. The subsidiary aim was to identify factors that could be associated with long-term outcome and quality of life.

II. To describe the age and gender distribution, injury mechanisms, injury severity, and outcome of pediatric trauma in the Stockholm region during 2002.

III. To investigate children's and adolescent's HRQL six years after minor to severe injury and to examine the relationship between HRQL and demographic and injury characteristics in the investigated cohort.

IV. To examine the relationship between child self-report and parent proxy report of HRQL and how parent's mental health status contributed to ratings of child HRQL six years after minor to severe injury.

4 MATERIALS AND METHODS

4.1 DESIGN

The research in this thesis was conducted using a quantitative descriptive design. In the first study (Paper I) a retrospective descriptive design was used to describe the characteristics and clinical outcome of adult patients after major trauma and to investigate the relationship between subgroups in the sample and between the sample group and an age and gender-matched reference sample 5 years after injury.

The second study (Paper II) was also a retrospective descriptive study where data were collected from children injured during 2002 to describe demographic and injury characteristics and clinical outcome. The sample in second study (Paper II) was the source for the last two studies (Paper III, IV) and used a cross-sectional design. Study III measured HRQL dimensions in a sample of children after injury and determined the relationship within subgroups of the sample. The last study (Paper IV) measured previously injured children's HRQL as reported by a sample of children and their parent and determined the relationship between scoring results and the impact of parent's self-reported mental health status. Table 6 gives an overview of the papers included in the thesis.

Descriptive studies are also called observational, as the subjects are observed without interventions. Cross-sectional studies are observational in nature and are known as descriptive research. In cross-sectional studies subjects are studied at one given point in time. This type of research can be used to describe characteristics that exist in a population, but not to determine cause-and-effect relationships between different variables. Retrospective studies focus on conditions in the past that might have caused subjects to become cases rather than controls. These designs are often used to make suggestions about possible relationships and or to gather preliminary data to support further research and experimentation. [128]

Table 6. Description of papers I to IV included in the thesis

Paper	Aim	Design	Inclusion criteria participants responders	Data collection	Data analysis
I	Outcome and health-related quality of life after major trauma	Retrospective descriptive 5 yrs after major trauma	≥15 yrs of age at injury, ISS ≥9, n=246 Responders, n=205 Matched reference group, n=410	Review hospital medical records Trauma registry SF-36 Additional questions	Descriptive statistics χ2-test Mann-Whitney U-test Kruskal Wallis test Tukey's HSD post hoc test
II	Demographic and injury characteristics and outcome after injury	Retrospective descriptive	≤15 yrs of age at injury, n=432	Trauma registry Re-review hospital medical records Review medical records, Department Forensic Medicine	Descriptive statistics
III	Outcome and health-related quality of life after injury	Descriptive cross-sectional 6 yrs after injury	≤12 yrs of age at injury , AIS ≥1, n=306 Responders, n=204	Trauma registry Re-review hospital medical records PedsQL 4.0 child versions	Descriptive statistics Cronbach's α coefficient χ2-test Mann-Whitney U test Kruskal-Wallis test Post hoc pair-wise comparisons by Mann-Whitney U-test
IV	Outcome and health-related quality of life child-proxy version and impact of parental mental health	Descriptive cross-sectional 6 yrs after injury	≤12 yrs of age at injury , AIS ≥1, n=306 Parents, n=306 Dyads of children-parents responses, n=177	Trauma registry Re-review hospital medical records PedsQL 4.0 child-proxy versions SF-36	Descriptive statistics Cronbach's α coefficient Wilcoxon Signed Rank test Intra-class correlation coefficient (ICC) Hierarchical multiple regression analysis

Abbreviations: AIS, Abbreviated Injury Scale; ISS, Injury Severity Scale score; SF-36, Short-form 36; PedsQL 4.0, Pediatric Quality of Life Inventory

4.2 STUDY AREA AND SETTING

The participants studied in this thesis come from the Stockholm area in Sweden. Stockholm is the largest capital and metropolitan region in northern Europe. At the time of these investigations the Stockholm metropolitan area had a population of 1.9 million. Of these, 350,000 were children 15 years or younger, corresponding to 25 percent of all children in this age group in Sweden [129]. Sweden is highly urbanized, with 84 percent of the population living in urban areas. [130]

Sweden is divided into 6 healthcare regions. Sixty hospitals provide specialist care, with emergency services available 24 hours a day. Eight are regional hospitals, where highly specialized care is offered and most teaching and research are based.

Costs for health and medical care represent about 10 percent of Sweden's gross domestic product (GDP). The health and medical care in Sweden is paid for by county council and municipal taxes. Contributions from the national government are another source of funding. [131] The Stockholm regional trauma center Karolinska University Hospital (Stockholm) and Astrid Lindgren Children's Hospital Karolinska University Hospital (Stockholm), which respectively provide adult and pediatric trauma care, participated in the studies included in this thesis.

4.3 PRE STUDY TRAINING

In the pre-planning phase of this thesis the author received training in trauma registry and trauma management by the American Trauma Society. Training in trauma registry was also conducted at Tri-Analytics Inc. (Maryland, USA). The author is a member of the AIS faculty of the Association for the Advancement of Automotive Medicine (AAAM). The data in this thesis were collected, abstracted, coded and scored by the author.

4.4 STUDY POPULATION AND PROCEDURES

PAPER I

Population

The first investigation (Paper I) was a long-term follow-up study that included 309 adult patients with major trauma, who had been injured during 1996 to 1997 in the Stockholm region and admitted to the Karolinska University Hospital (Stockholm, Sweden). The patients were identified by review of medical records and the trauma registry of the Karolinska University Hospital. Patients were included if admitted to the hospital with blunt or penetrating injury, 15 years of age or older when injured, and with an Injury Severity Score (ISS) of 9 or higher. Patients were excluded if they had severe psychiatric disorders (n=13), had severe cognitive impairment (n=12), were non-permanent residents of Sweden (n=2), could not speak Swedish well enough to participate (n=6), died after discharge (n=8), had protected identity (n=5), were in police custody (n=2), or had an unknown address and or phone number (n=15). Presence of psychiatric disorders and/or severe cognitive impairment was determined from review of the patient's medical records. Figure 3 displays a flow diagram of the sample.

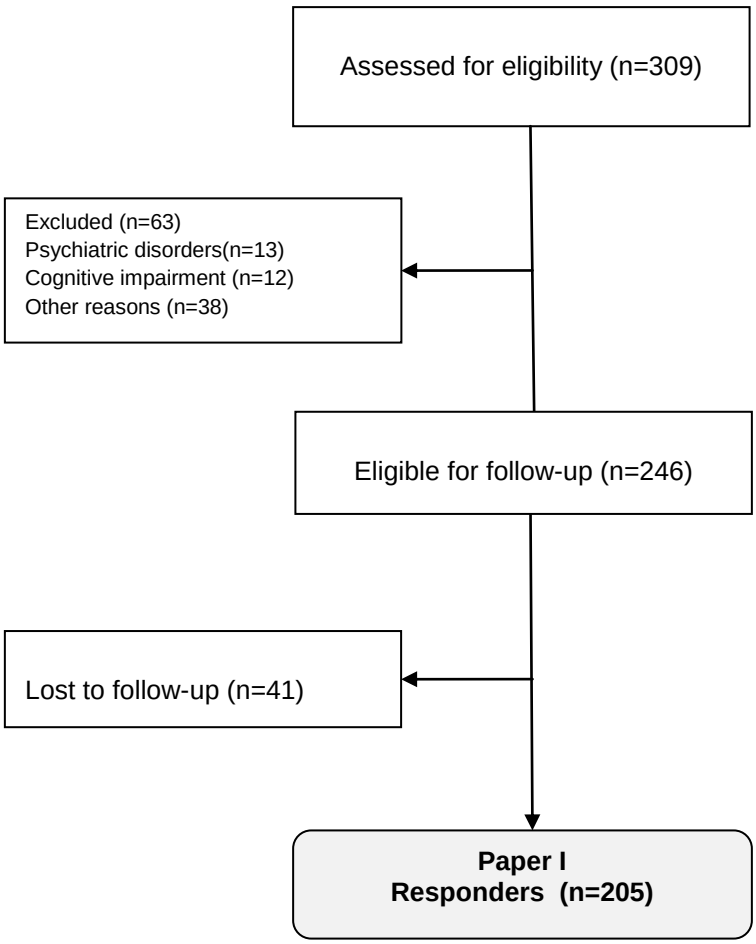


Figure 3. Paper I flow diagram of the sample

Reference sample

The first study (Paper I) used a reference group (n=410) that was drawn from the Swedish SF-36 norm database consisting of 8930 healthy persons (Health Care Research Unit, Sahlgrenska University Hospital, Gothenburg, Sweden). The reference group was stratified by age and gender and matched to the study population in Paper I by the research unit at Sahlgrenska University Hospital.

Procedure

All patient hospital medical records were initially reviewed retrospectively before this follow-up survey. Five years after injury, 246 patients were contacted by mail with a cover letter containing information about the study and the need for informed consent and a questionnaire with a range of questions and a self-addressed stamped return envelope. The patients were given the option of requesting a phone interview in lieu of

the written questionnaire. To maximize participation, two mailings were sent out; the second mailing was sent to those who did not respond within three weeks. Guidelines for mail and telephone administration of the SF-36 Health Survey were followed. [132,133] The questionnaire contained the SF-36 and additional questions used to obtain information on HRQL, physical therapy, rehabilitation, disability compensation, marital/cohabiting status, sick leave, educational level, employment status, physical and psychological impairments and disabilities, injuries after 1996 or 1997, nature and quality of information from the acute care hospital, and additional help that could have eased the patient's situation. The additional questions were added to the SF-36 Health Survey and used to gather information not covered by SF-36. These added questions were not tested for validity and reliability.

PAPER II

Population

The study population in the second investigation comprised 432 injured children. All children 15 years or under, admitted to the Stockholm regional pediatric trauma center, Astrid Lindgren Children's Hospital, Karolinska University Hospital (Stockholm, Sweden) in the year 2002, and who fulfilled the hospital's criteria for trauma team activation were included in the study. The cases were ascertained using the trauma registry of Astrid Lindgren Children's Hospital and all patients' medical records were re-reviewed. Table 7 displays the inclusion criteria for the trauma registry. Medical records at the Department of Forensic Medicine were used to identify the children in the Stockholm region who had died from injuries during the year 2002. Figure 4 displays a flow diagram of the sample for paper II to IV.

Procedure

Hospital medical records for all the patients identified were re-reviewed and medical records at the Department of Forensic Medicine were reviewed retrospectively prior to this follow-up survey. Two registered nurses trained as trauma registrars abstracted and coded the patients in the trauma registry. For this study the data in the registry were validated by randomly extracting 10 percent of the cases from the registry. Medical records for these cases were re-reviewed and data were abstracted into TRI-CODE® (Collector, Tri-Analytics Inc, Bel Air, MD, USA). In this process it was found that 78 percent of the cases had information

missing, invalid records or errors of coding. The whole data sets were validated by re-reviewing all medical records and entering into TRI-CODE®.

We divided the data into groups based on age, acute in-hospital care days, intensive care days, and ISS, which also made it possible to compare our results with other studies. In this study, outcome was measured by mortality, length of stay in pediatric intensive care (PICU) and length of stay in acute care hospital.

Table 7. Trauma team activation criteria year 2002

Criteria	
Physiological	Respiratory impairment Hypotension Altered consciousness or neurological impairment
	and/or
Anatomical	Penetrating injuries to neck, torso, and extremities proximal to elbow and knee Two or more long bone fractures Pelvic fractures Paralysis after trauma mechanism Amputation proximal to wrist and ankle Burn injuries or hypothermia combined with other trauma mechanism Near drowning with other trauma mechanism Flail chest
	and/or
Mechanism of injury	High-speed crash >70 km/h with restraint use or airbag >50 km/h without restraint use or air bag Vehicle entrapment, rollover Ejection from vehicle, death in same vehicle Pedestrian/bicyclist struck by vehicle Crush injuries torso

PAPER III

Population

The 306 cases included in this long-term follow-up study (III) derive from the sample in study II. Included were all children 12 years or younger at time of injury, with minor to severe injuries (AIS≥1), who fulfilled the hospital's criteria for trauma team activation, and were discharged alive after being admitted to the regional pediatric trauma center, Astrid Lindgren Children's Hospital, Karolinska University Hospital in Stockholm, Sweden. Exclusion criteria were: suspected child abuse case (n=3); unknown

address or phone number (n=2); inability of child or parent to understand Swedish (child, n=0; parent, n=0); and non-permanent residence in Sweden (n=8).

Procedure

Six years after injury, 306 children and their parents/guardians were contacted by mail with a cover letter, informed consent form, a questionnaire and a self-addressed stamped return envelope. At the time of request for inclusion in the follow-up, the children were between 6 and 18 years of age. Children 15 to 18 years of age were contacted by mail separately from their parents/guardians. Informed consent was obtained from all parents/guardians of children aged 6 to 17 years and from children who were 15 years of age or older. Parents/guardians of children aged 6 to 7 years were instructed to read the instructions and questions aloud to the child, whereas older children were instructed to answer the questions on their own.

PAPER IV

Population and Procedure

This sub-study of 306 children with injuries includes the cohort from study III and the children's parents (n=306). Inclusion and exclusion criteria were the same as in study III. Six years after injury, children aged 6 to 18 years at follow-up and their parents were contacted by mail with a cover letter, informed consent form, a questionnaire and a self-addressed stamped return envelope. Children 15 years of age or older were contacted separately from their parents by mail. Informed consent was obtained from all parents/guardians and children who were 15 years of age or older. Parents of children aged 6 to 7 years were instructed to read the instructions and questions aloud to the child, whereas older children were instructed to answer the questions on their own. Parents were asked to complete the PedsQL 4.0 proxy-version, and the SF-36 questionnaire.

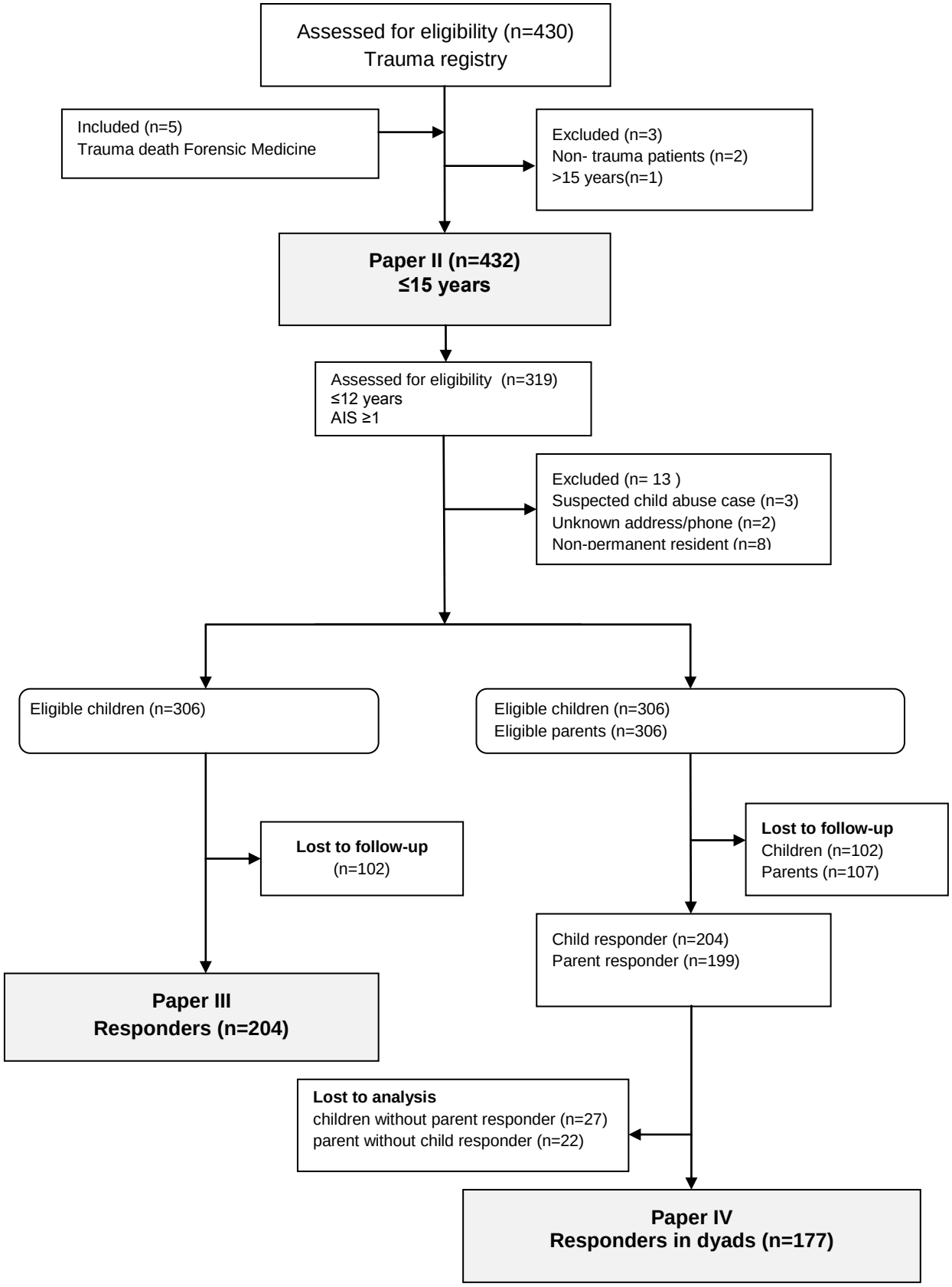


Figure 4. Flow diagram paper II to IV

4.5 MEASURES

Health-related quality of life (HRQL) was measured using the 36-item Short Form Health Survey (SF-36) and the Pediatric Quality of Life Inventory™ version 4.0 (PedsQL™) generic core scales. Additional questions were included in the questionnaire in study I to gather information on demographic and injury characteristics and in study IV on parent demographic and child injury characteristics.

The SF-36 Health Survey

The Swedish version of SF-36 was produced within the International Quality of Life Assessment (IQOLA) Project to match the original US version. [134] The Swedish version of SF-36 Swedish has well-established reliability and validity regarding its eight basic health dimensions. The instrument has been recommended in an international consensus meeting as a generic tool for quality of life assessment for adult trauma and adult intensive care patients. [135−137] The taxonomy of the instrument has three levels: (1) items; (2) eight scales; and (3) two summary measures that aggregate scales. SF-36 consist of 36 items divided into eight domains: physical functioning (10 items); role limitations related to physical problem (4 items); bodily pain (2 items); general health (5 items); vitality (4 items); social functioning (2 items); role limitations related to emotional problems (3 items); and mental health (5 items). All but one of the 36 items (self-reported health transition) is used to score the eight SF-36 scales. Table 8 displays the structure of SF-36. [134]

SF-36 items are scored in the following steps: (1) item recoding; (2) computing scale scores by summing across items in the same scale (raw scale scores); and (3) transforming raw scale scores to a 0−100 scale (transformed scale scores). The thesis followed the recommendation that at least 50 percent of the items in a given scale must be present for calculation of the scale score. [134]

For the purpose of the fourth study (IV), the five-item mental health domain (MH) was used, which is one of the eight scales of the SF-36. The MH scale has been shown to be useful in screening for psychiatric disorders. [138−140] The MH domain consists of the following questions: (1) Have you been a very nervous person? (2) Have you felt so down in the dumps that nothing could cheer you up? (3) Have you felt calm and peaceful? (4) Have you felt downhearted and blue? (5) Have you been a happy person? The response alternatives consist of 5-point Likert scales ranging from the "all

the time" to "none of the time". MH scores can range from 0 (worst) to 100 (best mental health).

Table 8. Structure of the SF-36 Health Survey

Physical Component				Mental Component			
Physical function 10 items	Role physical 4 items	Bodily pain 2 items	General health 5 items	Mental health 5 items	Role emotional 3 items	Social function 2 items	Vitality 4 items

The PedsQL 4.0 Generic Core

The children's self-perceived HRQL was assessed using the Pediatric Quality of Life Inventory™ version 4.0 (PedsQL™) generic core scales. The PedsQL 4.0 is a brief questionnaire encompassing 23 items that provides self-reports versions age-adjusted for children.[128] The instrument has good psychometric properties and covers a substantial segment of the domains of functioning using the international classification of functioning, disability, and health (ICF) of the World Health Organization (WHO). [66,141,142] In the area of trauma, the proxy-version was tested for reliability and validity for children aged 5 to 15 years with traumatic brain injuries or extremity fractures aged 5 to 15 years and thereafter recommended as a generic tool for measurement of children's HRQL after injury.[143] Swedish self and proxy versions are available for ages 5 to 18 years (Mapi Research Institute Lyon, France) and both versions have shown acceptable psychometric properties in studies with schoolchildren aged 8 to 14 years. [144]

The third study (III) used the PedsQL 4.0 [139] versions for ages 5 to 7 years (young child), 8 to 12 years (child), and 13 to 18 years (adolescent). Irrespective of age group, all questions are asked based on what has been a problem for the child within the past month. The version for ages 5 to 7 years presents three-point Likert scales with each response, supported by a sad to a happy face scale (0 = not at all a problem; 2 = sometimes a problem; 4 = a lot of a problem). Versions for ages 8 to12 and 13 to 18 consist of five-point Likert scales (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem). Raw score on each individual item is transferred to a 0 to 100 scale (3-point Likert scales: 0=100; 2=50, 4=0 and 5-point Likert scales: 0=100; 1=75; 2=50; 3=25; 4=0), where higher scores reflect better perceived HRQL. The individual scale scores are calculated as the

mean score by dividing the sum of the items by the number of items answered (this accounts for missing data). Summary scores range from 0 to 100, where 0 reflects the lowest HRQL and 100 the highest HRQL. All forms comprise 23 items that are divided into four domains: physical functioning, emotional functioning, social functioning, and school functioning. The scales can be combined into summary scores of physical health (the same as the physical functioning scale, 8 items), psychosocial health (emotional, social, and school functioning scales, 15 items), and total health (all of the four scales, 23 items). Table 9 displays the structure of the PedsQL 4.0 generic core scale for child and proxy versions.

In the fourth study (IV) we used the child and proxy versions for ages 5−7, 8−12, and 13−18 years. The parent proxy-report version is constructed to mirror the child's version and assesses the parent's perceptions of the child's HRQL. [141] In the parent proxy-report each item is ranked on the 5-point Likert scale for all age groups.

Tabell 9. Structure of the PedsQL 4.0 Generic Core Scale child and proxy versions

Total Health			
Physical Health	**Psychosocial Health**		
Physical functioning 8 items	Emotional functioning 5 items	Social functioning 5 items	School functioning 5 items

4.6 SOURCES FOR INJURY SCORING

A trauma registry is a database which can provide information for analysis and evaluation of the quality of patient care, including demographic and epidemiologic characteristics of trauma patients. [145] A critical component of data management is the coding and scoring of injuries and events. The reliability of the scores and codes contained in the registry is dependent upon accurate and complete data entry. The scoring and coding in the registry should be consistent and compatible with recognized standards. A trauma registry contains information on demographics, physiological status, anatomic injury diagnosis, cause of injury, treatments, and patient outcomes. Table 10 displays a list of the most common scores and codes utilized in a trauma registry.

Data source paper I

Information for paper I was collected from the trauma registry Collector® (Tri-Analytics Inc. Bel Air, Maryland, USA) of the Karolinska University Hospital (Stockholm, Sweden). The trauma registry include TRI-CODE® injury coding software, originally developed to reduce variability in assigning injury scores on the basis of text description. TRI-CODE® was used to assign international classification of disease codes, ninth revision (ICD-9), AIS-90 scores, and ISS. The NISS was assigned manually. All trauma team activation cases were classed as trauma cases by the designated triage nurse who received the calls from SOS Alarm center in the emergency department, and were documented after the patients' arrival in the trauma room. Data were entered into the registry retrospective to discharge from the acute care hospital.

Data source paper II to IV

Information was collected from the trauma registry (KVITTRA®, Combitech, Växjö, Sweden) of Astrid Lindgren Children's Hospital, Karolinska University Hospital. The hospital trauma registry contains information on demographics, physiological status, anatomic injury diagnosis, cause of injury, treatments, and patient outcomes. All trauma team activation cases are documented as trauma cases in the emergency room and data are entered into the registry retrospective to discharge from the emergency department or the acute care hospital. All 430 pediatric trauma cases during 2002 were identified and recoded for quality assurance using TRI-CODE® (Collector®, Tri-Analytics Inc. Bel Air, Maryland, USA). TRI-CODE® injury coding software, originally developed to reduce variability in assigning injury scores on the basis of text description, was used to assign international classification of disease codes, ninth revision (ICD-9), AIS-90 scores, and ISS. The NISS was assigned manually.

Table 10. Common scores and codes utilized in a trauma registry

- ICD-9-CM (ICD-10-CM) - International Classification of Diseases, 9th revision (10th revision), Clinical Modification.
- E-code – Classification for mechanism of injury.
- Glasgow Coma Score (GCS) – Classification for objective scoring of a patient's level of consciousness. The score measures Eye Opening, Verbal Abilities, and Motor Function. The score ranges from 3 to 15, with 3 being the lowest possible score and 15 the highest.
- Trauma Score (TS) – A physiological means of assessing the severity of the injury sustained. It is based on respiratory, cardiovascular and neurological assessments. Trauma scores range from 1 (the worst) to 16 (the mildest).
- Revised Trauma Score (RTS) – A weighted sum of coded variables that include the GCS, systolic BP, and respiratory rate.
- Abbreviated Injury Scale (AIS)
- Injury Severity Score (ISS)
- TRISS – A analysis that considers the RTS, CGS, and age to calculate a probability of survival.

Abbreviations: Systolic BP, systolic blood pressure.

Injury scoring (paper I to IV)

The AIS system [51] classifies injuries according to body region, type of anatomic structure, specific structure, and level and assigns severity on an ordinal scale from 1–6 where 6 is lethal. The AIS measures the threat to life of a single injury and does not combine the consequences of multiple injuries. The Maximum AIS (MAIS) is the highest AIS score in a patient with multiple injuries. The ISS system [55] allocates the AIS scores into 6 body regions and calculates the highest AIS score from the three most severely injured ISS body regions to assign the ISS score on an ordinal scale from 1–75 where 75 is lethal. The New Injury Severity Score (NISS) [58] is based on the same system as ISS but differs in that the three highest AIS scores in any body region are used to calculate a NISS score from 1–75. NISS has been reported to be superior to the ISS in terms of mortality prediction.

Definition of major complications related to injury (paper I)

In the first study (Paper I) information on in-hospital complications related to injury was collected from the trauma registry Collector® (Tri-Analytics Inc. Bel Air, Maryland, USA) of the Karolinska University Hospital (Stockholm, Sweden). Complications included acute respiratory failure, pneumothorax, pneumonia, gastrointestinal bleeding, hyperbilirubinemia, coagulapathy, intra-abdominal abscess,

septicemia, sepsis-like syndrome, renal failure, compartment syndrome, stroke and acute arterial occlusion. Complications were coded using Collector's® standardized codes for trauma registry.

4.7 DATA ANALYSES

Descriptive statistics were calculated for demographic and injury characteristics in Papers I, II, III, and IV. Categorical variables were summarized using frequencies and percentages, while ordinal or continuous variables were presented as mean and standard deviation (SD) or (if not normally distributed) as median and range (Paper I) and median and interquartile range (IQR) (Paper II, III, IV).

In Paper I Mann-Whitney *U*-test was used as a non-parametric test for comparison between two groups; for three or more groups Kruskal-Wallis test was used, and Tukey's HSD test as post hoc test. In Paper III potential differences between respondents and non-respondents as regards demographic and injury characteristics were analyzed using χ^2 tests and Mann-Whitney *U*-tests. Differences in median scale scores between different demographic and injury characteristics groups within the material were analyzed by Mann-Whitney *U*-tests for two group comparisons and Kruskal-Wallis for more than two groups (followed by post hoc pair-wise comparisons by Mann-Whitney *U*-test). In Paper IV Related-Samples Wilcoxon Signed Rank Tests were performed to test the differences in scale scores between children's and parents' reports. A step-wise multiple regression analysis (Paper IV) was performed to find out how parents' mental health status contributed to ratings of child HRQL in a model corrected for the variance of the child and parent background variables. The children's current age, sex (1=male, 2=female), and injury severity score (ISS) were entered in the first step. The parent's sex (1=male, 2=female), country of birth (1=Sweden, 2=any other country), and educational level (1=lower than university, 2=university degree) was entered in the second step. Finally parent's SF-36 mental health scores were entered in the third step.

The internal consistency of the PedsQL scales and the mental health scale in SF-36 was determined by calculating Cronbach's alpha coefficient of reliability (Paper III, IV). Two-way mixed model intra-class correlations (ICC) with absolute agreement were computed between the children's self-reported HRQL and the parent-proxy reports to estimate levels of agreement (Paper IV).

Software and level of significance

Data processing and statistical analyses in Paper I were performed using the Statistica version 6.1TM (StatSoft © Scandinavia AB 2003) and SAS version 8.0TM (SAS © Institute Inc, Cary, NC, USA). Data processing and statistical analyses in Paper II, III, and IV were performed using IBM SPSS Statistics 20.0 (IBM Corp., Armonk, NY, USA).

Variables were considered significant at p value of ≤ 0.05. When correlations were tested (Paper IV), values below 0.40 were taken to indicate poor agreement; between 0.40 and 0.59 fair agreement; between 0.60 and 0.74 good agreement; and above 0.75 excellent agreement.[146] Internal consistency coefficients of at least 0.70 were considered acceptable for group comparisons and coefficients of at least 0.90 for individual comparisons [147]

5 ETHICAL CONSIDERATIONS

Research ethics and respect for human beings requires that all potential study subjects be given adequate information to allow them to make an informed and voluntary decision whether or not to participate in the research. The studies included in this thesis were approved by the Ethical Committee at the Karolinska Hospital, Stockholm, Sweden, (Paper I, registration number 99-127) and by the Regional Ethical Vetting Board (Stockholm) (Paper II, III, IV, registration number 2008/101-31). The trauma registries used in this thesis adhere to the Personal Data Act (1998), Swedish Data Inspection Board, to protect the individual's privacy.

All the participants were contacted by mail with a cover letter containing written information that the study involved research, a description of the procedures to be followed, the expected benefits of the research to the subject and society in general, and a description of the extent and manner in which the information would be kept confidential. The participants were not offered any compensation whatsoever. The cover letter also contained information on how to contact the researchers involved in the study, and a phone number and email address to which inquiries about the research project could be directed. For the study described in Paper I, two mailings were sent out, to maximize participation. For the studied in Paper III and IV, such procedures were not permitted by the ethical review board. All questionnaires and informed consent forms were assigned a code number and the returned forms were stored in a locked space at the Karolinska University Hospital.

In Paper III and IV children under the age of 18 years participated. Research involving children need to include awareness of and respect for children's limitations, level of cognitive development and social and emotional needs. The inclusion of children in this thesis work provided children with a rare opportunity to be "heard" by adults which is a child's right in the Right of the Child, UNICEF and United Nations. [148]

6 SUMMARY OF RESULTS

6.1 PAPER I

In this long-term study 205 (83%) major trauma patients were successfully followed up. (Figure 1) The non-responders, demographic and injury characteristics, post-injury outcome and HRQL are presented under sub-headings.

Non-responders

Forty one (17%) patients did not respond. This group had significantly more males (99%) than the responders group (74%) ($p<0.05$).

Health-related quality of life 5 years after injury

Mean SF-36 scores in all eight domains were significantly lower than in a gender and age matched reference group of healthy individuals ($p<0.001$).

Demographic characteristics and HRQL

The median age of the patients at follow-up five years after injury was 39 years (range 20 to 87 years) and 74% were men. The majority (68%) had a high school education, of these 27% had university education. Seventy one percent lived in the same social situation as five years earlier. Patients that were married/cohabiting reported poorer scores in the domain bodily pain ($p<0.05$) compared to single, separated or widowed. Three age groups were compared: 15 to 30 year (n=64); 31 to 50 year (n=91); >50 year (n=49). The two oldest age groups had significantly lower SF-36 scores than the youngest age group in role physical ($p<0.01$); general health ($p<0.01$); social functioning ($p<0.01$); and role emotional ($p<0.01$). In the domain bodily pain the middle age group (31 to 50 yr) reported the lowest scores and there was a significant difference between this group and the youngest age group (15 to 30 yr, $p<0.05$). The two domains mental health and vitality showed no significant differences between age groups. Nor were there any significant differences between males and females in SF-36 scores.

Injury characteristics and HRQL

The majority of the patients (61%) had a maximum AIS (MAIS) score of 3; 31% received a score of 4 or higher; and 26% of the patients had a MAIS of 3 or higher in at least two injury severity score (ISS) body regions. The median ISS was 14 (range 9−57) and the median NISS was 17 (range 9−57). Nearly all patients (93%) sustained

injuries from blunt trauma; most of the injuries were traffic related (53%). Most patients who sustained penetrating injuries (7%) were young (median age 31 , range 18 to 51) and male and the injuries were caused by sharp objects such as knives (71%) and firearms (29%). ISS and NISS scores were divided into three groups: 9−15, 16−24, and >24. Injury severity scores and injury mechanisms were not found to be associated with differences in SF-36 scores. Recurrent injuries requiring admission to acute care hospital were associated with poor SF-36 scores in bodily pain, general health, vitality, social functioning and mental health (p<0.05). Table 11 displays the injury distribution in the ISS body regions and table 12 shows the distribution of injury mechanism.

Table 11. Injury distribution in the ISS body regions

ISS body regions	
Extremities or pelvic girdle	52%
Head and neck	49%
Chest	49%
External/skin	32%
Abdominal or pelvic content	29%
Face	20%

Table 12. Injury mechanism distribution

Injury mechanism	
Motor vehicle crash	35%
Fall	27%
Motorcycle crash	15%
Pedestrian struck by vehicle	7%
Bicycle crash	6%
Assault	3%
Other	7%

Post-injury outcome and HRQL

The median length of stay in acute care hospital was 8 days (range 1 to 94 days); 34% stayed two or more days in an intensive care unit, 66% underwent one or more major surgical procedures and 19% suffered major in-hospital complications related to the injuries sustained. Patients that suffered complications had lower scores in the SF-36 domains physical functioning, role-physical function, and general health (p<0.05).

Those who had surgical procedures performed reported poorer scores in the domain vitality and role emotional function ($p<0.05$). Table 13 displays the distribution of major in-hospital complications. Patients that stayed more than 5 days in the hospital had lower SF-36 scores in the domain role-physical function than patients who stayed 1 to 2 days ($p<0.05$). Patients cared for in ICU for more than 5 days reported lower scores in physical functioning than those who stayed 24 hours or less ($p<0.05$), and lower in general health than both those who stayed 24 hours or less and those who stayed 2 to 5 days ($p<0.05$). The group that stayed 24 hours or less in the ICU reported the poorest scores in the domain bodily pain ($p<0.05$).

Table 13. Distribution of major in-hospital complications

Complications	Patients (n)
Acute respiratory failure Pneumothorax Pneumonia	14
Gastrointestinal bleeding	2
Hyperbilirubinemia	1
Coagulapathy	1
Intra-abdominal abscess Septicemia Sepsis-like syndrome	24
Renal failure	2
Compartment syndrome	1
Acute arterial occlusion	1
Stroke	2

Rehabilitation and HRQL

Thirty-six patients reported that they had been admitted to a rehabilitation hospital and 56% had received physical therapy in out-patient clinics. Patients receiving care in rehabilitation hospitals had lower overall scores in SF-36 except in the domain bodily pain compared to patients that received care in out-patient clinics or no further care ($p<0.05$). Thirty-eight percent of the patient reported suffering from pain that originated from injuries in the extremities, neck and back regions, or from multiple body regions.

Return to work and HRQL

Five years after injury 68% of those who were of working age (≤65 years) at follow-up

had full-time work and 10% worked part-time. Several part-time workers reported that they were studying. Return to work was found to be associated with overall better SF-36 scores except in the domains role-emotional and mental health compared to the scores of patients who were on disability compensation, still on sick leave or retired ($p<0.05$).

Post-injury physical and psychological sequelae and HRQL

More than half of the patients (68%) reported that they were still suffering from physical disabilities including pain, and 41% from psychological disabilities, and 31% reported suffering from both physical and psychological disabilities. Table 14 displays the various disabilities the patients reported. Patients who reported suffering from physical or psychological disabilities had significantly lower overall scores compared to those who reported full recovery ($p<0.05$).

Table 14. Patients self-reported disabilities

Physical disabilities	Psychological disabilities
Bodily pain	Depression
Functional impairments	Fatique
	Problems with sleep
	Cognitive problems (problems with memory, attention or concentration, anxiety related to thoughts of the injury event or about future health)
	Sexual dysfunction

Information and follow-up and HRQL

Almost half (49%) of the patients expressed that the hospital could have done more to ease their situation by providing better care, consideration and information. Need for better follow-up by trauma specialist, social workers, physical therapy, and psychological help was also expressed. The majority of the patients thought that the information given regarding the injuries sustained and the medical treatment provided (72%), and the plans for continued care (66%) after discharge was good. Patients who reported that the acute care hospital could have done more also reported poorer scores in bodily pain, general health, vitality, social functioning, role-emotional function and mental health ($p<0.05$). Seven percent of these patients reported being mistreated during in-hospital care and expressed a desire for better care and consideration.

Phenomena perceived as mistreatment included poor care, abandonment, and lack of respect, integrity, and consideration. Patients that reported receiving fair or poor information reported lower scores in role-physical function, bodily pain and vitality (p<0.05); these patients experienced greater change in their life situations after injury, and they had higher educational levels; a larger number of these patients underwent surgical procedures; spent fewer days in ICU; fewer received rehabilitation therapy after discharge, and a larger number reported physical suffering and poorer SF-36 scores compared to those who reported having received good information.

6.2 PAPER II

A total of 432 children aged 15 years or younger met the inclusion criteria for this study. (Figure 5)

Trauma registry outcome

Of the initial cases in the trauma registry (n=430) it was found that three children had wrongly been included in the registry and were therefore excluded from this study: one patient was over 15 years of age and two patients were not trauma cases. Three children were declared dead on arrival at the hospital. One of these patients was miscoded as alive and two children were not registered; information on these children was obtained from the Department of Forensic Medicine. Sixty nine percent in the trauma registry had data that were either improperly coded (false-positive or false-negative coding errors) in AIS-90 and ISS scores or had data that should have been abstracted or coded. It was found that 7 percent of the pre-hospital medical records had missing documentation of physiological parameters, such as respiratory rate, systolic BP, and Glasgow Coma Score (GCS) (data not shown).

Pediatric trauma deaths

Six children died of causes related to injuries. Of those four were girls and two boys. Four children were 3 years old and two were 15 years old. Three were pronounced dead on the scene and three on arrival to the hospital. Two of the children were intubated and received cardiopulmonary resuscitation (CPR) en route to the hospital.

Demographic and injury characteristics

Of the 432 children 254 (59%) were boys. The median age at injury was 10 years (range 8 days to 15 yr), IQR 5 to 12 yr). The children were divided into age groups to

represent different stages in childhood: <1 year (n=16), 1 to 3 year (n=64), 4 to 6 year (n=49), 7 to 12 year (n=200), and 13 to 15 year (n=103). In the infant group half of the children were girls, in all other age groups boys dominated, with the largest different in the oldest age group. Most children (95%) sustained blunt trauma. Falls were more common among girls and in younger age groups. Traffic-related events were more common among boys and in older age groups. Eleven infants were injured in falls from baby strollers, baby walkers, changing tables, or baby carriers. Sport-related injuries were more frequent among girls. There was also more assault among girls, predominantly in the infant group. Table 15 shows the distribution of injury mechanism.

Table 15. Distribution of injury mechanisms

Characteristics	n=432 (%)
Traffic related	181 (42%)
Motor vehicle	76 (18%)
Mopeds/Motorcycles/all-terrain vehicles	20 (5%)
Bicycles	50 (12%)
Pedestrians	35 (8%)
Falls	133 (31%)
Assaults	7 (2%)
Sport-related	44 (10%)
Burns	17 (4%)
Other injuries including 5 near-drowning cases	50 (12%)

Injury characteristics

The majority of the children (n=309, 72%) had a MAIS score ≤2; 90 children (21%) had a MAIS score of 3, 28 children had a score of 4 or 5, and five children (1%) had a MAIS score of 6. Fifteen children (4%) had a MAIS of 3 or more in at least two body regions. The AIS score of 4 was most frequently seen in the infant group related to severe head injuries. The injuries were scored in the ISS and NISS scoring systems and no major differences were found between scores in the two systems. (data not shown) The median ISS was 4 (IQR 1−9): 298 (69%) of the children had an ISS ≤8; 134 (31%)

had an ISS ≥9; and 41 (10%) had an ISS ≥16. Table 16 displays injury distribution in the AIS body regions.

Table 16. Injury distribution in the AIS body regions

AIS body regions	
Head	50%
Lower extremity	29%
Spine	25%
Upper extremity	23%
Face	19%
Thorax	15%
Abdomen and pelvic contents	12%
External/skin, burns, other	9%
Neck	2%

Prehospital

Three hundred and eighty three children were transported from the scene of the injury to the hospital by ambulance or ambulance helicopter; of these nearly half had normal vital signs. The majority of the children (n=283, 66%) were cared for by practical nurses/ambulance technicians, 78 (18%) by specialist nurses (mainly anesthetist nurses), and 39 (9%) by anesthesiologists. The mean prehospital dispatch time from the injury scene to hospital was 38 minutes (SD 13.6).

In-hospital care

Almost half of the children (n=192, 45%) were treated at the emergency department and discharged home within 24 hours. The children who stayed more than a day in the hospital were treated an average of 2 days (IQR 1-3), of these 46 (19%) were treated in a pediatric intensive care unit (PICU). The mean age for children cared for in the PICU was 8 years (SD 4). The median ISS was 9 (IQR 6–18), 22% had an ISS of 16–24, and 15% had an ISS of > 24. Head injuries were most frequent (78%), followed by extremity injuries (49%) and injuries to the thorax (23%).

6.3 PAPER III

Two hundred and four (68%) children from the cohort in Paper II were successfully followed up 6 years after injury. The non-responders had less often been cared for in the PICU (p <0.001), had shorter stay in acute care hospital (p <0.001), and lower ISS scores (p <0.001) compared to the responders.

Demographic characteristics

The median age was 13 years (IQR 10−16 years) and 114 (56%) of the children were males. The children were divided in age groups representing the different stages in childhood after the different PedsQL versions: 6 to 7 yr (n=30); 8 to 12 yr (n=51; 13-15 (n=51); and 16 to 18 yr (n=72). The group representing the PedsQL version for adolescent 13 to 18 was split in two groups. The median length of stay in the pediatric hospital was 2 days (IQR 1−3 days) and 50 children (25%) were cared for in the PICU. Of those, the majority (n=41) stayed one day.

Injury characteristics

Traffic-related events (40%) and falls (40%) were the most common injury mechanisms. Head injuries (56%) and extremities (48%) were the most frequently injured AIS body regions. Head injury severity was scored with the AIS system: 62 children had moderate injuries (AIS 2); 17 children had serious injuries (AIS 3); and 9 children had severe to critical injuries (AIS 4 to 5). The AIS scores for extremity injuries were moderate (AIS 2) in 16 children and serious (AIS 3) in 25 children. The median ISS score was 5 (IQR 2−5); ≤8 (n=129, 63%), 9−15 (n=56, 28%), and ≥16 (n=19, 9%).

Reliability of the PedsQL 4.0

The analysis of internal consistency revealed acceptable Cronbach's α values for comparisons between groups (α > 0.70) in three of the four subscales and the two summary scales. [149,150] The PedsQL total health score approached an α value of 0.90, which is recommended for individual patient analysis. [149,150] In the youngest age group none of the subscales reached the recommended α of 0.70, the α for the psychosocial health scores and total health scores exceeded 0.70. The α for the subscale emotional functioning was <0.70 in all age groups except the age group 13 to 15 years and the α for the subscale school functioning was <0.70 in the two youngest age groups

(6−7 yr, 8−12 yr). There was a tendency towards a slight increase in internal consistency reliability coefficients with age across the PedsQL 4.0 scales and summary scores. (Table 17)

HRQL 6 years after injury

Children rated their health-related quality of life in parity with or better than norm data from healthy populations in Sweden [151] as well as Norway [152], the U.K. [153], and the U.S. [141] (Table 18) Of the demographic variables, age demonstrated a relationship to PedsQL scores. The youngest age group, 6 to 7 years, had significantly lower scores than the older age groups in the subscales emotional functioning (16 to 18 yr age group $p<0.001$), social functioning (8 to 12 yr age group $p<0.001$; 13 to15 yr $p<0.001$; 16 to 18 yr $p=0.001$), and in the summary scores psychosocial health (8 to 12 yr $p<0.001$; 13to 15 yr $p=0.004$; 16 to 18 yr $p<0.001$), and total health (8 to 12 yr $p=0.001$; 13 to 15 yr $p<0.028$; 16 to 18 $p=0.001$). Children with extremity injuries (AIS 2−5, n=41) showed lower scores in the subscale school functioning compared to children with head injuries (AIS 2−5, n=88), ($p=0.048$). No statistically significant differences were found between sexes, injury mechanism groups, ISS severity groups, head injury groups, or length of stay in acute care hospital (data not shown).

Table 17. Median (IQR) PedsQL scores (0-100) and Cronbach´s Alpha by age groups

PedsQL scores	Overall	α (n=204)	6−7 yr	α (n=30)	8−12 yr	α (n=51)	13−15 yr	α (n=51)	16−18 yr	α (n=72)
Total Scale Score	91.3 (83.7−95.6)	0.87 (188)	84.4 (73.3−88.0)	0.81 (27)	92.3 (88.0−94.5)	0.91 (49)	91.3 (81.5−95.6)	0.84 (49)	93.4 (83.1−99.4)	0.89 (63)
Psychosocial Health	90.0 (80−96.6)	0.83 (190)	80.0 (66.6−84.1)	0.71 (28)	90.0 (85.0−93.3)	0.87 (49)	90.0 (80.0−96.6)	0.79 (50)	93.3 (80.0−100)	0.83 (63)
Physical Health	93.7 (87.5−100)	0.77 (202)	93.7 (87.5−93.7)	0.63 (29)	96.8 (93.7−100)	0.79 (51)	93.7 (87.5−100)	0.68 (50)	100 (87.5−100)	0.85 (72)
Emotional functioning	90.0 (75.0−100)	0.64 (198)	80.0 (60.0−90.0)	0.44 (28)	90.0 (75.0−95.0)	0.65 (49)	90.0 (75.0−95.0)	0.73 (51)	92.5 (80.0−100)	0.56 (70)
Social functioning	100 (90.0−100)	0.80 (201)	85.0 (70.0−90.0)	0.62 (30)	100 (95.0−100)	0.86 (51)	100 (90.0−100)	0.78 (51)	100 (95.0−100)	0.67 (69)
School functioning	90.0 (70.0−95.0)	0.77 (197)	87.5 (70.0−90.0)	0.51 (30)	85.0 (70.0−90.0)	0.59 (51)	90.0 (73.7−100)	0.79 (50)	90.0 (65.0−100)	0.85 (66)

Abbreviations: PedsQL, Pediatric Quality of Life Inventory
Total Scale Score, significant differences between 6−7 yr and 8−12 yr (p <0.001); 6−7 yr and 13−15 yr (p <0.028); 6−7 yr and 15−18 yr (p <0.001).

Table 18. Comparison of scale statistics for responders in study III with samples of healthy children from Sweden, Norway, U.K. and the U.S.

PedsQL	Present study n=204, age 6-18 yr mean (SD) median (IQR)	Sweden [151] n=453, age 8-14 yr mean (SD)	Norway [152] n=425 age 13-15 yr mean (SD)	U.K. [153] n=1399 age 8-18 yr mean (SD)	U.S. [141] n=963 age 5-18 yr mean (SD)
Total Health	88.06 (10.75) 91.30 (83.79−95.65)	86.31 (11.03)	85.29 (11.11)	82.25 (13.09)	79.62 (15.26)
Psychosocial Health	86.65 (11.82) 90.00 (80.00−96.66)	86.66 (11.10)	82.16 (12.50)	80.50 (14.06)	79.37 (15.70)
Physical Health	90.72 (12.52) 90.72 (87.50−100)	85.60 (13.47)	91.12 (10.35)	86.08 (14.06)	80.19 (19.30)
Emotional functioning	85.17 (14.28) 90.00 (75.00−100)	83.73 (14.57)	77.15 (17.32)	76.99 (18.43)	78.10 (20.66)
Social functioning	92.04 (14.39) 100 (90.00−100)	91.63 (12.05)	88.12 (13.11)	86.85 (16.86)	84.09 (18.50)
School functioning	82.44 (17.68) 90.00 (70.00−100)	84.62 (13.50)	78.02 (15.47)	77.29 (16.92)	75.87 (19.71)

Abbreviations: PedsQL, Pediatric Quality of Life Inventory

6.4 PAPER IV

In Paper IV, 177 (58%) children and their parent (dyads) participated. The median age of the children was 13 years (IQR 10 to16 yr), ISS was 5 (IQR 2−9) and 96 (54%) were males. The majority of the parents who participated in the study were females (77%), Swedish-born (79%) and half had university degrees. Parents reported that 33% of the children had persistent problems after the injury, 17% had recurrent injuries requiring admission to hospital, 9% had received help from a counselor, 45% had received financial compensation, and 35% wanted better follow-up after discharge.

Agreement between parent proxy and child self-report HRQL

The analysis of internal consistency for PedsQL 4.0 for child self-report and parent proxy report exceeded the minimum reliability standard of a $\alpha > 0.70$ in all scales except the scale emotional functioning in the child self-report (α 0.60). [149,150] No statistically significant differences were found between children's self-report and

parent's proxy report in any of the PedsQL 4.0 scales or summary scales. The intra-correlation (ICC) estimates of agreement between parent proxy reports and children's self-reports were excellent (≥0.80) with the exception of the scale emotional functioning where the level was fair (0.53).

Hierarchical multiple regression

Parents' SF-36 mental health (MH) scores (median 88.0, IQR 68.0–92.9) seemed concurrent with norms for the general Swedish population. [120] Two sets of hierarchical multiple regression analyses were performed to investigate whether the parent's MH contributed to the child self-report and parent proxy report of HRQL. Seven independent variables, in fixed order of entry in three steps, were used as predictors in the two sets of models. Adding parental MH in the third and final step caused a statistically significant R^2-change for all PedsQL scales and summary scales with the exception of the child's self-reported scale emotional functioning.

7 DISCUSSION

The overall aim of the thesis was to investigate health-related quality of life and long-term outcome after injuries in different age groups and to identify factors associated with outcome. The main findings to be discussed are the: (1) Five years after injury adult major trauma patients report poor HRQL compared to a healthy population reference; (2) Children´s injury characteristics and overtriage; (3) Six years after injury children report HRQL in parity with or better than healthy populations; (4) Children´s and their parents´ reports on child´s HRQL were in agreement; (6) Parent´s mental health status has a possible impact on children´s HRQL (7) The Swedish version of PedsQL 4.0 (self-report) needs further evaluations.

7.1 ADULT TRAUMA

The adult patients reported poor HRQL 5 years after injury compared to an age and gender matched reference group representing healthy adults in Sweden. The patients scored significantly lower on all eight SF-36 health dimensions: decreased physical and social functioning, increased bodily pain, low vitality, low mental and general health status, and physical and emotional problems that affected quality of life. The result is concurrent with the few other long-term outcome studies carried out >2 years after injury in Europe, the United Kingdom, and Canada. [119-125] A few studies come from Scandinavia: Ringdal et al. [154] found in a Swedish longitudinal study (n=153, ISS 10.8 [SD 7.5]) that poor HRQL remained after 4.5 to 5.5 years in trauma patients after being cared for in an intensive care unit (ICU). Factors associated with poor HRQL was delusional memories (DM) related to the ICU care and pre-existing disease prior to injury; Orwelius et al. [155] in a Swedish longitudinal study (n=108, ISS 18.8 [SD 190.3]) found poor HRQL after 24 months compared to a healthy reference population. The predictor of poor HRQL was pre-existing diseases; Ulvik et al. [156] in a follow-up study (n=210, ISS 25 [4−54]) in Norway found that 74% of the patients had poor HRQL after 2−7 years. Soberg et al.[157] in a study from Norway found poor HRQL in patients 5 year after multiple trauma (n=105, mean ISS 34.6 [SD12.6]) compared to a healthy reference population. Poor HRQLwas associated with personal and injury related factors and functions in a bio-psychosocial perspective; and Overgaard et al. [158] in a study from Denmark found poor HRQL in a sample of 153 trauma patients (follow-up 6 to 9 years) that used normative data for comparison; Table

19 displays an overview of scale statistics for SF-36 and responders from three studies displaying scale data in their long-term follow-up studies of adult trauma patients, study I (Paper I), Sweden [154] and Denmark [158].

Table 19. Overview of scale statistics for SF-36 and responders from long-term follow-up studies of adult trauma patients from Sweden and Denmark.

SF-36 scales	**Paper I - Sweden** n=205 Follow-up 5 yr mean (SD)	**Sweden [154]** n=153 Follow-up 4.5-5.5 yr mean (SD)	**Denmark [158]** n=148 Follow-up 6 to 9 yr mean (SD)
PF	75.3 (27.1)	71.9 (30.1)	61.65 (26.22)
RP	56.9 (41.8)	57.3 (43.7)	75.86 (25.33)
BP	62.7 (31.2)	59.7 (29.4)	58.65 (23.69)
GH	65.7 (31.2)	65.7 (24.7)	73.82 (20.34)
VT	57.2 (25.2)	55.2 (26.2)	61.86 (43.00)
SF	77.0 (27.8)	72.5 (29.4)	71.91 (38.53)
RE	67.0 (41.4)	68.1 (39.2)	81.63 23.01)
MH	69.9 (23.0)	71.2 (22.5)	64.57 (28.89)

Abbreviations: PF, physical functioning; RP, role functioning physical; BP, bodily pain; GH, general health; VT, vitality; SF, social functioning; RE, role functioning emotional; MH, mental health.

Poor outcome in our study was associated with the length of hospital stay, intensive care days, surgical procedures, in-hospital major complications, age, recurrent injury, and inadequate information. A large number of the patients reported physical (68%) and psychological (41%) problems. Similar findings have been reported in numerous short-term studies and the few long-term cross-sectional and longitudinal studies after injury that have been performed using a variety of measurement tools.[159−173] In our study 68 percent of the patients had returned to full-time work and 10 percent to part-time work which was associated with overall better SF-36 scores except in mental health and emotional role functioning. This is in parity with other research findings. [154−158] In a recent 12 month follow-up study by Tøien et al. [174] of patients with a broad range of injuries (n=188, aged 18−65 years) 70 percent returned to the same level of work or education as prior to the injury event. Predictors of return to work at 12

months were: absence of head injury, good physical function, low depression score, and an optimistic life orientation.

The aim of trauma care is the reintegration of patients back into their families and communities. Returning to work, recreation, and the ability to perform activities of everyday life are crucial outcome after trauma. One long-term study from the U.S. reports an interesting finding: older patients were less dissatisfied than younger ones in their quality of life after trauma. This was interpreted by the authors as possibly related to different expectations of health, comparisons that these patients made with peer groups, and that older patients often have learned to cope and adapt. [175] In a study by Ristner et al. [176] on patients with orthopedic injuries factors associated with worse HRQL were a low sense of coherence, having less control of their lives, and showing signs of depression. Further studies are needed in this area to find factors that improve outcome.

Rehabilitation is an important link in the care change for patients with significant disabilities. In our study 36 percent received rehabilitation, but the majority of the trauma patients were discharged home. The patients expressed a need for improved follow-up by trauma specialist teams including social workers, physical therapists and psychologist. [32]

7.2 PEDIATRIC TRAUMA

Overtriage

Many children had minor injuries and were transported to the hospital with normal vital signs and discharged home from the emergency department within 24 hours. We presumed that these were cases in which patients were transported to a trauma team even though they did not require this high level of care. These cases appear to be an over utilization of the trauma team activation criteria in use at the time. [177] In this study we could not exclude the possibility of cases of underutilization (cases that required a high level of trauma care at a trauma center but did not receive it) since the study was not designed to investigate prehospital undertriage rate. Substantial improvement was shown to be needed in current trauma team activation critera to avoid overutilization of the trauma team.

Demograhic and injury characteristics

The mortality was low (1%). None of the deaths were associated with traffic-related events. Injuries were most frequent in children aged 10 to 15 years and traffic-related events were the main cause of morbidity, primarily in older children, followed by falls, predominantly in younger children. More than 50% of the children suffered head injuries. Several studies report that the highest incidence of traumatic brain injury (TBI) requiring hospital emergency care is found in young children, and that, in all age groups, falls are the most common injury mechanism, causing head injuries with a significant risk of long-term neurological damage. [1,2,24,25] There is a need of continuous vigorous injury prevention programs to prevent falls resulting in head injuries in young children.

Health-related quality of life in children

To our knowledge this is the first study in Sweden that has explored children´s perspective on their long-term HRQL after minor to severe trauma. Six years after pediatric trauma 204 children (68%) were successfully followed up after hospitalization at a regional trauma center. The children rated their HRQL in parity or better than other population-based studies in Sweden, Norway, U.S., and U.K. [141,151−153] Our findings are consistent with other long-term outcome studies that have used generic instruments to measure self-reported HRQL in children four or more years after trauma, which suggests that the majority of children recover after mild to severe trauma to regain good health and well-being. [178-180]

Younger age was the only demographic characteristics that we found to be associated with poorer HRQL. The youngest age group, 6 to7 years had significantly lower total PedsQL scores compared with the older age groups. This age group also had the highest prevalence of head injuries caused by falls. In a Swedish study by Sand et al. [181] of children with type 1 diabetes (follow-up age 5–18, n=108) the youngest age group, 5 to7 years had significantly lower PedsQL 4.0 scores in three of four scales (exception school functioning) and total score scales compared to the older age groups. The PedsQL 4.0 across ages 5 to 16 years has been psychometrically tested and the differences in scores between age groups has been found attributable to scale coarseness of the 3-point Likert response scale used in the form for ages 5–7 years and to lower item reliability among younger respondents. [182] In our study we found that the youngest age group had the lowest coefficient alpha reliability coefficients in

PedsQL 4.0 scales and summary scores compared to older children and adolescence. Although it could be that TBI and injury mechanism are factors that impact the HRQL in the younger age group, it seems more likely that the findings of lower HRQL could be related to the previous research findings in scale coarseness and item reliability.

Children´s self-reports and parent´s proxy reports and parents´ mental health

In the fourth study the PedsQL 4.0 instrument was used to determine the relationship between children´s and their parent proxy ratings of child´s HRQL six years after an injury to the child. The SF-36 health survey instrument was also employed to explore the parents' mental health status. Hierarchical multiple regression analyses were used to investigate the contribution of the parent's mental health status to both the child's and the parent's rating of the child's HRQL. To our knowledge this is the first study that has investigated the contribution of parent's mental health status on child-parent reports of children's HRQL after injury. The main finding of the present study is that a low score for parent's mental health status was the strongest predictor of poorer children's HRQL in parent proxy reports. It was also the strongest predictor of poorer HRQL as reported by children themselves.

In our study we found no discrepancies between the parents' proxy report and the children's self-report of the child's HRQL. The only PedsQL scale that showed a tendency to significant difference in ratings was emotional functioning, where parents tended to rate their children's function worse than the children themselves. The level of agreement between proxy-child HRQL report was strong in all scales with the exception of emotional functioning which was also the scale with the lowest internal consistency. This finding is in parity with a study by Gabbe et al. [183] that found in a longitudinal follow-up study 1, 6, and 12 months after child injury that agreement improved over time.

In our multiple regression models older children were found to report higher HRQL in emotional and social functioning. Conversely, parents of older children reported lower scores in emotional functioning, psychosocial health and physical health. These findings are somewhat in line with several previous investigations of child and parent reports on HRQL. For example, Achenbach et al.[97] found that parents are more adept at assessing a child's externalizing problems (e.g. aggression

and conduct) compared to internalizing problems (e.g. anxiety and depression). Eiser and Morse [99] have suggested that this could be applied to parents being more prone to rate the child's HRQL on the basis of visible domains such as physical functioning than on less visible domains such as emotional or social functioning. We also found that parents of female children reported higher scores in psychosocial health.

Children with higher injury severity scores (ISS) reported better social functioning in their HRQL. To our knowledge this finding has not been described earlier. In a Swedish qualitative study of adolescents with spinal cord injury (SCI), Augutis et al.[187], parents and peers were found to have formed an important support network around the injured child. Parents acted as advocates and containers for sadness, frustration and anger, and friends acted as promoters of activities and identity development. It was perceived that health care providers did not make sufficient use of this network. It is possible that children with more serious injuries receive better support from their social network. Further studies are needed in this area to investigate the impact of social support from family, friends and others regarding help to cope and adjust after different injuries.

Mothers as proxy reporters dominate most studies. Vance et al.[188] in a study of children with cancer reported that children who self-reported poorer HRQL had mothers who were more depressed. In the present study 77 percent of the parent responders was females, and if the proxy reporter was female, this predicted an increase in both child and parent reports of social functioning and in parent reports of physical health, but the strongest predictor of parents' ratings of their children's HRQL was the parents' mental health status.

7.3 METHODOLOGICAL CONSIDERATION

The major strengths of the thesis is that the subjects derives from complete cohorts from well-defined populations and geographical area (Stockholm region) and the long-time follow-up as recovery trajectory continues 5 to 10 years after injury, indicating that follow-up investigations should go beyond 5 years. [178,179,180]

Study I

The design in the first study (I) did not allow to control for pre-injury HRQL and other

confounding variables such as other health problems, employment status, and social support. Furthermore, we did not have access to data to control for variation in personality characteristics, coping, family dynamics and resources. Seventeen percent of the cohort was lost to follow-up. The responders were representative of the whole population except in term of gender, as the respondent group consisted of 74 percent men compared with 99 percent in the non-responders group.

Trauma registries

In extracting data from the pediatric trauma registry it was found that data was missing that should have been abstracted or coded, or that data had been improperly coded in AIS-90 scores and ISS. There were also errors in the prehospital medical records, were vital signs were not documented in patients medical records. Several other studies have reported data errors in trauma registries. A study from the U.S. reported substantial error rates in 9 percent and admission GCS scores 55percent. [184] The American College of Surgeons National Trauma Bank [185] was reported to have about 25 % of the records excluded from statistical analyses due to errors. Falk et al.[186] in a study from Stockholm based on medical records, reported that 65percent of the children´s medical records were lacking data on admission GCS scores and that the physician´s discharge note. These findings indicate that data validation is essential for trauma registries in order to improve registry data quality. The accuracy of medical records is equally essential as data are abstracted and collected from medical documentation to trauma registries and used for research.

Study III and IV

The strength in the children´s studies (Paper II, III, IV) is that we used the children themselves as the source when measuring HRQL; self-report are considered the gold standard for obtaining information about subjective phenomena such as HRQL. The Questionnaire were mailed and answered in the children´s home which could have affected the children´s answer compared to if the questions had been answered in a clinic separated from their parents. There is evidence that children as young as eight years are able to understand the questions and fill in the answers in a reliable way. [93,94]. The younger children (aged 6 to 7 years) were helped by their parents to fill in the PedsQL questionnaire. Therefore, we cannot rule out that the younger children´s report could have been affected by the method of data collection.

Another strength in the investigation of level of agreement between children´s self-report and parent proxy report were we used intra-class correlation to measure the proportion of overall variability accounted for by variability among individuals. [99] To better interpreter the results from the ICC we also determined the reliability of children´s and proxy ratings separately.

The Cronbach´s alpha coefficient were below the suggested level (α 0.70) required for group comparison in the scale emotional functioning for the cohort and below suggested level in the following age group scales: physical health, emotional functioning, social functioning and school function in the youngest age group 6 to 7 years; emotional functioning and school functioning in age group 8 to 12 years; physical health in the age group 13 to 15 years; and emotional functioning and social functioning in age group 16 to 18 years. We recommended further analysis of the instrument´s psychometric properties in children with different injuries and injury causes.

The cross-sectional design in the studies did not allow to control for pre-injury HRQL and other confounding variables such as recurrent injuries or other health problems. Furthermore, we did not have access to data to control for variation in personality characteristics, family dynamics and resources, or resources available in the community. Second, 32 percent of the cohort was lost to follow-up in study III and 45 percent in study IV which potentially limits the generalizability of the findings. The responders and non-responders were comparable in regard to demographic characteristics, but non-responders had less severe injuries and were more often discharge home from the emergency department compared to the responders. These factors may have influenced the recall of the injury event and the interest in participating. A reminder to non-responders would probably have helped achieve a higher response rate, but such procedures were not permitted by the ethical review board.

8 CONCLUSIONS

Traumatic injuries change the lives of otherwise healthy people. A large proportion of adult major trauma patients sustain long-term physical and emotional disabilities, which limits activities and restrict participation in social life impacting on community reintegration and quality of life.

- Adult major trauma patients have significant disabilities 5 years after injury. The majority of the patients expressed a need for improved follow-up by trauma specialist team.

- Children´s HRQL 6 years after trauma seems to be in parity or better than healthy peers.

- Additional research is also needed to monitor HRQL prospectively over time. Future investigations should also aim to identify factors that facilitate or delay long-term adaption for children with injuries and of the need for health care interventions and community support.

- Parent´s mental health status can possibly impact on children's HRQL long time after injury.

- Many pediatric trauma patients had minor injuries. Trauma team activation criteria should be improved to avoid overutilization.

- The quality and completeness of data in the trauma registry must be enhanced.

- Further studies are recommended to evaluate the PedsQL 4.0 versions for self-report in the pediatric trauma population and to explore the comparability of data derived from different age-adapted versions of the PedsQL 4.0.

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