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Original Article

Pediatric spinal cord injury in Sweden: incidence, etiology and outcome

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Study design: Retrospective descriptive study.
Objectives: To assess incidence, causes and early outcome of traumatic spinal cord injury (SCI) among children in Sweden, thereby identifying high-risk groups and situations as a basis for preventative measures and improved care.
Methods: Data from population registers, County Habilitation Centers as well as from informal sources were used to estimate the incidence of SCI in Sweden during the years 1985–1996 among children aged 0–15 years. Contacts with the treating hospitals, reviews of medical records and/or personal interviews were used to verify primary data. In total, 92 children were thus identified.
Results: The incidence was found to be 4.6/million children/year (95% CI 3.6–5.5). When excluding prehospital fatalities, the incidence was 2.4 (95% CI 1.8–3.1). The main cause of injury among fatalities was traffic accidents. Associated injuries occurred in 41% of the children. Among survivors (10–15 years), sports-related injuries (43%) were as common a cause as traffic accidents (39%). The survivors were treated in 18 different hospitals.
Conclusion: Pediatric SCI in Sweden is rare, presumably because of effective primary prevention. Preventative measures should be further differentiated for each age group of children in accordance with their differing risk profiles. In contrast to the effective preventative measures that have been implemented in Sweden, care of these patients is still too fractionated and decentralized for sufficient specialization to emerge.
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Keywords: pediatric; spinal cord injury; traumatic; epidemiology; care; prevention

Introduction

Since spinal cord injury (SCI) predominately occurs in younger adults, it is not surprising that most research has focused on such populations, while other demographic groups have received less attention.[1]

During the last decade, especially in the USA, childhood SCI have received increasing coverage in the literature. This subgroup has special needs because of the ongoing physical, intellectual, psychological and social development that characterizes the child and teenager.[2,3]

Knowledge of the incidence and etiology of pediatric SCI is important in order to identify risk groups, improve prevention and for planning of care and rehabilitation.[4]

Specifically, the development of the Model Spinal Cord Injury Programs, in addition to systematic trauma registration in the National SCI Database, have contributed to increased knowledge of pediatric SCI.[5]

However, this database is not population based and does not include persons treated outside the Model Systems.[5] Furthermore, children with SCI, especially the youngest, typically receive treatment at children's hospitals rather than at spinal units (personal communication, 24 January 2001).[6]

Incidence estimates of pediatric SCI are often uncertain because of differing reporting methods, data collection systems and classification patterns.[7] Hospital-based clinical series are biased by referral patterns and obviously only include patients admitted to a hospital. SCI patients who die at the scene or are dead on arrival are usually not reported. Clinical series rarely include detailed data from post mortems, the coroner- and birth-related SCI. Thus, incidence estimates often appear to be too low.[7] Furthermore, it is difficult to make analyses to identify statistically significant patterns because of small study groups.[1]

In Sweden, the estimated total incidence of SCI in all age groups is 15/million/year.[8] This is a low incidence as compared to the USA, where incidence rates among adults range from 28 to 54.8/million/year.[9]

Since 1994, a collaboration group representing all university hospitals in Sweden have developed a matrix for documentation and quality assessment of SCI care.[8]

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In 1998, 106 cases of traumatic SCI were thus documented, equaling an incidence of traumatic SCI of 12/million/year. The group also reported that about 20% of all cases were in fact treated outside university hospitals, thus making the documented incidence too low. Four children under the age of 16 years with SCI were reported in 1998 and one child in 1999 (personal communication, February 1999).[10]

This was the only information to be found about pediatric SCI in Sweden.

The objectives for this study were to assess the incidence, etiology and early outcome of pediatric SCI in Sweden during 1985–1996 in order to identify high-risk groups and situations as a knowledge basis for preventative measures and improved care.

Methods

The incidence estimates of pediatric SCI were calculated on data from population registers and County Habilitation centers for the years 1 January 1985 to 31 December 1996.[11]

The total population of Swedish children below 16 years of age during the 12 year period was 20 171 823 children, with an average population of 1 680 000 children/year (max/min: 1 767 000/1 613 000).[12]

Instead of using the total population to estimate the incidence for the total period, it is better to use the information from each year. The incidence for every year can be treated as a random variable over the 12-year period. The expected value and the confidence interval were then based on the incidence from each year.

The pediatric SCI population was assessed according to the following variables: gender, age at injury, cause of injury[13,14] and cause of death.[15,16] The level of injury and functional outcome according to ASIA/IMSOP standards[17] was documented among the survivors by personal contact and medical records between 1999 and 2002.

Definition
In this study, SCI was operationally defined as traumatic lesions of the cauda equina or the spinal cord proper leading to neurological impairment. Lesions with complete sensorimotor restitution were also included, as defined by ASIA Impairment Scale grade E,[17] if there was documented evidence of symptoms and signs of SCI with a duration of at least 2 weeks postinjury.[18]

Sources Three types of sources were used:

(1) Nationwide population-based registers admitted by the Swedish National Board of Health and Welfare, that is,
- Hospital Discharge Register (HDR),
- Cause of Death Register (CDR),
- Medical Birth and Malformation Register (MBR).

(2) Regional or local registers, that is,
- County Habilitation Centers in Sweden.

(3) Media/informal sources, that is,
- Notification in patient-orientated journals and informal contacts with staff working with SCI patients.

Inclusion criteria and exclusion criteria (Table 1)
The procedure of finding the children and the verification of the diagnosis is fully described in our paper Pediatric Spinal Cord Injury in Sweden. How to identify a cohort of rare events.[11]

Mortality Mortality directly related to the SCI was operationally defined as all deaths that occurred within 1 year postinjury.
Subjects that died later than 1 year postinjury were allocated to the survivor group. (In the current study, this occurred in two children who died 3 and 9 years postinjury, respectively.)

Data verification

- For children dead prior to hospital admission ($N=43$), data from the Cause of Death Register[15,16] were used as verification. Autopsy protocols were not reviewed.
- For children dead ($N=12$) within 1 year postinjury, the head of the department at the treating hospital verified the diagnosis by reviewing the medical records. The information originated from the Hospital Discharge Register[19] and the Cause of Death Register.[15,16]

Table 1 The inclusion and exclusion criteria and the requested classification codes from the Swedish National Board of Health and Welfare

Inclusion criteria	*Exclusion criteria*		*ICD codes*[a]
The injury occurred in Sweden between the years 1 January 1985 and 31 December 1996	Children with isolated root lesions or no injury to the intraspinal neural elements	806	Fractures to the spine with a spinal cord injury
	Children with congenital malformations of the spinal cord	952	A spinal cord injury without fracture of the spine
At the time of the injury the child was between 0 and 15 years of age	Children with acquired SCI of nontraumatic etiology	344	Other paralyzes

[a]The Swedish version of the Ninth edition of the International Classification of Disease (rev. ICD 9 used in the period 1987–1995)[13] and their equivalents in the eighth edition of this classification[14]

- For survivors ($N=37$), retrieved data were checked against the medical records, by requesting such verification from a senior staff physician at the treating hospital. Subjects were then contacted by telephone for further verification of diagnosis, and remaining putative true cases were then subsequently interviewed and examined for final verification and additional data retrieval. The information originated from the Hospital Discharge Register ($N=34$),[19] Habilitation centers ($N=2$) and informal contacts ($N=1$).

Etiological classification
Through the interviews, 10 cases classified as fall accidents, and two cases originally classified as traffic accidents were reclassified as sports injuries.

Level of injury
The level of injury was assessed through the registered ICD codes, medical record reviews, interviews and, in some cases, clinical examination.

Functional outcome according to ASIA/MSOP standards
Most assessments were made between the years 1999 and 2002 by personal contact with the survivors. For three children, data from medical records were used to assess their functional outcome.

Care provider
The survivors were treated at county hospitals, university clinics and/or university clinics with specialized SCI units. The sources utilized were data from the Hospital Discharge Register, medical records and the patients. If a child was treated in two or more hospitals, the hospital where the child had been treated the longest period was chosen.

Ethical considerations The Ethics Committee at Umeå University agreed to the project (permit no. Um dnr 96-289). Permission was also received from the Swedish Data Inspection Board.

Results

Incidence for ages 0–15 years
The estimated incidence was found to be 4.6/million children/year (95% CI 3.6–5.5) for children aged 0–15 years. If prehospital fatalities were excluded, the incidence was 2.4 (95% CI 1.8–3.1).

In all, 21 children (23%) of the total group ($N=92$) were aged 15 years at the time of the injury.

Out of the survivors ($N=37$), 12 children were 15 years of age (32%). Out of the children dead prior of hospital admission ($N=43$), seven children were aged 15 years (16%). Two children out of the group who died within 1 year postinjury were aged 15 years.

Mortality
In all, 55 children (60%) of the total group ($N=92$) died within 1 year after the SCI.

Deaths prior to hospital admission In all, 42 of the 43 children died at the scene of the accident or on the way to hospital were injured in traffic accidents. As main diagnosis three had SCIWORA (ICD 952), and the others were registered as SCI (806.00). Average age at injury was 9 years (SD = 4; range 2–15 years), 19 were girls and 23 were boys (Figure 1 and 3).

The retrieved register information gave no information about the level of injury.

Deaths within 1 year postinjury In total, 12 children died during initial hospitalization; all within 3 months postinjury. All, but one child, were injured by traffic (Figure 1). The average age at injury for this group was 7.3 years (SD = 5.3; range 0–15 years), 10 girls and two boys. All had cervical injuries except one child that suffered a thoracic injury, with an additional brain injury (Figure 1 and 3).

The survivors
Children surviving at least the first year postinjury ($N=37$) had an average age at injury of 11.8 years (SD 4.4; range 2–15 years) (Figure 1).

Associated injuries
Of the total group ($N=92$), 38 children (41%) had associated injuries, for example, multiple fractures and/or thoracic injuries and/or abdominal injuries and/or head injuries (Table 2). All head injuries but one were caused by traffic.

Causes of injury
Among fatalities, traffic accidents dominated. In the group of survivors (10–15 years), sports injuries were as common as traffic accident (Figure 1).

Traffic accidents None of the bicyclists survived. The mean age was 9.2 years (SD 3.6; range 4–15). The pedestrians had a mean age of 8.9 years (SD 2.8; range 5–14) (Figure 2; Table 3).

Sports-related injuries The second leading cause of injury was sports-related injuries. All cases were aged between 13 and 15 years. The causes were: motor-cross/bicycle (competition) $N=2$, horseback riding $N=3$, icehockey $N=2$, diving $N=3$ and skiing $N=2$.

Four out of 12 children were females, injured during horseback riding ($N=3$) and skiing ($N=1$).

Falls Out of six injures among the survivors, four children were injured by falling from heights. Only one girl was injured in a falling accident (Figure 1).

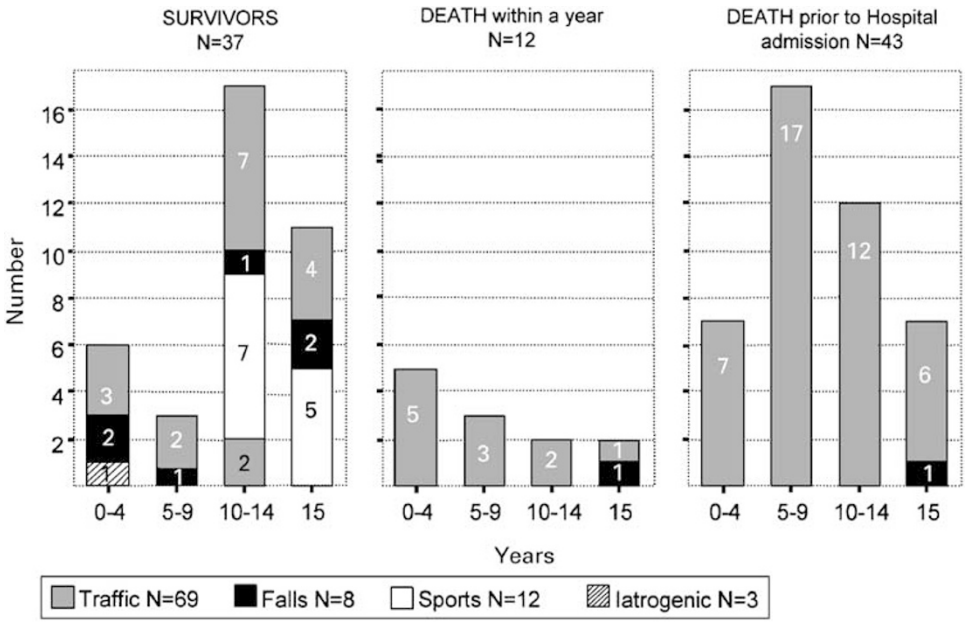

Figure 1 Causes of injury by age group and outcome, $N = 92$

Table 2 Children with SCI registered with additional injuries from HDR, CDR and the habilitation, $N = 92$

		Associated injuries	
Outcome	*Survivors, N = 37*	*Death within a year, N = 12*	*Death prior to hospital admission, N = 43*
Associated injuries	11	9	18
Head injuries	2/11	6/9	16/18

Iatrogenic injury Three children, two girls and one boy, sustained an SCI at surgery for spinal deformity (Figure 1).

Sciwora
Of the total group ($N = 92$), five children were registered as SCIWORA. Among the fully verified survivors, three children had sustained a SCIWORA (aged 3, 4, 9 years).

Gender
There were 47 male and 45 female subjects. The distribution of male subjects increased by age among the survivors (Figure 3).

Types of lesions
Cervical injuries among the survivors were as common as thoracic lesions ($N = 16$). The average age for children with cervical lesions was 12.2 years (SD 4.2; range 3–15 years), for children with thoracic lesions 11.1 years (SD 4.8; range 2–15 years) and for children with lumbar lesions 13.2 years (SD 1.3; range 11–15 years) (Figure 4).

Almost half ($N = 17$) of the group of survivors had a complete SCI (ASIA grade A) (Figure 4, Table 4).

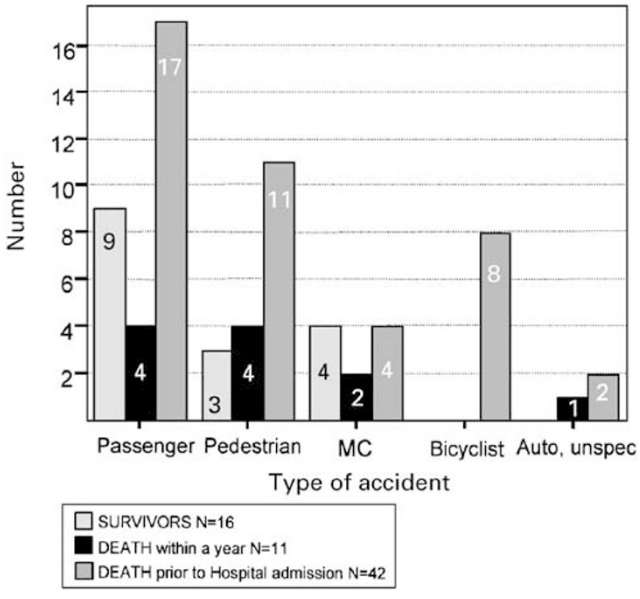

Figure 2 Distribution of traffic accidents by outcome, $N = 69$

Care provider
The survivors ($N = 37$) were treated in 18 different hospitals.

Table 3 Distribution of traffic accidents by age groups, $N = 69$

	Age groups (years)				
Type of traffic accident	*0–4*	*5–9*	*10–14*	*15*	*Total*
Passengers	13	6	8	3	30
Pedestrians	0	11	7	0	18
Bicycle	1	4	2	1	8
Moped/MC	0	0	3	7	10
Unspecified	1	1	0	1	3
Total	15	22	20	12	69

The average age of children treated at an SCI unit was 14 years (SD 1.3; range 9–15 years), whereas children treated at another ward at a university hospital or at a county hospital had a lower average age, 8 and 8.9 years, respectively (Table 5).

Discussion

Pediatric SCI is rare in Sweden; although this is in accordance with clinical experience, the actual incidence has not been previously established. The incidence is lower than those reported from the USA and New Zealand, except from the article by Woodruff, 1994[20–32] (Table 6).

However, there are differences in case definition, case ascertainment and upper age limit making comparisons of incidence and external causes problematic.[28,30]

The New Zealand study by Dixon[31] has been criticized while the data were based on ICD codes and was not further verified, possibly leading to inclusion of false positives.[32]

Inclusion of patients aged 15 and older will inflate the incidence rate for the pediatric group, since the incidence peak for all SCIs is 15–24 years.[24,27]

The incidence found in this study may be underestimated because of omission of the SCI diagnosis in cases of severe fatal multitrauma, as discussed by Dickman.[7]

The mortality was high (60%). Kewalramani also found high mortality (58%) because of the commonly severe, multiple injuries sustained in traffic accidents.[30] Orenstein *et al*[33] reported that the high mortality in younger patients was not only caused exclusively by the preponderance of more rostral cervical injury levels, but also, and more importantly, because of concomitant head and multiple trauma.[33] In the present study, associated injuries occurred frequently among children who died prior to hospital admission.

The external causes found in this study were largely in accordance with those found in earlier reports[1,34–37] except from violence[9,38,39] and perinatal injury,[40–42] which did not occur in the present study.

Traffic was the main cause of injury among Swedish children. Further studies are needed in order to assess

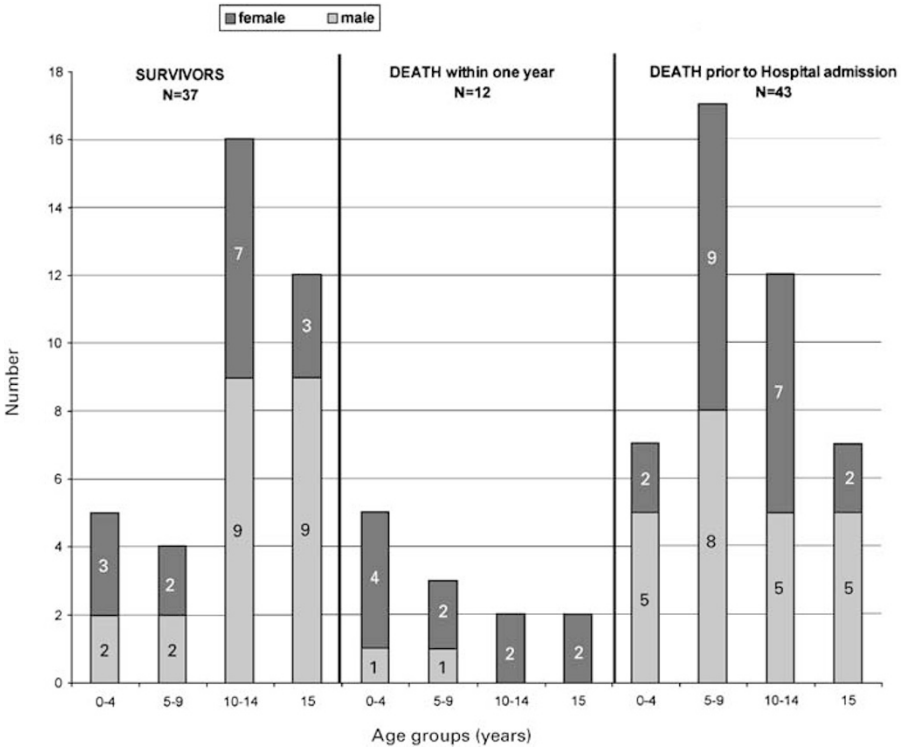

Figure 3 Distribution of gender by age group and outcome, $N = 92$

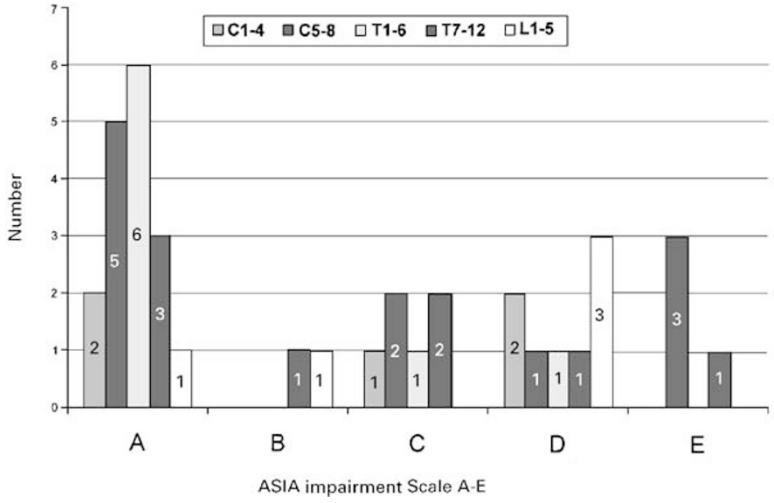

Figure 4 Distribution of ASIA impairment scales A–E by level of injury among the survivors, $N = 37$

Table 4 Distribution of injury level and care provider among the survivors, $N = 37$

	Level of care and rehabilitation			
Level of injury	*University*	*County hospital*	*SCI unit*	*Total*
Cervical	2	4	10	16
Thoracic	1	7	8	16
Lumbar		1	4	5
Total	3	12	22	37

Table 5 Distribution of ASIA scales A–E by care provider and average age among the survivors, $N = 37$

		ASIA					
		A	*B*	*C*	*D*	*E*	*Total*
Care provider	University hospital	2	0	0	0	1	3
	Average age	4.5	—	—	—	15.0	8.0
	County Hospital	6	0	1	3	2	12
	Average age	6.2	—	15.0	14.3	6.0	8.9
	SCI unit	9	2	5	5	1	22
	Average age	14.6	13.0	14.0	13.2	14.0	14.0
	Total	17	2	6	8	4	37
	Average age	10.4	13.0	14.2	13.6	10.3	11.8

whether the children were properly restrained and if the injuries could have been prevented. The current study showed an increased mortality in children aged 5–9 years. This may be a result of insufficient parental supervision in the traffic environment and also increasing objection among children as regards the use of restraints in cars. All injured bicyclists in the group died. Further studies are warranted to ascertain as to when children are mature enough to ride a bicycle in the traffic environment. Only two children, out of the eight children injured in a bicycle accident, were older than 11 years.

Sport was the second leading cause of injury among the surviving teenagers, this in accordance with earlier reports.[1,34–37]

All sport-related injuries, but two, (a bicyclist and a motor-cross accident during competition), were registered as falls. Through interviews with the survivors these errors in classification could be corrected. Among the deceased this was not possible, and either of the two deaths registered as an injury because of fall could have been sports related. There are difficulties comparing the causes of SCI reported in published studies, since there is no detailed standard for categorization. Causes of injury can often fit into several etiological groups[26] and the ICD codes for external causes do not include sports-related injuries as a discrete category.[13,14] The distribution of gender did not differ from previous reports. With increasing age, males have higher SCI morbidity.[43]

The current study could not confirm among the survivors, the previously documented tendency for children to sustain upper cervical level injuries.[7,33,44] On the other hand, there was no information about the level of injury among the children who died prior to hospital admission.

The assessment of functional outcome among survivors was in accordance with the findings of DeVivo, *et al*.[35]

For pediatric SCI, the additional problems related to ongoing physical and emotional growth are superimposed on the generic consequences of such an injury. This may create quality problems of care when the

Table 6 The estimated incidence of pediatric SCI reported from the USA, New Zealand, the Netherlands, Portugal and Sweden 1980–2002

References	*Place*	*Study years*	*Age groups (years)*	*Pediatric SCI/million children/year*	*Death prior to hospital admission included (Yes/No)*	*Estimated overall incidence of traumatic SCI/million population/year*
Surkin *et al*[20]	Mississippi, USA	1992–1994	0–14	11.3	Y	77
Buechner *et al*[21]	Rhode Island, USA	1994–1998	0–14	9	N	56
Martins *et al*[22]	Portugal (central region)	1989–1992	0–14	27	Y	57.8
Warren *et al*[23]	Alaska, USA	1991–1993	0–14	14	Y	83
Thurman *et al*[24] (personal communication - 2001-01-16[25])	Utah, USA	1989–1991	0–14	16.7[25]	Y	43
Price *et al*[26]	Oklahoma, USA	1988–1990	0–14	6	N	40
Woodruff and Baron[27]	West Virginia, USA	1985–1988	0–14	1.0	N	
Acton *et al*[28] (personal communication 2002-09-11[29])	Arkansas, USA	1980–1989	0–14	4.98[29]	N	33.18 (1989) Caroll[9]
Kewalramani *et al*[30]	California, USA	1970–1971	1–15	18.2	Y	
				8.9	N	
Dixon *et al*[31]	New Zealand	1979–1988	0–14	8.6	N	43.3
		1988	0–14	16	N	49.1
Van Asbeck *et al*[32]	Netherlands	1994	0–10	$N=2$	N	10.4
Augutis *et al*[11]	Sweden	1985–1996	0–15	4.6	Y	15[8]
				2.4	N	
Augutis and Levi, 2003			0–14	3.8	Y	
				1.9	N	

incidence is low and the children are treated at many different hospitals.

Traffic accident was the main cause of injury. Prevention of pediatric SCI is part of the overall prevention of accidents in children and adolescents. The incidence of accidents among Swedish children is among the lowest in the world. This is likely a result of vigorous preventative work performed for over 50 years. Laws and regulations have made the environment for the child safer, in addition to information and education of the parents.[45]

The low incidence of pediatric SCI together with the overall low incidence of SCI in Sweden further support that prevention in traffic can be effective.

Still, accidents are the most common cause of death in Sweden among children and adolescents aged 1–14 years.[45]

Children are vulnerable in traffic when complex situations exceed their cognitive, developmental, behavioral, physical and sensory abilities. Children are impulsive and have difficulty judging speed, spatial relations, distance and velocity. These abilities develop gradually and individually. The teenagers tend to take more risks as they are influenced by their emotions, stress and peer pressure.[46] They move more frequently in the adult environment, but they lack the experience and mature behavior of an adult.

As sport was the second leading cause of injury among the teenagers, preventative measures, especially information of safer sports rules and equipment in schools and for sport organizations, must be undertaken in sports carrying a risk for SCI.

Consequently, SCI prevention must be tailored according to the specific risk profile of each age group.

Conclusions

Pediatric SCI in Sweden is rare, presumably because of effective primary prevention. Preventative measures should be further differentiated for each age group of children in accordance with their differing risk profiles. In contrast to the effective preventative measures that have been implemented in Sweden, care of these patients is still too fractionated and decentralized for sufficient specialization to emerge.

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