

Original Article

Pediatric spinal cord injury in a subset of European countries

M Augutis^{*1}, R Abel² and R Levi³

¹Department of Public Health and Research, Sundsvall Hospital, Sundsvall, Sweden; ²Orthopädische Universitätsklinik, Heidelberg-Schlierbach, Germany; ³Karolinska Institute and Rehab Station Stockholm, Sweden

Study design: Postal survey.

Setting: A total of 19 countries in Europe.

Objectives: Firstly, to collect information about incidence and systems of care for pediatric spinal cord injury (pedSCI); including prevention, initial care and follow-up in a subset of European countries. Secondly, to initiate a network of involved professionals for exchange of information and development of research and care programs.

Methods: A short semi-structured questionnaire was sent to respondents working with spinal cord injury (SCI) in 19 countries in Europe.

Results: Only in Portugal and Sweden, is the incidence of pedSCI (fatal injuries included) established, that is 27 children/million children/year and 4.6 children/million children/year, respectively. For the other countries, the estimated incidence of pedSCI (nonfatal injuries) varied from 0.9 to 21.2 children/million children/year in the age group of 0–14 years. Although the incidence varies considerably, pedSCI is rare throughout Europe. The management differs between the countries depending on the age of the child and the local organization of health care.

Conclusions: The survey confirms that pedSCI is rare. In order to establish high-quality standardized care, further integration of knowledge in this area is needed throughout Europe. The contacts initiated by this survey may be used to create an international network serving as a reference for health professionals, researchers and families, thereby possibly alleviating some of the unwanted variations of care identified in this study.

Spinal Cord (2006) 44, 106–112. doi:10.1038/sj.sc.3101793; published online 30 August 2005

Keywords: pediatric; spinal cord injury; incidence; system of care

Introduction

Spinal cord injury (SCI) alters every aspect of a person's life significantly and usually irreversibly. In addition to the inherent complexity of spinal cord lesions afflicting persons regardless of the age of the afflicted individual, pediatric SCI (pedSCI) is further complicated by issues related to ongoing physical and emotional growth.^{1,2}

Optimal initial medical and surgical management is of primary importance, but attention must also be given to preventive measures as well as to the injured child's psychosocial development and general quality of life. This may minimize disability and improve community participation in persons with pedSCI.³ PedSCI requires a comprehensive system of medical care tailored to the individual's needs and must furthermore be developmentally based.³

PedSCI is reported to be rare.^{4–14} A low incidence and prevalence may result in scattered experiences in

treatment and a low priority given to development of research and care programs.¹⁵ Thus, there is a need for increased exchange of information, experiences and best practice between countries. The rarity of this disorder would also merit extra European Economic Community (EEC) funding to enable cooperation between professionals in Europe.

An example of a successful international network from a similar field is the Paediatric Rheumatology International Trials Organisation (PRINTO), supported by the EEC, which facilitates and conducts high-quality research, and also provides information to afflicted children and their parents.¹⁶

The aim of this survey was primarily to collect information about incidence and systems of care, including prevention, initial care and follow-up for pedSCI in a subset of European countries, and Secondly, to initiate a network of involved professionals for exchange of information and development of research and care programs.

*Correspondence: M Augutis, Department of Public Health and Research, Sundsvall Hospital, Sundsvall 851 86, Sweden

Methods

The member states of the European Union at the time of the study ($N=15$) were chosen for inclusion, also including Norway and Iceland due to the *European Economic Area (EEA)* agreement.¹⁷ Switzerland and two Baltic countries (Latvia and Lithuania) were also included due to previous contacts and/or a known interest in pedSCI.

The International Spinal Cord Society (ISCoS) membership list was used to identify contact persons in these 19 European countries, that is, Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Latvia, Lithuania, The Netherlands, Norway, Portugal, Spain, Sweden, Switzerland and The United Kingdom.

The list targeted persons who had a known special interest in pedSCI and/or who had previously published articles on SCI epidemiology. If no such person could be identified, a representative of a major rehabilitation center was contacted.

A semi-structured questionnaire requesting information about established or estimated incidence of pedSCI, management, follow-up and prevention was administered by mail/e-mail to the contact person (Table 1).

The contact person was asked to refer the questionnaire to another colleague if such a person was thought to be more knowledgeable with regard to the subject matter of the study.

Several subsequent reminders were made by phone, e-mail and letters in cases of initial nonresponse.

Additional contacts by phone or e-mail were also made if there were any ambiguity concerning the subsequent interpretation of submitted questionnaires.

The questionnaires were sent out in November 2002 and the last questionnaire was analyzed in March 2004, when 18 out of 19 questionnaires had been submitted.

For the countries who could submit the approximate number of pedSCI cases annually and where the corresponding number of children at risk was available, a calculation of estimated incidence was made (Table 2). The midyear population (0–14 years), for each country, was calculated from a publicly accessible database¹⁸ (Table 2).

In March 2004, a second survey was performed. The results of the first survey, presented in Tables 2–4, were sent to all responders of the first survey ($N=18$) for comments and subsequent validation. One additional question was also included, regarding cooperation between pediatric and adult SCI rehabilitation facilities. Out of 18 respondents, 17 submitted the second questionnaire.

Results

In nine countries, the questionnaire was referred from the initial respondent to a colleague. In one country, the questionnaire was referred four times until a qualified respondent was found.

Table 1 Context of the questionnaire

The context of the questionnaire

Published national incidence or empirically based estimates based on the experience of the respondents (Table 2)
 Organization of initial care and subsequent rehabilitation (Table 3)
 Organization of follow-up (Table 4)
 Prevention programs
 Professionals with special interest in pediatric SCI
 Cooperation between adult SCI care and pediatric SCI care
 General/additional comments

Figure 1 demonstrates the substantial differences in the estimated number of pedSCI/year between the countries. Those with pedSCI who reached the hospital alive were found to vary from four cases in 30 years (0.13 cases/year) to about 60 cases/year.

Incidence

- Only Portugal⁶ and Sweden¹⁴ could provide an established incidence of pedSCI, that is 27 children/million children/year and 4.6 children/million children/year, respectively (fatal injuries included).
- The Public Health Resource Unit in Oxford, UK, provided an incidence estimate for the UK, based on a literature review, data from the national database held by the British Association of Spinal Cord Injury Surgeons (BASCIS) and an analysis of in-patient, outpatient and daycare activity data for pedSCI treated at Stoke Mandeville.¹⁹
- Unpublished data previously presented at the VIII congress of Nordic Medical Society of Paraplegia (NMSOP) in Helsinki, Finland, 2003, by Thomas Glott, Norway provided some additional basis for the Norwegian incidence estimation (Table 2).
- The above-mentioned data, as well as those national incidence estimates that could be calculated, are presented in Table 2.
- Submitted data from Greece, Italy and The Netherlands represented only a part of the country with no corresponding clear-cut population-at-risk figure. This precluded calculation of a meaningful incidence estimate for these countries.

Initial care, rehabilitation and follow-up

As can be seen in Tables 3 and 4, management differs between countries, and also within countries, depending on the age of the child and depending on variations in health care organization. Some information deserve special mentioning:

- The only countries where pedSCI (0–12 years) is treated in a local pediatric hospital without specialized rehabilitation are the UK and Sweden (Table 3).

Table 2 Incidence of pedSCI, estimated number of new children with SCI/year, age, midyear population (0–14 years)/million,¹¹ estimated incidence and pedSCI prevention efforts in 18 European countries

Country	Incidence of pedSCI. Cases/million children/year	Estimated number of new cases with SCI/year	Age (years)	Midyear population by (0–14 years)/million ¹¹	Estimated incidence ^a	PedSCI prevention/comments
Austria		6–10	3–10	1.316	8.5–14.2	No/general trauma
Belgium		5–6	5–15	1.777	3.8–4.6	No
Denmark		1	0–15	1.015	0.9	—/road safety-adult SCI
Finland		5	0–16	0.922	4.8	Yes/adult SCI
France		50–60	0–15	11.175	4.2–5.0	Yes/road safety
Germany		30–40	0–15	12.301	2.3–3.0	No
Greece		Less than 10 (in 5 years) ≈ 2) (data only from one Neuropathic Bladder Unit)	6–13	1.544	—	No/unsure
Iceland		4 (in 30 years) = 0.13	0–15	0.063	1.9	Yes/general child trauma
Ireland		1	4–17	0.829	1.3	Yes/road safety
Italy ¹²		16 (1997–1999) = 5.3	0–15	8.141	—	Unknown/adult SCI
Latvia		5	7–16	0.353	21.2	No
Norway ¹⁷	1.5	14 (1991–2001) = 1.4	0–15	0.907	1.4	No/general trauma
Portugal ¹⁴	27 ^b	46	0–14	1.699	27.0 ^b	No
Spain		59	0–14	5.794	10.2	Yes/in schools
Sweden ⁹	4.6 ^b /2.4 ^c	7 ^b /4 ^c (based on an average population of 1.68 million in the ages 0–15 years/year)	0–15	1.597	4.1 ^b /2.4	No/road safety and general trauma
Switzerland		5–9 (+ 40%) ≈ 7–13	0–14	1.255	5.6–10.4	No answer
The Netherlands		10 (data only from the Hoogstraat)	0–20	2.983	—	No
United Kingdom ¹⁵	5.2 ^b	60 ^b	0–14	10.971	5.5 ^b	Yes/www.rosipa.com

^a $\frac{\text{Reported occurrence per year}}{\text{Midyear population (0–14 years)}} \times \text{Number of reported age groups}$

^bChildren dead prior to hospital admission are included

^cSurvivors

- In Scandinavia, with the exception of Sweden, pedSCI is typically treated at a major university hospital, at a neuropediatric specialty ward (Table 3).
- In Norway, Denmark and Iceland there is a recommendation that SCI specialists should always be consulted and work in cooperation with pediatricians both in the initial treatment and the follow-up of the injured child/teenager.
- There exists specialized neuropediatric rehabilitation with follow-up programs in Austria, Belgium, France, Germany, Ireland and Italy, Spain and The Netherlands (Table 4).
- Sometimes children in Italy receive their care and rehabilitation abroad (Table 3).
- PedSCI in Greece and Portugal is treated at regional pediatric hospitals with no specialized rehabilitation (Table 3), although in Portugal the follow-up is performed by a specialized pediatric hospital (Table 4).
- PedSCI in Spain is treated in one of three places: Spinal cord injury hospital, General Rehabilitation Departments or Cerebral palsy units. No information

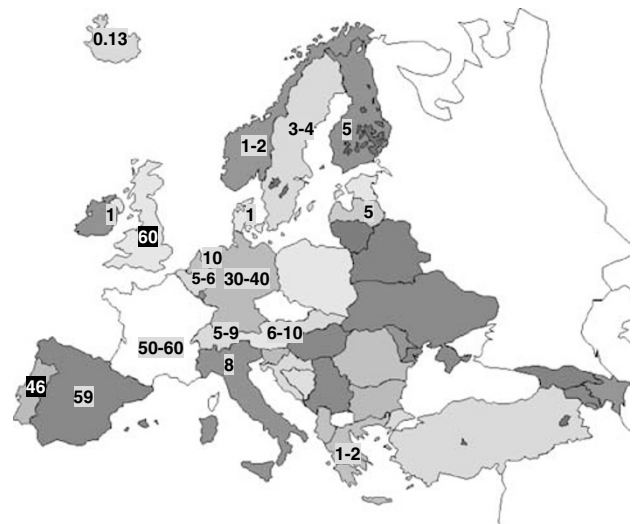
**Figure 1** Reported estimated number of pedSCI/year from 18 countries. From Portugal and the UK, children dead prior to hospital admission are included

Table 3 Initial care and rehabilitation in different settings of care for children (0–15 years) with SCI in 18 European countries

Settings of care	<i>Pediatric department at a local hospital (no specialized rehabilitation)</i>			<i>Pediatric department at a regional hospital (no specialized rehabilitation)</i>			<i>Specialized pediatric rehabilitation department/ neuropediatric</i>			<i>Specialized SCI unit for adults</i>			<i>General rehabilitation department for adults</i>			<i>Other departments (i.e. university traumatology)</i>		
	<i>Age (years)</i>																	
<i>Countries</i>	0–6	7–12	13–15	0–6	7–12	13–15	0–6	7–12	13–15	0–6	7–12	13–15	0–6	7–12	13–15	0–6	7–12	13–15
Austria	1	2	2		2	2	3	3	3	1	1	1	3	3	2			
Belgium							1	1	1									
Denmark							1 ^a	1 ^a	1 ^a	1	1	1						
Finland	3			2	2		1	1	1	3	3	1	3			1	1	1
France	2	2	2	2	2	2	1	1	1	3	3	3	3	3	2	3	3	3
Germany	3	2	3	2	2	2	1	1	1	2	2	2	3	3	3			
Greece	2	2	3	1	1	2	3	3	3	3	2	1	3	2	1		3	3
Iceland	3	3	3	1	1	1	3	3	3	3	3	3 ^a	3 ^a	3 ^a	3 ^a	3	3	3
Italy	3	3	3	1	1	1	2	1	1	3	2	2	3	3	3	2 ^b	2 ^b	2 ^b
Ireland	First weeks	First weeks	First weeks	First weeks	First weeks	First weeks		1	1									
Latvia	3	3	3	1	2	3	1	2	3	2	1	1	3	3	3	2		
The Netherlands	First weeks	First weeks	First weeks	First weeks	First weeks	First weeks	1	1	1	1	1	1	2	2	2			
Norway	2	2	2	2	2	2	1	1	2	1	1	1	3	3	3			
Portugal				1	1	1												2
Spain																		
Sweden	1	1	1	1	1	1	2	2	2	3	2	1	3	2	3			
Switzerland	2	2	2	1	2	2	2	2	2	2	1	1	3	3	2	1	3	3
UK	1	1	2	1	1	1	2	2	2	2	2	1	3	3	3			

1 = Often, 2 = Seldom, 3 = Never

^aIn cooperation with a specialized SCI team

^bTreated outside the country

Table 4 Follow-up in different settings of care for children (0–15 years) with SCI in 18 European countries

Settings of care	Pediatric department at a local hospital (no specialized rehabilitation)			Pediatric department at a regional hospital (no specialized rehabilitation)			Specialized pediatric rehabilitation department/ neuropediatric			Specialized SCI unit for adults			General rehabilitation department for adults			Other department: Out-patient pediatric rehabilitation/ Habilitation		
	0–6	7–12	13–15	0–6	7–12	13–15	0–6	7–12	13–15	0–6	7–12	13–15	0–6	7–12	13–15	0–6	7–12	13–15
Austria																		
Belgium							1	1	1									
Denmark							1 ^a	1 ^a	1 ^a				1					
Finland				1	1		1	1	1				1					
France	2	2	2	2	2	2	1	1	1	3	2	2	3	2	2	3	3	3
Germany	2	2	2	2	2	2	1	1	1	2	2	1	3	3	3			
Greece				1	1	1										1	1	1
Iceland	3	3	3	1	1	1	3	3	3	3	3	3	1 ^a	1 ^a	1 ^a			
Italy	2	3	3	1	2	2	1	1	1	2	2	2	2	3	2	2 ^b	2 ^b	2 ^b
Ireland							1	1	1									
Latvia	3	3	3	2	2	2	1	2	2	2	1	1	3	3	3	1	1	1
The Netherlands	3	3	3	3	3	3	1	1	1	1	1	1	2	2	2			
Norway	1	1	1	1	1	1	1	1	1	1	1	1	3	3	3			
Portugal							1	1	1						2			1
Spain																		
Sweden	1	1	1	1	1	2	2	2	2	2	2	1	3	3	2	1	1	2
Switzerland	2	2	2	1	2	2	2	2	2	2	1	1	3	2	2			
UK	1	2	2	1	1	1	2	2	2	2	2	2	3	3	3			

1 = Often, 2 = Seldom, 3 = Never

^aIn cooperation with a specialized SCI team^bTreated outside the country

was given according to ages in relation to these settings (missing data in Tables 3 and 4).

- In countries lacking specialized neuropaediatric rehabilitation, adolescents (13–15 years) are often admitted into clinics for adults (Table 3).

Prevention

Only Spain reports prevention programs specifically focusing on pedSCI. However, several countries have general programs for pediatric injury prevention and road safety legislation that is, seatbelts, car seats, helmets and speed limits. Prevention programs towards SCI are mainly focusing on adolescents and adults (Table 2).

General comments

- Most countries lack reliable statistics concerning pedSCI. Many respondents ($N=14$) expressed a desire to get the opportunity to have more contacts in this field, in order to exchange knowledge in research and the development of care programs.
- The open comments in the questionnaire revealed some additional relevant information, for example, that in Germany there is a ward dedicated for pedSCI and children with spina bifida, that in France there is a dedicated unit for children with high-level injuries who need ventilators, and the existence in Finland of a fairly recent doctoral thesis on this subject.²⁰

The second survey

Cooperation between pediatric and adult SCI care exists in 13 of the 18 responding countries, mainly at the time when an adolescent is transferred into adult care (having reached the age of 'adulthood'). In a few countries there is an ongoing cooperation with frequent consultations as soon as a child is injured.

As for the validation, all countries responded that the tables reflected the results of the first survey truthfully and represented the current situation regarding pedSCI in their respective country. Thus, only minor revisions were consequently necessary in the preliminary data that went into Tables 3 and 4.

An incidence estimate was received from the Swiss Paraplegic-Center, which was not previously available in the first survey (Table 2).

Discussion

Incidence

Only four countries have previously attempted to analyze the situation for pedSCI in their country.^{6,14,19,21}

The incidence estimates imply large variations. Countries with a similar socio-economic profile would be expected to have fairly similar incidences, but differences nevertheless are seen. This may of course be due to true incidence variations and also due to scattered care, varying reporting methods, whether fatal accidents are included or not and/or due to differences in operational definitions of the diagnosis. In a multi-

lingual region like Europe there are also language barriers that may confound communication.

The chosen method of this study was time-consuming, as the contact person from each country first had to be identified and several reminders subsequently had to be made. The second survey, including data validation, presumably increased the reliability of the survey, but still the incidence estimates must be considered highly preliminary. Nevertheless, this study confirms that pedSCI generally is rare in Europe.

Care

Even though many countries have specialized neuropaediatric facilities that can admit pedSCI, the patients are nevertheless often treated in other settings of care (Table 3). During the time of this survey, it was decided that Stoke Mandeville, UK, will open a separate unit for pedSCI (personal communication A Graham 2004-03-30).

Although pedSCI is rare,⁴⁻¹⁴ it is not currently included in the list of rare diseases provided by the EURODIS.¹⁵ A 'rare disease' is defined in this context as a 'life-threatening or chronically debilitating disease, which is of such low prevalence that special combined efforts are needed to address it. As a guide, low prevalence is taken as prevalence of less than 5 per 10 000 in the Community'.²²

It is likely that pedSCI, actually fulfilling this definition, would benefit from special combined efforts directed towards the group. Empirical knowledge, research and preventative efforts need to be coordinated between the European countries.

Exchange of information, research and development of care programs are time-consuming and costly. The low incidence and scattered care would merit extra EEC funding.

Further questions that arise are: How do children afflicted by SCI and their families share best practice and knowledge gained from the adult care when they are treated in scattered care or in a pediatric setting? Or, if a child is treated in an adult setting, how does the child receive developmentally based care, rehabilitation and follow-up?

To be able to integrate all knowledge and experiences that are already available in the field of pedSCI in Europe, the establishment of a European/international network would likely be of benefit to all professionals and, most importantly, to the children with SCI and their families.

This survey hopefully provides a preliminary foundation to be used as an argument for gaining economic support from the EEC and for the ongoing work with a European network of professionals in order to improve the care, rehabilitation, follow-up, prevention and research for the child with a spinal cord.

Conclusions

The survey confirms that pedSCI is rare in Europe and that further dissemination and coordination of knowledge in this field is needed throughout the region. The

contacts initiated in the process of the survey may be used to create an international network aiming to become a competent reference body for health professionals, researchers and families, thereby hopefully solving some of the problems arbitrary and/or scattered care identified in this study.

Acknowledgements

We thank all the respondents, who took time and answered the questionnaire;

Austria: HP Jonas, *Belgium:* C Vander Linden, *Denmark:* F Biering-Soerensen, *Finland:* M Kannisto, *France:* JA Urtizberea, *Greece:* CA Rapi, *Iceland:* Ó Thorarensen & S Knútsdóttir, *Ireland:* C Conway, *Italy:* M Franceschini & R Maschke, *Latvia:* A Nulle, *The Netherlands:* MJ van Tolde-Jager, FWA van Asbeck, *Norway:* T Glott, *Portugal:* F Martins, *Spain:* O Arroyo, *Switzerland:* D Michel, S Benno, *UK:* A Graham.

This work was supported by the Hans Frankel scholarship, a grant from the Sunnerdahl Foundation for disabled children and young people, and the Mid Sweden Research and Development Center, Vasternorrland, County Council, Sweden.

References

- 1 Massagli T, Jaffe K. Pediatric spinal cord injury: treatment and outcome. *Pediatrician* 1990; **17**: 244–254.
- 2 Flett PJ. The rehabilitation of children with spinal cord injury. *J Paediatr Child Health* 1992; **28**: 141–146.
- 3 Vogel LC, Anderson CJ. Spinal cord injuries in children and adolescents: a review. *J Spinal Cord Med* 2003; **26**: 193–203.
- 4 Surkin J et al. Spinal cord in Mississippi, findings and evaluation, 1992–1994. *Spine* 2000; **25**: 716–721.
- 5 Buechner J, Speare M, Fontes J. Hospitalizations for Spinal Cord Injuries, 1994–1998. *Med Health R I* 2000; **83**: 92–93.
- 6 Martins F et al. Spinal cord injuries—epidemiology in Portugal's central region. *Spinal Cord* 1998; **36**: 574–578.
- 7 Warren S, Moore M, Johnson MS. Traumatic head and spinal cord injuries in Alaska (1991–1993). *Alaska Med* 1995; **37**: 11–19.
- 8 Thurman D et al. Surveillance of spinal cord injuries in Utah, USA. *Paraplegia* 1994; **32**: 665–669.
- 9 Price C et al. Epidemiology of traumatic spinal cord injury and acute hospitalization and rehabilitation charges for spinal cord injuries in Oklahoma, 1988–1990. *Am J Epidemiol* 1994; **139**: 37–47.
- 10 Woodruff BA, Baron RC. A description of nonfatal spinal cord injury using a hospital-based registry. *Am J Prev Med* 1994; **10**: 10–14.
- 11 Acton P et al. Traumatic spinal cord injury in Arkansas 1980–1989. *Arch Phys Med Rehabil* 1993; **74**: 1035–1040.
- 12 Kewalramani LS, Kraus JF, Sterling HM. Acute spinal-cord lesions in a pediatric population: epidemiological and clinical features. *Paraplegia* 1980; **18**: 206–219.
- 13 Dixon G, Danesh J, Caradoc-Davies T. Epidemiology of spinal cord injury in New Zealand. *Neuroepidemiology* 1993; **12**: 88–95.
- 14 Augutis M, Levi R. Pediatric spinal cord injury in Sweden: incidence, etiology and outcome. *Spinal Cord* 2003; **41**: 328–336.
- 15 www.eurordis.org/article.php?id_article=252 *What is a rare disease.* 2004, Eurodis.
- 16 Printo. www.printo.it, 2003.
- 17 <http://www.eu-norway.org/about/ceaforside.htm>, *The EEA agreement.* 2005, Mission of Norway.
- 18 <http://www.census.gov/ipc/www/idbprint.html>, *US Bureau of the census international data base, midyear population, by age and sex.* 2003, US Census Bureau.
- 19 Griffin M. *Review of Paediatric Spinal Cord Injury in the Thames Valley.* Public Health Resource Unit: Oxford 2002, p 33.
- 20 Kannisto M. Pediatric spinal cord injury, years after the lesions. PhD thesis, *Hospital for Children and Adolescents.* University of Helsinki, Finland: Helsinki 1999, p 109.
- 21 Glott T. SCI in children and adolescents. Presented at *The VIII Congress of Nordic Medical Society of Paraplegia.* Helsinki, Finland 2003.
- 22 Health, E.c.P. and http://europa.eu.int/comm/health/ph_threats/non_com/rare_diseases_en.htm, *Rare diseases.*