Epidemiology of Pediatric Traumatic Spinal Cord Injury in a Population-Based Cohort, 1998-2012

Lee L. Saunders, PhD,¹ Anbesaw Selassie, DrPH,² Yue Cao, PhD,¹
Kathy Zebracki, PhD,³ and Lawrence C. Vogel, MD³

¹Department of Health Sciences and Research, Medical University of South Carolina, Charleston; ²Department of Public Health Sciences, Medical University of South Carolina, Charleston; ³Shriners Hospitals for Children, Chicago, Illinois

Background: Traumatic spinal cord injury (SCI) that occurs in children and adolescents who are still developing represents a different challenge than SCI in adults. However, information on the epidemiology and incidence of SCI in a population-based cohort is lacking. **Objective:** To describe the epidemiology of pediatric SCI in a population-based cohort in the United States and to assess trend in incidence over a 15-year period (1998-2012). **Methods:** Children and adolescents (0-21 years) with SCI were identified through the South Carolina SCI Surveillance Registry using hospital discharge records from 1998 to 2012. Overall age-adjusted incidence rates were calculated for each year, and incidence rates were stratified by age, gender, and race. **Results:** The overall age-adjusted incidence rate was 26.9 per million population, and there was a trend ($P = .0583$) toward decreasing incidence of pediatric SCI. When stratified by race, there was a significant decrease in incidence among Whites ($P = .0052$) but not among non-Whites. Younger participants were more likely to be female, to be injured through sports, and to be more likely to have concomitant traumatic brain injury. Since 1998, the proportion of older pediatric patients (16-22 years) with SCI has increased, as has the proportion of non-White patients. **Conclusions:** Although there was an overall trend toward decreasing incidence in this population-based cohort, when stratified by race, this trend only occurred in the White population. **Key words:** epidemiology, incidence, pediatric, spinal cord injuries

Because children and adolescents are still developing, traumatic spinal cord injury (SCI) that occurs in the pediatric population represents different challenges than SCI in the adult population.¹⁻³ Although etiology of injury has been shown to differ between pediatric and adult populations,⁴ information on the incidence and trend of pediatric SCI in the United States is lacking, as most studies focus solely on adult patients or combine children and adolescents with adults. Understanding the incidence, trend, and epidemiology of pediatric SCI is crucial to planning the allocation of resources and development of prevention programs.

Internationally, incidence rates of pediatric SCI have been reported as between 2.4 and 4.6 per million population, depending on inclusion criteria. Pickett et al⁵ found an overall incidence of 3.37 per million population; however, they included all ages, with the youngest being only 9 years old.

Their findings were based on fewer than 5 cases. A Swedish study, defining children as 0 to 15 years, found an annual rate of 4.6 per million population including prehospital deaths and 2.4 per million excluding prehospital deaths.⁶

In the United States, few studies have focused on the incidence of pediatric SCI, with rates ranging from 6 to 116.7 per million population, depending on the cohort and the ages included. Vitale et al⁷ reported an annual incidence rate of 19.9 per million children (ages 0 to 18 years), with an estimated 1,455 admitted to the hospital each year. They did not use the standard Centers for Disease Control and Prevention (CDC) definition of SCI, as they included cases presenting as late effects of SCI (International Classification of Diseases, Ninth Revision, Clinical Modification [ICD-9-CM] code = 907.2).⁸ Two analyses have been published from population-based, state surveillance system registries. A study in Mississippi revealed annual

Corresponding author: Lee L. Saunders, PhD, Department of Health Sciences and Research, Medical University of South Carolina, 77 President Street, MSC 700, Charleston, SC 29425; phone: 843-792-8828; e-mail: saundel@musc.edu

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rates of 11.3 and 116.7 per million population among ages 0 to 15 years and 15 to 19 years, respectively.⁹ In Oklahoma, Price et al¹⁰ found an annual incidence rate of 6 per million in those 0 to 14 years and 94 per million in those 15 to 19 years. While providing valuable information, these population-based studies only included data through 1994 and did not assess trend. Thus, updated information on the incidence of pediatric SCI is needed.

Because population-based information on the epidemiology of pediatric SCI in the United States is lacking and outdated, the purpose of this study is to describe the epidemiology of pediatric SCI in a population-based cohort in the United States and to assess trend in incidence over a 15-year period (1998-2012).

Methods

The South Carolina SCI Surveillance Registry (SCISR) is a population-based registry of SCI occurring in the state each year. All nonfederal hospitals in South Carolina are mandated to report discharge data on all hospitalizations involving SCI to the State Budget and Control Board through the uniform billing discharge data (UB-04 Form). The SCISR does not include information from military or veterans hospitals and therefore represents the civilian population of South Carolina. Included in the registry are patient demographics, admission and discharge status, external cause of injury (E-codes), acute care charge, admission source, discharge disposition, and 1 primary and up to 10 secondary diagnosis codes based on ICD-9-CM codes. Data in the SCISR are validated through verification of randomly selected medical charts and have been shown to be 99% accurate and complete.¹¹ Surveillance data reported are hospital discharges from 1998 to 2012.

ICD-9-CM codes of 806 [.0-.9] and 952 [.0-.9] were used to identify incident cases of SCI as defined by the CDC for surveillance of SCI.⁸ Duplicate admissions were eliminated by using personal identifiers. Out-of-state residents were excluded, as well as cases presenting as late effects of SCI (ie, not incident cases). Pediatric cases were selected using the age range 0 to 21 years,⁴ and those persons injured at the age of 22 or older were included in a separate analysis of adults.¹² Mortality was assessed through December 31, 2011, using the

multiple causes of death data in South Carolina, which captures all deaths in the state.

Measures

Age at injury was dichotomized as 0 to 15 years and 16 to 21 years. Race was categorized as White and non-White for all analyses. Level of injury was classified as tetraplegia, paraplegia, and unspecified based on the ICD-9-CM SCI codes. An approximation of the American Spinal Injury Association Impairment Scale (AIS) was based on the fifth digit of ICD-9-CM diagnosis codes,¹³ and participants were classified as (1) tetraplegia, complete; (2) tetraplegia, incomplete; (3) paraplegia, complete; (4) paraplegia incomplete; and (5) unspecified. Etiology was grouped as motor vehicle crash (MVC), violence, sports, and falls; all other etiologies were categorized together. Acute care length of stay (LOS) was measured from hospital admission to discharge. Concomitant traumatic brain injury (TBI) (yes, no) was pulled from the ICD-9-CM codes using the CDC TBI surveillance definition.⁸

Analysis

Analyses were conducted using SAS v9.3 (SAS Institute, Cary, NC). Crude incidence rates were calculated by dividing the observed number of SCI cases each year by the referent population (ie, the population of South Carolina of persons 21 years or younger). The South Carolina population was pulled from CDC WONDER Online Database for the (1) total population under 21, (2) males, (3) females, (4) Whites, and (5) non-Whites.¹⁴ Age-adjusted rates were calculated by race (White, non-White) and gender using direct standardization and the 1990 South Carolina population of 0 to 21 year olds. All rates are expressed per million population.

Poisson regression was used to examine the trend of the rates. The rarity of SCI in the referent population makes Poisson regression appropriate and desirable for this analysis.¹⁵ The first Poisson model assessed overall trend in age-adjusted rates between 1998 and 2012. Additionally, stratified analyses were conducted to assess trend in incidence rate over time by age group (0-15 years, 16-21 years), gender (male, female), and race (White, non-White). An advantage

of Poisson regression is the ability to estimate log rate ratios (RR). The betas represent the natural logarithm of the RR for exposed relative to the unexposed group, and the RR is estimated by exponentiation of the coefficients. These measures provide estimates of the change in rate of SCI. An alpha level of 0.05 was used to reject the null hypothesis. When overdispersion was found, the model was refit with an adjustment using a scaling factor (deviance/degrees of freedom).¹⁶ Additionally, spline regression with a smoothing effect was used to plot the trend and construct 95% confidence intervals (CIs).

Results

Overall, between 1998 and 2012, there were 490 incident cases of pediatric SCI (**Table 1**). Of those, 74.1% were male, and the mean age at

injury was 16.2 years ($SD = 5.0$). The cohort was 58.8% White, 38.0% African American, and 4.1% other. Thirty-four percent were discharged home, 26.7% to a rehabilitation facility, 21.5% to another inpatient facility or hospital, and 9.9% to a home health service. Five percent died before leaving the hospital, and 2.9% were discharged with other arrangements. Unintentional injuries made up 82.0% of injuries. MVCs were the most frequent cause of injury (46.7%), followed by violence (14.9%), sports (11.6%), and falls (6.3%). Etiology differed significantly by race ($P < .0001$), with non-Whites being more likely to have been injured through violence (29.4% vs 5.0%). Average LOS for the initial acute care hospitalization was 16.2 (18.9) days (range, 1-156 days; median, 11 days). Significant differences were seen between the 2 age groups (0-15 years and 16-21 years) by

Table 1. Characteristics of the population by age group

Characteristic	Overall (<i>n</i> = 490)	Age group		<i>P</i> value
		0-15 years (<i>n</i> = 134)	16-21 years (<i>n</i> = 356)	
Gender				.0175
Male	74.1	66.4	77	
Female	25.9	33.6	23	
Race				.4087
White	58.8	61.8	57.7	
Non-White	41.2	37.2	42.3	
Injury severity				< .0007
Tetraplegia, complete	7.9	6.1	8.5	
Tetraplegia, incomplete	33.8	40.5	31.2	
Paraplegia, complete	9.5	3.1	11.9	
Paraplegia, incomplete	35.4	25.2	39.1	
Unspecified	13.5	25.2	9.4	
Etiology				.0005
MVC	46.7	44.8	47.5	
Violence	14.9	5.2	18.5	
Sports	11.6	17.9	9.3	
Fall	6.3	8.2	5.6	
Other	20.4	23.9	19.1	
Concomitant TBI				.0271
Yes	24.5	31.8	21.8	
No	75.5	68.3	78.2	
Average LOS, days (<i>SD</i>)	16.2 (18.9)	13.4 (20.3)	17.2 (18.2)	.0472

Note: Values given as %, unless noted otherwise. LOS = length of stay; MVC = motor vehicle crash; TBI = traumatic brain injury.

Table 2. Characteristics of the population by year group

Characteristic	Year of injury				P value
	1998-2000 (n = 109)	2001-2004 (n = 133)	2005-2008 (n = 134)	2009-2012 (n = 109)	
Age group					.0263
0-15 years	34.9	29	28	16.8	
16-22 years	65.1	71	72	83.2	
Gender					.5095
Male	70.8	76.6	71.2	77.6	
Female	29.3	23.5	28.8	22.4	
Race					.0119
White	71.8	59.3	51.5	54.3	
Non-White	28.2	40.7	48.5	45.7	
Etiology					.5841
MVC	46.2	51	44.7	43.9	
Violence	10.4	13.1	15.2	21.5	
Sports	12.3	13.8	9.9	10.3	
Fall	8.5	4.8	7.6	4.7	
Other	22.6	17.2	22.7	19.6	

Note: Values given as %. MVC = motor vehicle crash; TBI = traumatic brain injury.

gender, level of injury, etiology, concomitant TBI, and LOS (**Table 1**). Over time, those injured were more likely to be 16 to 22 years old ($P = .0263$) and more likely to be non-White ($P = .0119$), but significant differences were not seen with regard to gender or etiology (**Table 2**). Although we did not see a significant relationship between etiology and year, we did find a significant trend when dichotomizing etiology as violent versus

nonviolent ($P = .0212$). As of December 31, 2011, 8.1% were deceased.

Trend analysis

The frequency, crude rate, and age-adjusted incidence rates are presented in **Table 3**. The overall age-adjusted incidence rate for the pediatric population was 26.9 per million population.

Table 3. Frequency, crude rate, and age-adjusted rates^a of SCI in South Carolina, 1998-2012

Year	No. of cases	Crude incidence rate	Adjusted incidence rate ^b	Year	No. of cases	Crude incidence rate	Adjusted incidence rate ^b
1998	33	25.89	26.45	2006	30	23.54	24.44
1999	31	24.32	25.21	2007	40	31.39	32.18
2000	45	35.31	36.08	2008	38	29.82	30.58
2001	45	35.31	36.54	2009	38	29.82	31.05
2002	33	25.89	26.74	2010	24	18.83	19.77
2003	24	18.83	19.31	2011	22	17.26	18
2004	31	34.52	35.6	2012	25	19.62	20.19
2005	26	20.4	21.37				

^aRates per million population.

^bAdjusted for age.

Overall rates for age groups 0 to 15 years and 16 to 21 years were 10.0 and 66.5, respectively. Rates were higher for males (38.5) than females (14.0) and for non-Whites (26.0) than Whites (24.3).

There was a trend toward decreasing age-adjusted SCI incidence over time (RR = 0.98; 95% CI, 0.96-1.00; $P = .0583$) (Table 4). When stratifying analyses by race, we found a significant decrease in incidence for Whites (RR = 0.95; 95% CI, 0.90-0.99; $P = .0052$) but no change for non-Whites (Table 4). Stratification by age group and by gender showed no significant trends for either group. Figures 1 and 2 display the overall and stratified age-adjusted trend lines from the spline regression models.

Discussion

Pediatric and adult SCI are often analyzed together, making it difficult to decipher trends specific to the pediatric population. We assessed the age-adjusted trend of pediatric SCI between 1998 and 2012 in a population-based cohort in the

Table 4. Age-adjusted Poisson model results of year of injury

Variable	RR ^a	95% CI	P value
Overall	0.98	0.96-1.00	.0583
Stratified by race			
Non-White	1.01	0.98-1.05	.5150
White	0.95	0.93-0.98	.0002
Stratified by gender			
Male	0.98	0.95-1.01	.1507
Female	0.98	0.94-1.01	.1085
Stratified by age group			
0-15 years	0.94	0.88-1.00	.0684
16-21 years	0.99	0.97-1.02	.5558

Note: CI = confidence interval; RR = rate ratio.

^aRR for every 1-year increase.

state of South Carolina. Overall, there was a trend toward decreasing incidence across the period ($P = .0583$); when the cohort was stratified by race, Whites showed a significant decrease over time.

Figure 1. Total pediatric spinal cord injury (SCI) rates in South Carolina, 1998-2012.

The overall average age-adjusted rate was 26.9 per million population, which is higher than results by Vitale et al,⁷ who found an incidence rate of 19.9 per million between the ages of 0 and 18 years. We found an overall age-adjusted rate of 10.0 per million population in person 0 to 15 years old, compared with rates of 6 per million¹⁰ and 11.3 per million for those 0 to 14 years old⁹ in 2 population-based studies in the United States. However, there is some variation in the selection of cases between studies. Our findings were much higher than those in the international literature (2.4 to 4.6 per million population).^{5,6}

We found that non-Whites had a slightly higher incidence than Whites (26.0 vs 24.3). Whites had a statistically significant decrease in trend ($P = .0002$), whereas there was not a significant change in the incidence of SCI among non-Whites. Looking at non-Whites as a group compared with

Whites, we found the proportion of non-Whites significantly increased across years. (We did not have enough cases within other races to assess the trend in those specific groups.) Especially troubling is the proportion of SCIs caused by violence in non-Whites compared with Whites (29.4% vs 5%). Additionally, the overall proportion of violent etiology was much higher in our cohort (14.9%) than what was seen by Vitale et al⁷ (9.2%). The racial disparity in violent etiology was also found in an analysis of data from the Shriners Hospitals for Children and the National SCI Statistical Center (NSCISC) database.⁴ Although the NSCISC¹⁷ reports (among adults) that violent etiology peaked in the 1990s and has since fallen, we did not see that decrease within our data. Efforts at SCI prevention related to violence should be targeting adolescents, specifically non-White adolescents.

Figure 2. Pediatric spinal cord injury (SCI) rates by race and gender in South Carolina, 1998-2012.

Our results also showed differences between older (16 to 21 years) and younger (0 to 15 years) children with regard to gender, injury severity, etiology, concomitant TBI, and acute care LOS. Analysis of the Shriners/NSCISC database revealed similar findings with regard to gender (a higher portion of males among older ages).⁴ We found a lower portion of complete injuries than reported in the Shriners/NSCISC data, but that is not surprising; those with the most severe injuries would be more likely to seek care at a rehabilitation facility, and the surveillance system captures everyone regardless of rehabilitation care. Population-based data on the dual diagnosis of TBI in the pediatric SCI population have not been available in the literature, but we found that persons in the youngest group were more likely to have concomitant TBI. A study in Norway indicated that a greater proportion of persons 0 to 29 years had dual diagnosis (54%) compared with those 30 to 59 years (39.2%) and 60 years and older (46.7%); however, the investigators did not further break down the younger group to look specifically at children and adolescents.¹⁸

Limitations

Although this study provides valuable information regarding the incidence and trend of pediatric SCI, there were limitations. First, our analyses relied on administrative billing data for the identification of SCI cases. Although we used the CDC definition of SCI identified through ICD-9-CM codes, the accuracy of codes in the fourth and fifth digits (ie, those that identify injury completeness) may be unreliable, especially from hospitals in rural areas.¹⁹⁻²¹ However, chart review is routinely performed in South Carolina,

and the predictive value positive rate of the data is high (range, 82%-94% depending on the year).¹² Second, only data pertaining to the acute hospitalization were available, and thus we did not have information on rehabilitation or any outcomes after hospital discharge.

Conclusion

Future studies should assess long-term outcomes in this population-based cohort of pediatric patients with SCI, as most research studies are conducted through rehabilitation settings. There is a need to assess both short- and long-term outcomes of those who may not have received optimal rehabilitative care. Additionally, as violent etiology has increased over time, further investigation is needed into the prevention of violence-related SCI, specifically among minority adolescents. However, MVCs remain the leading cause of SCI, and thus further prevention programs aimed at reducing MVCs are needed.

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REFERENCES

1. Vogel LC, Hickey KJ, Klaas SJ, Anderson CJ. Unique issues in pediatric spinal cord injury. *Orthop Nurs*. 2004;23(5):300-308.
2. Zebracki K, Anderson CJ, Chlan KM, Vogel LC. Outcomes of adults with pediatric-onset spinal cord injury: Longitudinal findings and implications on transition to adulthood. *Top Spinal Cord Inj Rehabil*. 2010;16(1):17-25.
3. Vogel LC, Chlan KM, Zebracki K, Anderson CJ. Long-term outcomes of adults with pediatric-onset spinal cord injuries as a function of neurological impairment. *J Spinal Cord Med*. 2011;34(1):60-66.
4. DeVivo MJ, Vogel LC. Epidemiology of spinal cord injury in children and adolescents. *J Spinal Cord Med*. 2004;27(suppl 1):S4-S10.
5. Pickett GE, Campos-Benitez M, Keller JL, Duggal N. Epidemiology of traumatic spinal cord injury in Canada. *Spine*. 2006;31:799-805.
6. Augutis M, Levi R. Pediatric spinal cord injury in Sweden: Incidence, etiology and outcome. *Spinal Cord*. 2003;41(6):328-336.
7. Vitale MG, Goss JM, Matsumoto H, Roye DP Jr. Epidemiology of pediatric spinal cord injury in the United States: Years 1997 and 2000. *J Pediatr Orthop*. 2006;26(6):745-749.

8. Butler J, Langlois JA. *Central Nervous System Injury Surveillance: Annual Data Submission Standards-2000*. Atlanta, GA: US Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2001.
9. Surkin J, Gilbert BJ, Harkey HL 3rd, Snizek J, Currier M. Spinal cord injury in Mississippi. Findings and evaluation, 1992-1994. *Spine*. 2000;25(6):716-721.
10. Price C, Makintubee S, Herndon W, Istre GR. 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(1):37-47.
11. Varma A, Hill EG, Nicholas J, Selassie A. Predictors of early mortality after traumatic spinal cord injury: A population-based study. *Spine*. 2010;35(7):778-783.
12. Selassie A, Cao Y, Saunders LL. Epidemiology of traumatic spinal cord injury among persons older than 21 years: A population-based study in South Carolina, 1998-2012. *Top Spinal Cord Inj Rehabil*. 2014;21(4):333-344.
13. Jones T, Ugalde V, Franks P, Zhou H, White RH. Venous thromboembolism after spinal cord injury: Incidence, time course, and associated risk factors in 16,240 adults and children. *Arch Phys Med Rehabil*. 2005;86(12):2240-2247.
14. Centers for Disease Control and Prevention. Bridged-race population estimates 1990-2012 request on CDC WONDER online database. 2012. <http://wonder.cdc.gov/Bridged-Race-v2012.HTML>. Accessed May 7, 2012.
15. Dupont WD. *Statistician Modeling for Biomedical Researchers: A Simple Introduction to the Analysis of Complex Data*. Cambridge, MA: Cambridge University Press; 2002.
16. McCullagh P. Quasi-likelihood functions. *Ann Stat*. 1983;11(1):59-67.
17. National Spinal Cord Injury Statistical Center. *Spinal Cord Injury Facts and Figures at a Glance*. Birmingham, AL: University of Alabama; February 2013.
18. Hagen EM, Eide GE, Rekand T, Gilhus NE, Gronning M. Traumatic spinal cord injury and concomitant brain injury: A cohort study. *Acta Neurol Scand Suppl*. 2010(190):51-57.
19. Krisa L, Gaughan J, Vogel L, Betz RR, Mulcahey MJ. Agreement of repeated motor and sensory scores at individual myotomes and dermatomes in young persons with spinal cord injury. *Spinal Cord*. 2013;51(1):75-81.
20. Mulcahey MJ, Gaughan J, Betz RR. Agreement of repeated motor and sensory scores at individual myotomes and dermatomes in young persons with complete spinal cord injury. *Spinal Cord*. 2009;47(1):56-61.
21. Mulcahey MJ, Gaughan J, Betz RR, Johansen KJ. The International Standards for Neurological Classification of Spinal Cord Injury: Reliability of data when applied to children and youths. *Spinal Cord*. 2007;45(6):452-459.