

The South Carolina Spinal Cord Injury Surveillance and Registry Annual Report

Project Number SCIRF 0908, PI Anbesaw Selassie

Reporting period: July 1, 2013-June 30, 2014

I. Project Summary – Bridge funding for the South Carolina Spinal Cord Injury Surveillance and Registry (SCISR) has been in effect for the past four years, which enabled the surveillance and registry system to continue data collection on all statewide hospital discharges with TSCI. Over the course of the funding, the project made significant progress to accomplish the following primary objectives that are aligned with the mandate of the Spinal Cord Injury Research Fund (SCIRF)

1. Updating the spinal cord injury registry with hospital discharge and emergency department encounters due to Traumatic Spinal Cord Injury (TSCI) in South Carolina on semi-annual basis to establish timely enumeration SC residents with TSCI.
2. Enhance and validate hospital and ED encounter data on a random sample of persons with TSCI.
3. Provide mail contact information to ongoing researchers regarding persons discharged alive with TSCI who consented to be included for future studies.
4. Annual update of the registry by identifying persons who died after acquiring TSCI including the underlying and contributing causes of death. This is accomplished by matching the registry data with the statewide multiple causes of death data (MCDD) on annual basis.
5. Analyze the registry data to identify risk characteristics and the trend of TSCI to inform public policy, the scientific community, advocacy organizations, and the general public.
6. Provide customized data and summary statistics to academic institutions, hospitals, and other clinical consortia throughout the state for grant applications.
7. Disseminate key findings of the surveillance registry to inform public policy using peer-reviewed manuscripts as the medium

The successful partnership forged among the Medical University of South Carolina (MUSC), the Department of Disabilities and Special Needs (DDSN), the Department of Health and Environmental Control (DHEC), the SC Budget and Control Board Division of Research and Statistics remains instrumental in accomplishing the goals and objectives the SC TSCI surveillance registry.

II. Project Performance – the following narrative describes successes and/or shortcomings of achieving the plan of action laid out for the 12 months.

1. Identify all South Carolina residents with spinal cord injury discharged from acute care facilities in the 2013 calendar year.

We accomplished this goal. From the SC statewide hospital dataset, we have obtained names, addresses, hospital IDs, medical record numbers, dates of admission and discharge, up to fifteen ICD-9-CM coded diagnoses, primary and secondary external causes of injury codes (E codes), lengths of stay, total charges, discharge disposition, principal payer, type of care, and basic demographic information including age, gender, and race. These data are available to us by legal authority (Amendment of Ch. 38, title 44, 1976) vested on the South Carolina Head and Spinal Cord Injury Information System, which currently is housed in the SC Department of Disabilities and Special Needs (DDSN), a strong partner in this project. The 2013 discharge data will be matched with the multiple cause of death data file to identify SC residents who died after hospital discharge when it becomes available. Usually, it takes 10-12 months to get all the reported deaths with complete information after the end of the calendar year

2. Acquire supplementary information from randomly selected medical records of persons with TSCI in 2013.

This objective is in progress. Chart abstraction is synchronized with other programs to reduce cost and maximize efficiency. Currently, TSCI abstraction is coordinated with epilepsy abstraction using trained DHEC abstractors. The abstractors use the laptop computers to enter the data obtained from the medical record review. This process also enables us to estimate the validity of the discharge code against physician narratives. Generally the codes are 98-99% correctly assigned. This suggests the UB-04 data is reliable and valid to continue using for the surveillance of TSC in SC.

3. Identify SC residents with TSCI age 15 and older known to be alive at the time of discharges for recruitment to a follow-up study.

The surveillance and registry data includes personal identifiers including full names, addresses, and dates of birth, injury, and discharge. Because of the legal authority of the system, persons with TSCI are contacted by mail to determine if they are willing to participate in the study. Those who consent to participate are flagged for further recruitment to various studies. This service is perhaps one of the most useful activities to promote research and improve the lives of persons with TSCI. To date we have over 387 individuals who are readily accessible for recruitment to various studies.

4. Develop reports and manuscripts to inform public policy in South Carolina and beyond.

This objective is in progress. In the reporting year, the project has performed important scientific investigation on multiple research topics, which are summarized below.

- a) Saunders L. , **Selassie A.**, Cao Y., Zebracki K., Vogel L. Epidemiology of Pediatric Traumatic Spinal Cord Injury in a Population-based Cohort, 1998-2012. *Top Spinal Cord Inj Rehabil* (submission under review)
- b) **Selassie AW**, Cao Y, Saunders L. Epidemiology of Traumatic Spinal Cord Injury Among Persons Older than Age 21: A Population-based Study in South Carolina, 1998-2012 .*Top Spinal Cord Inj Rehabil* (submission, under review)
- c) **Selassie AW**, Snipe L, Focht KL, Welldaregay W. Baseline Prevalence of Heart Diseases, Hypertension, Diabetes and Obesity in Persons with Acute Traumatic Spinal Cord Injury: Potential threats in the Recovery Trajectory. *Top Spinal Cord Inj Rehabil* 2013;19(3):172-182 doi: 10.13/sci1903-172
- d) Cao Y., **Selassie A.**, Krause J. Risk of Death after Hospital Discharge with Traumatic Spinal Cord Injury: A Population-Based Analysis, 1998-2009. *Arch Phys Med Rehabil.* 2013; 94(6):1054-1061, PMID: 23391523

5. Serve as information clearing house to statewide service delivery organizations and community-based advocacy and support groups.

Among the most usefulness of the surveillance and registry data, provision of customized information to statewide information seekers is perhaps the main one. During the 2013 budget year, the surveillance registry provided SCI data to professionals in Health South, Roper rehabilitation hospital, Grand Strand Hospital, the SC Spinal Cord Association, Head and Spinal Cord Injury Division of SC Department Disabilities and Special Needs. Additionally, there were two faculty and two students from the College of Health Professions and the College of Medicine who specifically requested data for research projects. Some of the data was presented at the annual SCI conference.

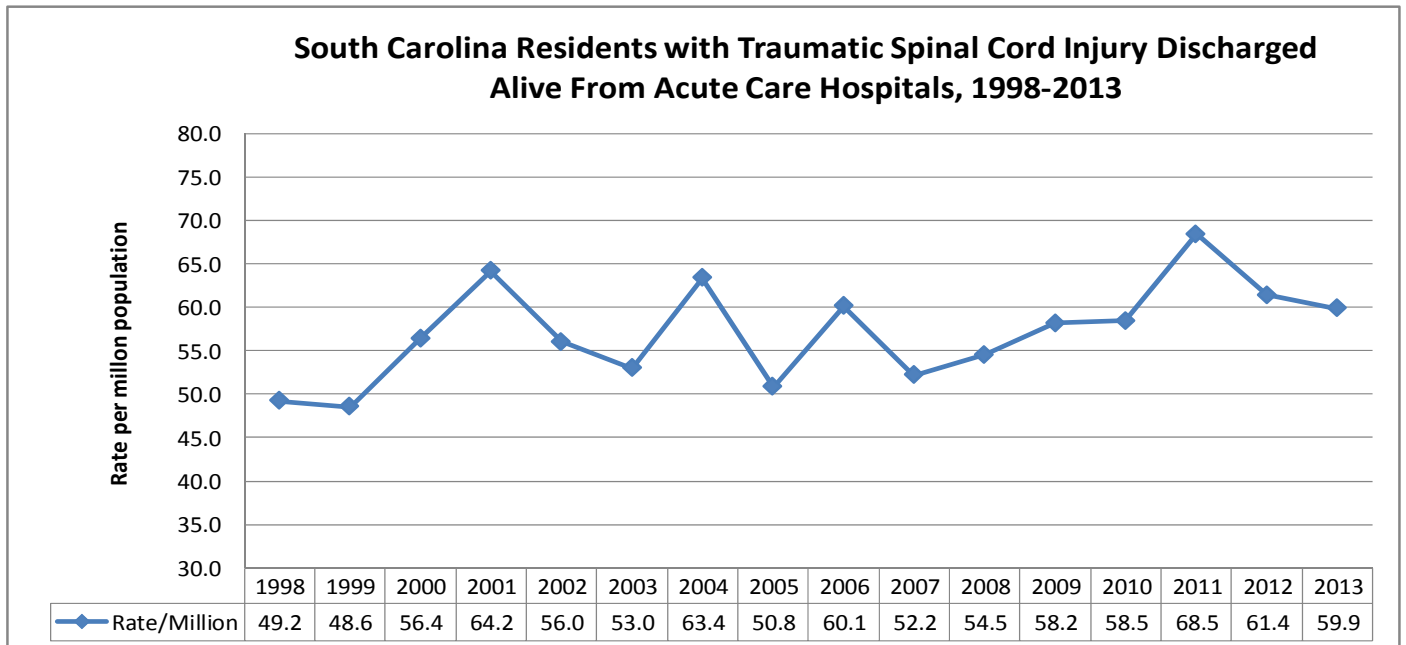
- III. Brief summary of the epidemiology of SCI in South Carolina – From 1998 through 2013, there were 3,983 SC residents discharged alive with a diagnosis of TSCI from acute care hospitals. The trend of TSCI over the span of 16 years in SC is undulant with an average annual incidence rate of 57.7/million SC residents. Of these, 204 (6.7%) were younger than age 18. The risk of TSCI in males three times higher than in females. Motor vehicle crash and falls continue to be leading causes of TSCI followed by interpersonal violence. Sport-related SCI is rare and not a causes of concern in SC. Death after discharge is significantly higher within the first year with 52 percent of the deaths occurring between the 1st and the 52nd week; 21.2% occurred within the second and third year. Taken

together, the first three years after hospital discharge accounted for nearly three-fourths (73.5%) of the deaths. Mortality is comparable with the general population after the fifth year of discharge. This suggest that acute and post-acute rehabilitation is lagging in the state program and most chronic diseases are not adequately manage during the acute phase of TSCI. Below is the Appendix of data tables.

Appendix of Data Tables

Traumatic Spinal Cord Injury Among SC Residents Discharged Alive, 1998-2013
The FREQ Procedure

Year	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1998	193	4.85	193	4.85
1999	193	4.85	386	9.69
2000	227	5.70	613	15.39
2001	261	6.55	874	21.94
2002	230	5.77	1104	27.72
2003	220	5.52	1324	33.24
2004	267	6.70	1591	39.94
2005	217	5.45	1808	45.39
2006	262	6.58	2070	51.97
2007	232	5.82	2302	57.80
2008	247	6.20	2549	64.00
2009	267	6.70	2816	70.70
2010	271	6.80	3087	77.50
2011	320	8.03	3407	85.54
2012	290	7.28	3697	92.82
2013	286	7.18	3983	100.00



Perspective: Average Rate for the USA ~ 40/million/Year; Average Rate of South Carolina 57.7/ million population/Year

**Traumatic Spinal Cord Injury Among SC Residents Discharged Alive, 1998-2013
The FREQ Procedure**

Age Groups	Frequency	Percent	Cumulative Frequency	Cumulative Percent
0-11	61	1.53	61	1.53
12-17	143	3.59	204	5.12
18-24	475	11.93	679	17.05
25-34	574	14.41	1253	31.46
35-44	594	14.91	1847	46.37
45-64	1329	33.37	3176	79.74
65+	807	20.26	3983	100.00

Race AND Sex	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Non-White Male	1387	34.82	1387	34.82
White Male	1561	39.19	2948	74.01
Non-White Female	282	7.08	3230	81.09
White Female	753	18.91	3983	100.00

Traumatic Spinal Cord Injury Among SC Residents Discharged Alive, 1998-2013
The FREQ Procedure

Expert Imputed Frankel Grades				
Estimated Frankel Grades	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1	399	10.02	399	10.02
2	856	21.49	1255	31.51
3	1580	39.67	2835	71.18
4	657	16.50	3492	87.67
5	491	12.33	3983	100.00

Type of Lesion	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Open SCI	95	2.39	95	2.39
Closed SCI	3802	95.46	3897	97.84
Undetermined	86	2.16	3983	100.00

Level of TSCI	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Cervical	2368	59.45	2368	59.45
Thoracic	813	20.41	3181	79.86
Lumbar	386	9.69	3567	89.56
Sacroccocyx	416	10.44	3983	100.00

Traumatic Spinal Cord Injury Among SC Residents Discharged Alive, 1998-2013
The FREQ Procedure

Table of Year by Neurological Deficit						
Year	Type of Deficit					
Frequency Percent Row Pct Col Pct	Complete Tetraplegia	Complete Paraplegia	Incomplete Tetraplegia	Incomplete Paraplegia	Undetermined/ Unspecified	Total
1998	14	11	95	52	21	193
	0.35	0.28	2.39	1.31	0.53	4.85
	7.25	5.70	49.22	26.94	10.88	
	6.45	5.64	4.42	4.88	5.93	
1999	10	10	88	60	25	193
	0.25	0.25	2.21	1.51	0.63	4.85
	5.18	5.18	45.60	31.09	12.95	
	4.61	5.13	4.09	5.63	7.06	
2000	11	11	113	69	23	227
	0.28	0.28	2.84	1.73	0.58	5.70
	4.85	4.85	49.78	30.40	10.13	
	5.07	5.64	5.25	6.47	6.50	
2001	19	16	109	91	26	261
	0.48	0.40	2.74	2.28	0.65	6.55
	7.28	6.13	41.76	34.87	9.96	
	8.76	8.21	5.07	8.54	7.34	
2002	12	12	126	57	23	230
	0.30	0.30	3.16	1.43	0.58	5.77
	5.22	5.22	54.78	24.78	10.00	
	5.53	6.15	5.86	5.35	6.50	
2003	11	12	112	61	24	220
	0.28	0.30	2.81	1.53	0.60	5.52
	5.00	5.45	50.91	27.73	10.91	
	5.07	6.15	5.21	5.72	6.78	
2004	24	24	112	74	33	267
	0.60	0.60	2.81	1.86	0.83	6.70
	8.99	8.99	41.95	27.72	12.36	
	11.06	12.31	5.21	6.94	9.32	
2005	11	16	108	49	33	217
	0.28	0.40	2.71	1.23	0.83	5.45
	5.07	7.37	49.77	22.58	15.21	
	5.07	8.21	5.02	4.60	9.32	

Table of Year by Neurological Deficit						
Year	Type of Deficit					
Frequency Percent Row Pct Col Pct	Complete Tetraplegia	Complete Paraplegia	Incomplete Tetraplegia	Incomplete Paraplegia	Undetermined/ Unspecified	Total
2006	15 0.38 5.73 6.91	13 0.33 4.96 6.67	136 3.41 51.91 6.32	81 2.03 30.92 7.60	17 0.43 6.49 4.80	262 6.58
2007	11 0.28 4.74 5.07	7 0.18 3.02 3.59	148 3.72 63.79 6.88	51 1.28 21.98 4.78	15 0.38 6.47 4.24	232 5.82
2008	10 0.25 4.05 4.61	12 0.30 4.86 6.15	125 3.14 50.61 5.81	74 1.86 29.96 6.94	26 0.65 10.53 7.34	247 6.20
2009	16 0.40 5.99 7.37	9 0.23 3.37 4.62	173 4.34 64.79 8.04	48 1.21 17.98 4.50	21 0.53 7.87 5.93	267 6.70
2010	14 0.35 5.17 6.45	5 0.13 1.85 2.56	154 3.87 56.83 7.16	84 2.11 31.00 7.88	14 0.35 5.17 3.95	271 6.80
2011	13 0.33 4.06 5.99	13 0.33 4.06 6.67	204 5.12 63.75 9.48	76 1.91 23.75 7.13	14 0.35 4.38 3.95	320 8.03
2012	16 0.40 5.52 7.37	14 0.35 4.83 7.18	173 4.34 59.66 8.04	63 1.58 21.72 5.91	24 0.60 8.28 6.78	290 7.28
2013	10 0.25 3.50 4.61	10 0.25 3.50 5.13	175 4.39 61.19 8.14	76 1.91 26.57 7.13	15 0.38 5.24 4.24	286 7.18
Total	217 5.45	195 4.90	2151 54.00	1066 26.76	354 8.89	3983 100.00