Cumulative Technical Progress Report
May 2015

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Title: Measuring Outcomes after SCI throughout South Carolina: A System of Tracking, Research, and Statewide Outcomes Database
Grantee Organization: Medical University of South Carolina
Project Period: 12/1/2009 – 11/30/2016
Report: 2015 cumulative progress report
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Summary of Progress towards Objectives

Primary Objectives:

1. *Measure outcomes of individuals with SCI in the state of South Carolina routinely as they come into the surveillance system, currently just after the first year post-injury (we will investigate options for earlier identification).*
2. *Measure outcomes on all existing cases in the surveillance system in order to capture those already in the surveillance system (i.e., beyond one year).*

We have made substantial progress on objectives 1 & 2. The preliminary task required that we develop the instrumentation and the scope of the outcomes to be measured. This was done during the early stages of the project and was integrated with another study focused on access to care as related to participant outcomes. Therefore, prior to beginning data collection, a great deal of thought, conceptualization, and instrument development was undertaken to identify the key elements of importance for people with SCI, including those issues most pertinent to persons with SCI in South Carolina.

We have since collected baseline data on 963 persons who were identified as injured in years 1998 through 2013(Table 1 shows n=953 as data from 10 participants is still being cleaned). This includes the addition of those injured in 2013 (n=50 respondents). We initially started data collection on persons discharged through 2010 but have routinely included persons identified in subsequent years through 2013. Data collection for those injured in 2014 will begin in July 2015. Table 1 shows the number of persons in the surveillance system, the number approached (the frame minus those deceased/ineligible), and the number of participants by year of discharge from the hospital. For all persons who have participated, we collected information on multiple outcomes including: access to health care, hospitalizations, pressure ulcers, subsequent injuries, chronic health conditions, employment, and health behaviors (e.g. smoking, alcohol use). A smaller subset of items are cross-walked with information collected in the SCI Model Systems (SCIMS) to allow for comparisons at the national level, but our measurement collected a much broader array of outcomes.

Table 1. Sample frame and participation rates by year of injury.

Year of Injury	Frame	Deceased/ Ineligible	Approached	Participants	Participated
1998	197	58	139	34	24%
1999	194	55	139	41	29%
2000	224	52	172	41	24%
2001	260	59	201	48	24%
2002	235	49	186	47	25%
2003	237	60	177	64	36%
2004	296	73	223	79	35%
2005	229	51	178	48	27%
2006	283	60	223	70	31%
2007	252	46	206	67	33%
2008	251	39	212	85	40%
2009	277	48	229	81	35%
2010	193	29	164	70	43%
2011	243	23	220	71	32%
2012	240	12	228	66	29%
2013	239	30	209	41	24%
TOTAL	3,850	744	3,106	953	31%

3. *Perform routine follow-ups during the first five years post injury, then again at five year intervals thereafter (10 and 15 years)*.

The progress made on objective 3 has also been substantial. We began follow-up surveys in 2012 and have had outstanding participation each year. Follow-ups are conducted in the summer each year, and the follow-up for 2015 is scheduled to begin in July 2015. Of 111 eligible in 2012, 94 participated, and of 316 eligible in 2013, 245 participated. In 2014, we had 349 eligible participants, and 239 participated. The follow-up surveys collect data in the same domains as the baseline survey, which will enable us to follow health changes over time.

Table 2. Follow-ups by years post-injury.

FU Year	2012	2013	2014	2015*	2016
2	0	48	43	--	
3	26	43	40	--	
4	26	51	42	--	
5	23	48	52	--	
10	18	38	40	--	
15	2	18	22	--	
20					
TOTAL	95	246	239		

*projected to start in July 2015

4. *Develop and test specific hypotheses to be answered and perform the appropriate data analysis and dissemination, with a focus on the relationship of health services and additional risk factors with outcomes and the potential cost effectiveness of intervention (including inpatient rehabilitation).*

   Specific hypotheses and scientific goals needed to be developed as we put together the preliminary instrumentation for the study. In the beginning of 2013, we completed a 'final' dataset of baseline data for persons who sustained their injury through 2011, and are in the process of cleaning the newer data to merge. Some preliminary information on service usage has been published as a Research Brief on the South Carolina SCI Association website: (http://www.scspinalcord.org/health-care-and-research/south-carolina-spinal-cord-injury-research-fund/research-brief-south).

   While data collection was still in the early phase, two manuscripts on the epidemiology of SCI in South Carolina were developed (both in press; See Dissemination: Saunders, Selassie, Zebracki, & Vogel, in press; Selassie, Cao, & Saunders, in press). The rates of SCI in South Carolina for persons 0-21 years old were 26.9 per million population and 70.8 per million population for those 22 or older. While the rate significantly increased in the adult population between 1998-2011, there was a trend towards decreasing rate in the pediatric population. In both the pediatric and adult populations, age-adjusted incidence rates were higher among non-whites than whites.

   We recently had a manuscript published online by *Spinal Cord* on the rate of smoking and attempts at smoking cessation in persons with SCI in South Carolina (See Dissemination: Saunders & Krause, epub ahead of print). This paper identified very high smoking rates in this population (35.3%), which is significantly higher than the general population in South Carolina (21.0%), as well as recent smoking rates of persons who received inpatient rehabilitation at Shepherd Center (22.6%).

   In addition, we submitted a manuscript on hospitalizations and emergency department visits in persons with SCI in South Carolina to the *Archives of Physical Medicine and Rehabilitation*. This paper is a collaborative effort between Drs. Saunders, Murday, Cao, Krause and Beth Corley, and looks at self-report and administrative billing data of hospitalizations and emergency department visits in the prior 12 months (based on the baseline survey). The paper uniquely was able to analyze both self-report as well as administrative data together, as most research focuses on only one or the other.

5. *Beginning at the end of the third year, after sufficient time for accrual of data, develop a de-identified dataset that includes variables similar to the SCI Model Systems, such that it could be utilized by qualified investigators in SCI throughout the state. By including a core number of variables in common with the SCI Model Systems, we would be able to benchmark outcomes in South Carolina against the SCI Model Systems and use this information to advocate for better services for those with SCI within South Carolina. The de-identified data set will be updated at the end of years four and five.*

   While we have made significant progress in data collection, we are still in the process of collecting new data, and thus a de-identified dataset has not yet been completed. In the spirit of assisting other SCI investigators around the state, we have used available collected data to assist in other research studies. For example, we were able to identify ambulatory persons for a gait study and sent out recruitment brochures for PI, Chris Gregory, PhD. This effort was successful in recruiting interested participants. We assisted Nate Bell, who is working with Dr. David Murday, on developing a pilot project looking at geographic disparities in access to health care.

We have also agreed to work with investigators who wish to analyze the outcomes data from the study.

Additionally, we have included variables that can be cross-walked with data collected through the SCIMS. Variables also collected in the SCIMS are: demographics, injury characteristics, education, employment, alcohol use, hospitalizations (and days in the hospital), pressure ulcers, hours out of bed, days out of the house, self-rated health, pain, depression, and quality of life. Table 3 displays the demographic characteristics of the South Carolina population and the SCIMS.

Table 3. Comparison of South Carolina with the SCIMS on key demographic characteristics.

Characteristic	South Carolina	SCIMS*
	Column %	
Sex		
Male	71.5	80.7
Female	28.5	19.3
Race/Ethnicity		
White	60.6	67.0
Black	34.4	24.4
Hispanic	2.0	7.9
Other	3.0	0.7
Age at Injury	49.5	42.6

*from: 2013 Facts & Figures (https://www.nscisc.uab.edu/PublicDocuments/fact_figures_docs/Facts%202013.pdf)

6. *Routinely disseminate information on services and resources throughout the state of South Carolina to participants as they enter the surveillance system and during routine follow-ups.*

   As stated above, we have disseminated information on service use through the SCSCIA website (http://www.scspinalcord.org/health-care-and-research/south-carolina-spinal-cord-injury-research-fund/research-brief-south). Dr. Saunders presented in March 2013 to researchers and stakeholders at the SCI Research Fund conference, as well as in March 2014 to stakeholders at the Breeze Conference in Columbia, SC. Participants receive information from the study through bi-annual newsletters. Additionally, all potential participants were sent relevant information on SCI services in South Carolina. In May 2015, Dr. Saunders will travel to an international SCI conference in Montreal, Canada to present the results from the smoking analysis, as well as results focused on health care access and utilization in the cohort.

<u>Supplemental Objectives (not covered by the funding request)</u>

1. *Build capacity for additional research by adding a review and funding mechanism that allows investigators to add items or instruments to the database for research purposes consistent with collecting pilot data and the initial intention of our previous Call for Proposals. This in essence would replace our previous type of call for proposals, while meeting needs of investigators by having a centralized data collection mechanism that will be more cost effective and efficient.*
2. *Insure the capacity for collection of clinical data to augment the outcome data (e.g., clinical or biomarker data could be collected at different sites throughout the state). The availability of the database will open up the capacity for this type of clinical study, as there will be basic data on*

individuals with certain types of injuries and outcomes and this will allow investigators to identify needed participants.

We will continue to support these supplemental objectives, although no specific funding mechanism within the SCI Research Fund has been developed for investigators to analyze data from the database, other than the pilot grant mechanism.

3. *In the past year, we added another objective to the project that goes beyond the original objectives, which is to enroll participants who self-identify through the South Carolina SCI Association newsletters. Through this avenue, we identified 47 potential participants (not included in the original sampling frame), who self-identified to participate. We sent introductory letters to these participants and will send recruitment materials at the end of May 2015.*

Dissemination

Publications

1. Saunders, L. L., Selassie, A., Cao, Y., Zebracki, K., & Vogel, L. (in press). Epidemiology of pediatric traumatic spinal cord injury in a population-based cohort, 1998-2012. *Topics in Spinal Cord Injury Rehabilitation*.
2. Selassie, A. W., Cao, Y., Saunders, L. L. (in press). Epidemiology of traumatic spinal cord injury among persons older than age 21: A population-based study in South Carolina, 1998-2012. *Topics in Spinal Cord Injury Rehabilitation*.
3. Saunders, L. L., Krause, J. S., Saladin, M., Carpenter, M. J. (epub ahead of print). Prevalence of cigarette smoking and attempts to quit in a population-based cohort with spinal cord injury. *Spinal Cord,* first published online 28 April 2015, doi: 10.1038/sc2015.71.
4. Saunders, L. L., Murday, D., Corley, B., Cao, Y. Krause, J. S. (under review). A comparison of rates of hospitalization and emergency department visits using self-report and administrative billing data among a population-based cohort of persons with spinal cord injury. *Archives of Physical Medicine and Rehabilitation.*
5. Saunders, L. L., Krause, J. S. (manuscript in preparation). Healthcare access and socioeconomic status: A comparison of population-based and clinically-based cohorts.

Presentations

1. Saunders, L. L., Krause, J. S., Saladin, M., & Carpenter, M. Prevalence of cigarette smoking and attempts to quit in a population-based cohort with spinal cord injury. Poster presentation at the 4th ISCoS and ASIA Joint Scientific Meeting, Montreal, Canada: May 2015.
2. Saunders, L. L. & Krause, J. S. Socioeconomic status and health care access after spinal cord injury: A comparison of population-based and clinically-based cohorts. Poster presentation at the 4th ISCoS and ASIA Joint Scientific Meeting, Montreal, Canada: May 2015.
3. Saunders, L. L., Murday, D., & Krause, J. S. Health care access and utilization after spinal cord injury. Poster presentation at the annual conference of the Academy of Spinal Cord Injury Professionals, St. Louis, MO: September, 2014.
4. Saunders, L. L., & Krause, J. S. Chronic disease prevalence among persons with traumatic spinal cord injury. Oral presentation at the annual conference of the American Spinal Injury Association, San Antonio, TX: May 2014.

5. Saunders, L. L. Measuring outcomes after spinal cord injury in South Carolina. Oral presentation at the Breeze Leader Conference, Columbia, South Carolina: March 2014.
6. Saunders, L. L., Krause, J. S. Secondary conditions after spinal cord injury in a population-based cohort. Oral presentation at The Science of Prevention: Managing Secondary Health Conditions in People with Spinal Cord Injury, the pre-course to the annual conference of the American Spinal Injury Association, Chicago, IL: May 2013.
7. Saunders, L. L. Health outcomes among persons with spinal cord injury in South Carolina. Oral presentation at the South Carolina Spinal Cord Injury Research Fund Scientific Conference, Charleston, South Carolina: March 2013.

Webcasts

1. Saunders, L. L. Health Care Access and Utilization after Spinal Cord Injury. Webcast presented November 20, 2014. Archived: http://academicdepartments.musc.edu/chp/longevity_after_injury/Events/webcasts.htm
2. Saunders, L. L. Secondary Conditions after SCI in a Population-based Cohort. Webcast presented May 22, 2013. Archived: http://academicdepartments.musc.edu/chp/longevity_after_injury/Events/webcasts.htm

Preliminary Results

Table 4. Cohort demographic and injury characteristics

Characteristic	%
Sex	
Male	71.5
Female	28.5
Race/Ethnicity	
White	60.6
Black	34.4
Hispanic	2.0
Other	3.0
Age at survey	49.5 (16.9)
Years post-injury	5.8 (3.8)
Injury Severity	
C1-C4, Non-ambulatory	6.3
C5-C8, Non-ambulatory	12.1
Non-cervical, Non-ambulatory	16.9
Ambulatory	64.8

Table 5. Socio-economic characteristics

Characteristic	%
Annual household income	
<$25,000	60.2
$25,000 - $74,999	28.8
$75,000+	11.1
Highest level of education	
Less than high school	20.3
High school degree/GED	37.2
Associates/Technical degree	27.5
Bachelor's degree or higher	15.0
Currently Employed (ages 18-64)	18.9
Employed at injury	64.1
Among Unemployed (18-64 years)	
Hope to return to work	62.4
Actively looking for work	26.7

Table 6. Employment characteristics by whether participants were employed at injury.

	Employed at Injury	
	Yes	**No**
	Column %	
Worked at all post-injury	40.9	15.0
Currently working	23.9	6.5
Years to first job		
Mean (s.d.)	2.2 (2.3)	2.8 (2.3)

Table 7. Insurance status pre- and post-injury*

Characteristic	Pre-injury	Post-injury
	Column %	
Medicaid	19.8	33.1
Medicare	23.4	46.3
Worker's Compensation	7.9	3.8
Private	35.2	24.1
Other	17.2	16.0
No Insurance	18.7	15.8

*Percentages do not add to 100% as persons could select more than one type

Table 8. Healthcare Access and Utilization.

Variable	%
Healthcare Access	
Routine check-up	
Past year	70.4
1-2 years ago	12.1
More than 2 years ago	17.5
Time in the past year no insurance	
Yes	20.8
Regular health care provider	
No	10.5
Yes-one	73.1
Yes- more than one	16.4
Missed care due to cost or transportation	38.7
Trouble paying medical bills in past year	42.5
Currently have unpaid medical bills	52.8
Healthcare Utilization	
Hospitalizations in the past year	
0	60.9
1	28.2
2+	10.9
Days hospitalized	
Mean (s.d.)	12.4 (14.6)
ED visits in past year	
0	51.2
1	29.3
2+	19.5
Surgeries in the past year	
0	69.4
1	26.3
2+	4.3

Table 9. Alcohol Use and Smoking

Variable	%
Alcohol Use	
Consumed alcohol in the past 30 days	51.0
Binge drinking in past 30 days	24.8
Smoking	
Smoking Status	
Current	35.3
Former	29.5
Never	35.2

Table 10. Health Outcomes

Variable	%
Pressure Ulcers	
PUs in past year	30.0
Hospitalized due to PU in past year	13.4
Current PU	15.3
Among those w/ a PU in past year, % who postponed/missed care due to cost or transportation	17.5
Subsequent Injuries	
Injury in past year	27.3
Of those injured, percent limited in normal activities >1 month	37.1
Broken bone since SCI	15.5
Amputation since SCI	4.9
Depression	
Major Depressive Disorder (MDD)	23.6
Seen a mental health care professional in past year	14.2
Felt needed mental health care but could not access because cost/transportation	22.8
Among those with MDD	
Seen a mental health care professional in past year	20.7
Felt needed mental health care but could not access because cost/transportation	50.0
Chronic Health Conditions (Lifetime)	
Diabetes	14.9
Heart Attack	6.9
Coronary Heart Disease	7.6
Stroke	8.3
Hypertension	41.0
High cholesterol	31.0
Cancer	8.9