

## Cumulative Technical Progress Report November 2015

Grant Number: SCIRF 09-001

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 continue to make progress on this ongoing objective. At the time of the submission of this report, we have a total of 1023 individuals enrolled from the surveillance system and a total of 1051 total enrolled participants (28 were from the SCI Association which is discussed later).

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 objective 2, interrelated with objective 1. The preliminary task required development of 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 were undertaken to identify key elements of importance for people with SCI, including issues most pertinent to persons with SCI in South Carolina. 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). Some of this data has been analyzed and submitted for publication (also discussed later in the report).

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. To date, we have a total of 696 follow-up measures collected. We are in the process of collecting the data for the current year, so these numbers will improve prior to initiating the next full follow-up midyear next year.

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.scspscinalcord.org/health-care-and-research/south-carolina-spinal-cord-injury-research-fund/research-brief-south>).

Two manuscripts on the epidemiology of SCI in South Carolina were developed and published (See Dissemination: Selassie, Cao, & Saunders, 2015; Saunders, Selassie, Cao, Zebracki, & Vogel, 2015) in *Topics in Spinal Cord Injury Rehabilitation*. The rates of SCI in South Carolina were 26.9 per million population for persons 0-21 years old and 70.8 per million population for those 22 or older. While the rate significantly increased in the adult population between 1998 and 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 published a manuscript in *Spinal Cord* on the rate of smoking and attempts at smoking cessation in persons with SCI in South Carolina (See Dissemination: Saunders & Krause, 2015). 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 self-report and administrative data together, as most research focuses on only one or the other. This manuscript is currently under review.

We have been analyzing two types of data, with Dr. Murday and Beth Corley taking the lead on the data analytics. These two analyses of data focus on future utilization among persons with given characteristics and differentiating between high and low utilizers, and the extent to which the utilization patterns are due to SCI specific causes. Depending on the results, these may be developed into manuscripts.

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.*

The data set is constantly expanding and we have not put together a de-identified data set per se, but we will put one together if requested by an investigator for a specific analysis. That way, the request would use the maximum available data. We have put together data sets that have been used with Dr. Murday and Ms. Corley. We also have assisted others around the state with the recruitment of using the database. 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. 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. Recently, we assisted Dr. Aiko Thompson with recruitment for three SCI studies. She currently holds a SCSCIRF grant.

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.scspscinalcord.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 traveled 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. Additionally, Dr. Cao presented on “Neighborhood disadvantage and self-reported health after spinal cord injury” at a national conference in September 2015.

#### Supplemental Objectives (not covered by the funding request)

*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.*

1. 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. This actually has begun at Roger C. Peace as a distinct initiative.
2. 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 sent recruitment materials at the end of May 2015. To date, we have received 28 responses.

### Future activities

Our plan is to continue to collect data through the end of the no-cost extension and likely request an additional year to continue the work, as we have been good stewards of the resources and are still collecting important new data. We are also conducting important data analyses.

## **Dissemination**

### Publications

1. Selassie, A., Cao, Y., & Saunders, L.L. (2015). 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*, 21(4), 333-344.
2. Saunders, L.L., Selassie, A., Cao, Y., Zebracki, K., Vogel, L. (2015). Epidemiology of pediatric traumatic spinal cord injury in a population-based cohort, 1998-2012. *Topics in Spinal Cord Injury Rehabilitation*, 21(4), 325-332.
3. Saunders, L. L., Krause, J. S., Saladin, M., Carpenter, M. J. (2015). Prevalence of cigarette smoking and attempts to quit in a population-based cohort with spinal cord injury. *Spinal Cord*, 53(8), 641-645. 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. Cao, Y., Krause, J. S., & Saunders, L. L. Neighborhood disadvantage and self-reported health after spinal cord injury. Oral presentation at the annual conference of the Academy of Spinal Cord Injury Professionals, New Orleans, LA: September 2015.
2. 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 4<sup>th</sup> ISCoS and ASIA Joint Scientific Meeting, Montreal, Canada: May 2015.
3. 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 4<sup>th</sup> ISCoS and ASIA Joint Scientific Meeting, Montreal, Canada: May 2015.
4. 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.

5. 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.
6. Saunders, L. L. Measuring outcomes after spinal cord injury in South Carolina. Oral presentation at the Breeze Leader Conference, Columbia, South Carolina: March 2014.
7. 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.
8. 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](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](http://academicdepartments.musc.edu/chp/longevity_after_injury/Events/webcasts.htm)