

TECHNICAL PROGRESS REPORTING

SCIRF # 2016-SI-01

PI: Dr. Kevin Kopera

Grant Title: Prospective Study Registry of Individuals in SC with SCI

10 month Technical Progress Report

Specific Aim 1: To create a web-based registry database using REDCap to collect demographic and injury characteristics of individuals with Spinal Cord Injury (SCI). This Registry Database will consist primarily of data elements from the National Institute of Neurological Disorders and Stroke (NINDS) Common Data Elements (CDE) for Spinal Cord Injury (<https://commondataelements.ninds.nih.gov/default.aspx>). In addition to the CDE's, unique data elements will be included.

STATUS: Completed

DETAILS: The registry database has been completed in RedCap based off of the NINDS CDE for Spinal Cord Injury.

Specific Aim 2: To obtain IRB approval in Greenville, SC to begin enrolling patients at Roger C. Peace Rehabilitation Hospital.

STATUS: Completed

DETAILS: IRB application was submitted to the Greenville Health System IRB on August 11, 2016 and approved on September 14, 2016.

Specific Aim 3: Begin enrollment of inpatient and outpatient SCI through Roger C. Peace. Individuals will be consented to participate in the Registry Database. In addition, to participating in this database, SCI individuals will also be asked if they can be contacted regarding future research study participation.

STATUS: In Progress

DETAILS: We officially opened the study to enrollment in November 2016. To date (March 17, 2017), 5 participants have been enrolled from the inpatient population. We are currently working with our outpatient program therapists to determine the most effective way to open enrollment to our outpatient population. We will begin enrolling in our outpatient physician clinic this summer.

Specific Aim 4: Troubleshooting and database revisions based in initial participants enrolled.

STATUS: In Progress

DETAILS: Our inpatient identification, Informed Consent process, data collection, and participant stipend payment processes have been developed and successfully put in place. Minor database revisions have occurred.

Long Term Aim: The long term goal of this project is to create a prospective registry database accessible to other South Carolina institutions treating patients with SCI. REDCap has the ability to allow GHS to

March 22, 2017

house database data, however allow individual sites to enter and maintain their own data. GHS would have the ability to run statewide data queries following appropriate regulatory approval.

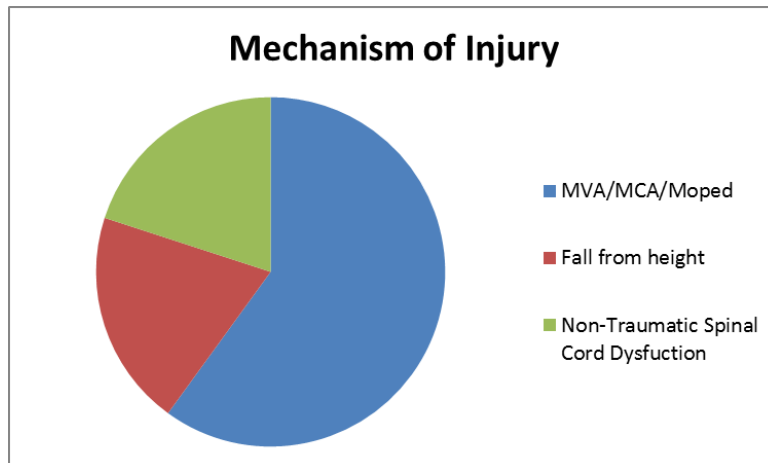
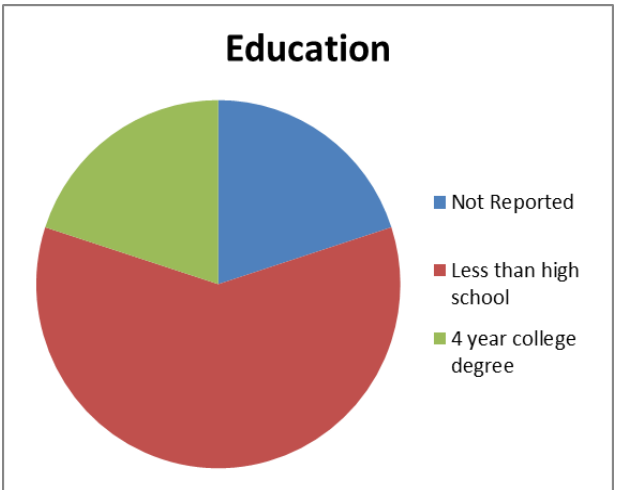
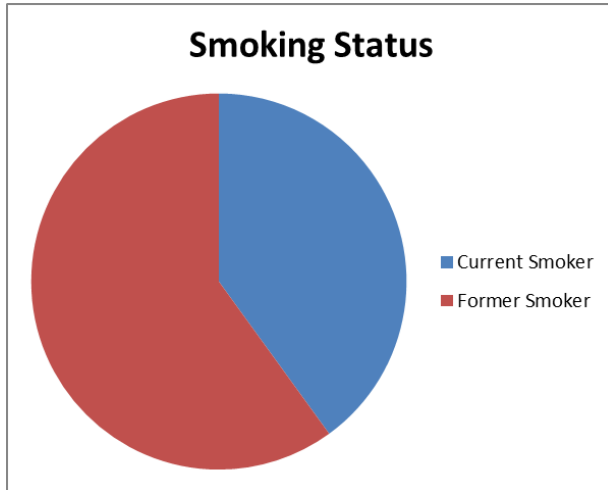
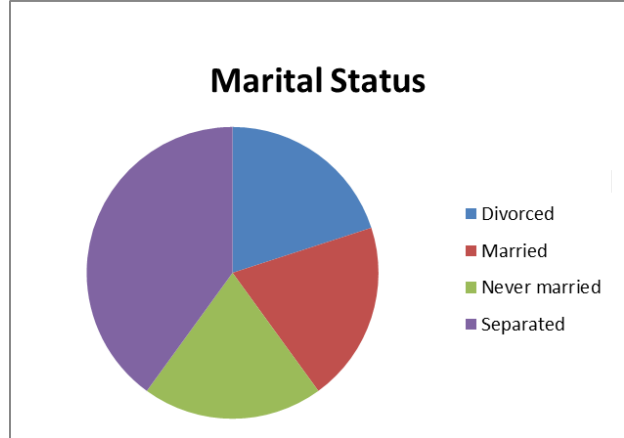
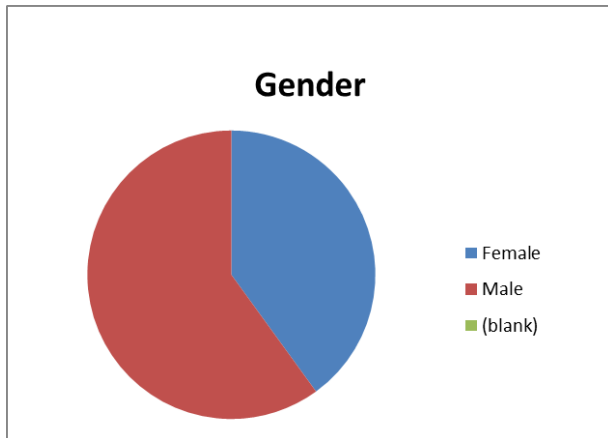
This registry will all for the collection of demographic and functional information from individuals with SCIs in South Carolina to enhance medical based knowledge in order to better the lives of other people with the same types of injuries.

STATUS: In Progress

DETAILS: Once we are able to fully implement the SCI Registry Database into our outpatient clinic, we will increase discussions with other sites throughout South Carolina. We plan to request a no-cost extension for this current grant, and we are beginning to prepare a grant request for additional funding for future years.

Data Analysis

Demographics	Average
Age	40 (18 – 60)
Days hospitalized (n= 3)	77 (37-119)



Injury Information

Adding new Record ID 9999

Record ID 9999

Acute admission date (MM/DD/YYYY) M-D-Y

Injury date (MM/DD/YYYY) M-D-Y

Date of inpatient discharge (MM/DD/YYYY) M-D-Y

Place of discharge

Total number of days hospitalized

Injury etiology

- Sports/leisure
- Assault
- Transport (MVA, MCA, Moped)
- Fall from height
- Fall from standing
- Other traumatic cause
- Non-traumatic spinal cord dysfunction
- Unspecified or unknown

Vertebral injury

Injury level

Any associated injuries

Did this patient have spinal surgery for this injury?

If yes, please list the surgery date(s)

Expand

Does this patient require ventilatory assistance?

Patient Demographics

Adding new Record ID 9999

Record ID 9999

Date form completed
(MM/DD/YYYY)

* must provide value

M-D-Y

Birth date
(MM/DD/YYYY)

* must provide value

M-D-Y

Patient Age

[View equation](#)

Patient gender

Race category (choose all that apply)

- American Indian or Alaska Native
- Asian
- Black or African-American
- Native Hawaiian or Other Pacific Islander
- White
- Unknown
- Not reported

Ethnicity

Marital Status

How many members are there in your household (including yourself)

Area of residence

How many years of education have you completed?

What is your primary occupation?

- Paid work (employed, self-employed, including military)
- Homemaker
- Student (including on the job training)
- Retired (disability pension)
- Retired (non-disability)
- Unpaid work (volunteer)
- Unemployed (none of the above)
- Other (specify)
- Unknown