



## Krause's Corner



Dear friends,

We are truly excited to share the great news that we have received funding for three new or extensions of existing SCI research studies!

Study 1:

### **Aging and Participation after Spinal Cord Injury: Promoting Utilization to Enhance Community Outcomes**

We are continuing our aging study to 50 years! My mentor, Dr. Nancy Crewe, the most compassionate person I have known in the field of SCI rehabilitation, started the study in 1973. This was the same year as the passing of the Rehabilitation Act, which was done to help people with disabilities fully participate in society.

This project will be conducted over the next five years. We will do open-ended focus groups with up to 60 people with SCI and we will obtain detailed life stories from 20 people as examples of living well with SCI. Our study participants include some of the pioneers in the field of independent living. We are very proud of what they had done. We also will collect data by mail or online that will help us to understand the problems faced and how they change over time. Some participants will complete their 10<sup>th</sup> follow-up over 50 years! This is truly unique.

Study 2:

### **Risk of opioid use disorder and related consequences: A longitudinal study of spinal cord injury**

This is a five-year project to develop new tools to reduce opioid misuse, opioid use disorder (OUD), and opioid related consequences among those with SCI. We will reach out to over 4000 people who have participated in our previous research with mail surveys and will interview a select group of people who have opioid experiences.

Study 3:

### **Understanding and Promoting Longevity after Spinal Cord Injury: A Mixed Methods Study of Participation, Employment, and Quality of Life**

This three year project will look at how non-health related factors impact long-term survival. The project will include in-depth with 30 – 40 participants who have outlived all expectations. We will do survival analysis to see how things like living in the community, working, and being active affect longevity.

We work to use the information from these projects to educate those providing services. We will continue to share information that may be of benefit and to do everything possible so that they have the greatest possible impact.

Thank you for your support and let's look forward to making this happen. - Jim

# Participant Milestone



This month, we are highlighting Don Bania, who is an SCI disability advocate and reached his 50 years living with an SCI in August 2020! Read Don's Celebration letter at the link below:

<https://scspinalcord.org/don-bania>

## Research Updates

**45 Year Longitudinal Aging Study:** This project is wrapping up the 45th year of study. The adjusted response rate after taking into account the deceased participants is 86.5%. This study is the most long-standing study of SCI anywhere in the world. **How amazing that we have 29 individuals who have been in this study for 45 years** and over 500 others who have joined the study since that time who are still actively participating!

**Negative Health Spirals Study:** We are analyzing the data and it is helping us understand how negative health patterns or spirals emerge. **Many people are caught off guard by something that happens, particularly a pressure ulcer, and then simply cannot stop the spiral.** Some people have lived with conditions for a very long time. Others have had complications that led to life changes, such as amputation. We are learning from the data we analyze and the openness and sharing of our participants of their life experiences. We will continue to share our findings in newsletters and on the website where we summarize our findings.

**Employment:** The purpose of this study is to assess quality employment indicators and outcomes in persons with SCI. We have published over a dozen manuscripts from the study results. From the results of our paper on benefits of working after SCI, **people with SCI stress the importance of employment as a means of financially supporting one's self and family, and getting health insurance and other fringe benefits.** The participants also identified important other aspects of working that included developing relationships and social networks, having a sense of purpose and accomplishment, and feeling that they had better mental health.

**Number, Primary and Secondary Diagnoses, and Costs of Inpatient Hospitalizations in a Population-based Cohort of People with Spinal Cord Injury:** We have completed three new manuscripts. We just had a manuscript entitled "The association between participation and quality of life indicators with hospitalizations in ambulatory adults with spinal cord injury" accepted for publication in the journal *Spinal Cord*.

In our manuscript, "Costs of Healthcare Services among High Utilizers of Healthcare Services over the First 10 Years after Spinal Cord Injury (SCI)", we found that **most of emergency department and hospital charges were for a relatively small portion of participants (69% of the charges were among the "high users" who made up only 16.5% of the cohort).** Therefore, efforts to prevent health problems should be aimed at people who are high users of costly healthcare.

**Number, Primary and Secondary Diagnoses, and Costs of Emergency Department Visits (ED) in a Population-based Cohort of People with SCI:** We are looking at ED visits and hospitalizations at the SCI Model System through the Shepherd Center in Atlanta, GA. We are finding that people with SCI are more likely to have ED visits and more likely to be hospitalized with ED occur compared with people in the general population. People with SCI also report a much different pattern of reasons for going to the ED.

**South Carolina SCI Outcomes Study:** This is an opportunity for us to continue to identify important outcomes for people with SCI in South Carolina and to do research that will hopefully lead to effective changes to improve outcomes. We are in the process of

collecting data from participants through a self-report assessment. We have collected 57 assessments from newly injuries participants (1.5 years post injury) and 336 follow up assessments (3, 4, 5, 10, 15 and 20 years post injury).

**Knowledge Translation Study:** We are making progress on our pressure ulcer data analysis, which will be the next topic for a calculator. The calculators were

designed to help people understand their risk for different outcomes, such as fall related injuries, and what factors may be leading to a higher or lower risk. You can find 3 calculators (**life expectancy, unintentional injuries due to falls, unintentional injuries**) and a variety of other tools available on our SCI Health Employment Longevity Project website:

<https://chp.musc.edu/research/help/tools>.

## Research Brief

### Costs of Healthcare Services among High Utilizers of Healthcare Services over the First 10 Years after Spinal Cord Injury (SCI)

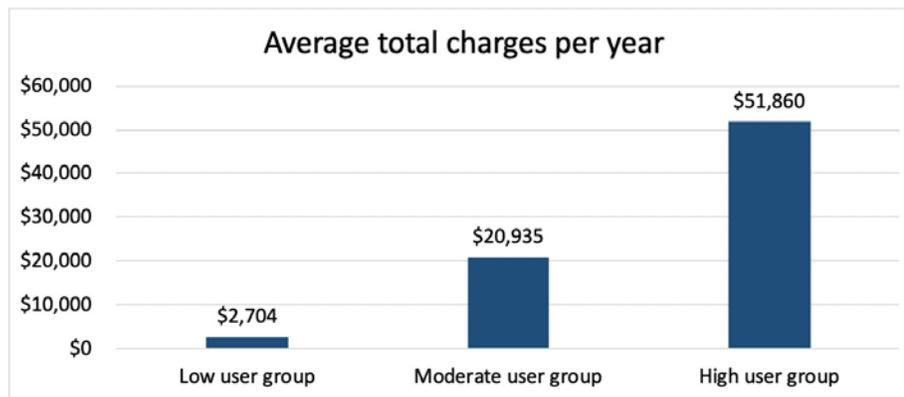
#### Introduction

People with spinal cord injury (SCI) have high rates of being re-hospitalized or visiting the hospital emergency department (ED). The purpose of our study was to find the causes of hospitalizations and the types of people with SCI who use the most services.

We had 303 participants, most being male (71%) and white (60%). We used administrative billing data for the cost and causes of hospitalizations. We also had the participants fill out a survey about themselves, and their behaviors, health status, and access to healthcare. From this information, we were able to identify who is most likely to use costly healthcare services.

#### Key Research Results

- Total hospital charges for these participants were \$49.4 million over the 10-year period.
- The primary hospital diagnoses were septicemia, UTI, complication of a device, and pressure ulcers.
- Participants fell into 3 categories:
  - Low use of costly healthcare (53% of the participants)
  - Medium use of costly healthcare (30% of the participants)
  - High use of costly healthcare (16.5% of the participants)



- The high use group had an average of 9.6 inpatient hospitalization days per year and 2.6 ED visits per year.
- High users were more likely to be male, nonwhite, have a severe SCI, have a lot of pressure ulcers, and have income of less than \$35,000 per year.
- As seen below, average total hospital charges ranged from \$2,704 in the low use group to \$51,860 in the high use group

## Conclusions & Implications

Our study found that most of inpatient charges were for a relatively small portion of participants (69% of the charges were among the “high users” who made up only 16.5% of the cohort). Therefore, efforts to prevent health problems should be aimed at people who are high users of costly healthcare.

**Reference:** Krause, J. S., Murday, D., Corley, E.H., & DiPiro, N.D. (2018). Concentration of Costs among High Utilizers of Healthcare Services over the First 10 Years after Spinal Cord Injury Rehabilitation: A Population-based Study. Archives of Physical Medicine and Rehabilitation.

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## Resource Highlight



Check them out:

<https://unitedspinal.org/>

**United Spinal Association** is dedicated to enhancing the quality of life of all people living with spinal cord injuries and disorders (SCI/D), including veterans, and providing support and information to loved ones, care providers and professionals. They have developed a tremendous amount of resources including a **national** network of peer support groups called the “**Spinal Network**”.

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