



Research Updates

A few words of wisdom based on what we have learned from our participants. During this time of COVID-19, it is more important than ever to not get complacent because you have avoided health problems successfully so far. Keep a watchful eye. To the best of your ability, surround yourself with people who care and people who know of your situation. Many participants have not shared their situation with family and friends, so they have not had the support necessary when problems have occurred. If you have something that starts to develop, do not take it lightly. Many of the things we have seen are truly preventable at the beginning. However, once they have reached a certain point, it has been difficult for some folks to recover. The old expression that an ounce of prevention is worth a pound of cure.

45 year Longitudinal Aging Study: This study 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 Benefits of working after spinal cord injury manuscript, **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.

We again are very pleased to report additional acknowledgment for our work. Although not directly related to the current project, we had a manuscript on opioids and employment, entitled "Employment status, hours working, and gainful earnings after spinal cord injury: Relationship with pain, prescription medications for pain, and non-prescription opioid use," noted as the Editor's Choice for the month of March by the journal *Spinal Cord*.

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 *Spinal Cord*. This manuscript was also submitted as an abstract to the annual conference of the American Congress of Rehabilitation.

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 in-patient 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. We expect new findings in about nine months.

Number, Primary and Secondary Diagnoses, and Costs of Emergency Department Visits (ED) in a Population-based Cohort of People with Spinal Cord Injury: We are looking at ED visits and hospitalizations at the SCI model system, the Shepherd Center, in Atlanta Georgia. 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 are also much more likely to go to the ED by ambulance.

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 for 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).

Online Risk Calculators are now [available to check out](#)

Knowledge Translation Study: We are truly thrilled that three individualized tools for determining risk of outcomes are now available online. As part of our Knowledge Translation grant, we are developing online risk calculators, where a person will enter personal demographic information/risk factors and receive immediate results.

Our first calculator, **life expectancy**, <https://chp.musc.edu/research/help/tools/life-expectancy-calculator> emphasizes socioeconomic factors that include education, work, and employment. Life expectancy estimates help people to get an idea of the average number of years of life left for people with SCI who have characteristics similar to them. Taking into account socioeconomic factors, the calculator shows how, in general, life expectancy relates to educational accomplishments, working, and having different levels of income. Life expectancy estimates are only general and no one lives to their exact life expectancy – some people will outlive the estimate, even substantially, while none of us is guaranteed tomorrow.

Two additional calculators focus on unintentional injuries:

Unintentional injuries <https://chp.musc.edu/research/help/tools/unintentional-injury-calculator>

Unintentional injuries due to falls <https://chp.musc.edu/research/help/tools/fall-related-unintentional-injury-calculator>.

Unintentional injuries are important to consider for people with SCI for many reasons. First, SCI itself is an injury, so we have all experienced the harsh realities that may follow a serious injury. Some of the activities that people do that result in the initial SCI are those that they continue to do after SCI. So, as much as we may not want to think about it, we continue to be at risk for additional injuries. In addition, some of the complications of SCI, such as pain, spasticity, difficulty sleeping, or dealing with depression or anxiety, may lead to taking prescription

medications. Coupled with other high-risk activities like nonmedical use of certain drugs and heavy drinking, this may also lead us to greater risk of injury.

Lastly, the consequences of having additional injuries, including those related to falls and those unrelated to falls, maybe severe. The calculators we developed will help people to understand how their activities relate to their risk of injuries. This will help people with SCI to make informed decisions regarding their own activities and to talk with their healthcare provider about how to lead the safest, most satisfying life.

Research Brief

Given the social isolation that is occurring during our response to COVID-19, we thought that this research brief is more relevant than ever.

Social isolation after spinal cord injury

What is the study about?

Social isolation has been addressed only to a limited degree among people with spinal cord injury (SCI). The purpose of this study was to help us understand social isolation among people with SCI. This includes both how often people are limited in *making social connections*, as well, as how they *feel emotionally about social activities*. The study was conducted with an older group of participants with SCI.

Who participated and how was the study was conducted.

768 participants completed self-report assessments in 2012-2014. The average age was 54.3 years old with an average of 27 years since SCI onset. We assessed both social disconnectedness (participation in social activities, social network) and perceived isolation (subjective measure on perceived lack of social support, loneliness).

What did the study find?

People who felt isolated and alone did indeed have greater social disconnectedness, which means they participated in fewer social activities and had a smaller social network. Being older and having a more severe SCI were related to greater social isolation.



Implications/recommendations?

Social support and being connected socially are very important after SCI. People who have survived a long time with SCI and appear to be more socially connected and felt less isolated. **It is important to continue to build and keep support networks as you age with SCI. Developing peer support networks of older individuals who have been successful in adapting to SCI may help those whose injuries are more recent.** Interventions that help people with SCI to increase their social contacts and be more engaged with social activities may be promising in reducing social isolation. The ultimate benefit of preventing social isolation is increased participation, quality-of-life, and longevity.

Reference: Newman, S., Li, C., & Krause, J.S. (2016). Social isolation after spinal cord injury: Indicators from the Longitudinal Aging Study. *Rehabilitation Psychology*, 61(4), 408-416. The contents of this research brief were developed under grants from the US Department of Health and Human Services Administration for Community Living, NIDILRR grant numbers 90RT5003, 90DP0098, 90IF0112, and 90IF00.

Krause's Corner

On July 23, 2020, we recognize the 30th Anniversary of the passing of the **Americans with Disabilities Act (ADA)**. This was landmark legislation designed to provide opportunities for people with disabilities, including areas of employment and independent living.

The ADA was a major step in the right direction, yet we still are falling well short of the goal of equal opportunity and treatment. We are often the last ones to benefit from a strong economy, yet the first ones to feel the setback when the economy wanes. We continue to have unmet needs in areas such as attendant care and vocational rehabilitation (VR) services. I was blessed to have outstanding VR services that predated the ADA, for which I am personally grateful. Yet, I know my case was the

exception, rather than the norm, and that since that time funding for services simply has not kept up with needs.

It is crucial that we educate others, advocate for needed services, and demand better enforcement of the ADA. We need social justice for people with disabilities. Our research both documents the resilience and outstanding outcomes of people with SCI – demonstrating what is possible; yet equally demonstrates our vulnerability and the importance of support services for us to maintain independence, health, and life itself.

Let us work toward obtaining social justice for all with SCI and other disabling conditions through advocacy and let our voices be heard.

To learn more about the department's ADA celebration, visit dol.gov/odep/topics/ADA.htm. To learn more about its disability-related policy work, visit dol.gov/odep.

Resource Highlight



Check them out:

<https://FacingDisability.com/>

FacingDisability is a nonprofit, which connects families who suddenly have to deal with a spinal cord injury to people like them who have already been there. They have hundreds of videos from medical experts and people living with SCI on topics that include the questions that people want answers to right away: "Spinal Cord Injury 101", sex and fertility issues, pressure ulcers, hospital transitions and how to cope, caregiver issues and family, adaptive sports to name a few.

Please feel free to contact us:

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