MUSC Medical University of South Carolina

Newsletter

South Carolina Spinal Cord Injury Outcomes Database

Special message

We know everyone is feeling the impact of the coronavirus (COVID-19). As a person who has lived with SCI for 48 years, I know that this is a serious situation and recommend everyone take precautions. We all have faced adversity and we can use what we have learned to help us through this. Our research team has continued to work through this pandemic, although remotely. Below are some resources that may be helpful. We will get through this. - Jim Krause

The South Carolina Spinal Cord Injury Association (SCSCIA) is a chapter of United Spinal. SCSCIA provides a variety of services, including information, education, referral, peer support, and support to families and professionals who serve those with spinal cord injuries. They are here for you. For information and referrals, please call them at 803-252-2198 or email them at info@scspinalcord.org

SCSCIA Online Peer Support Groups

Occur every Wednesday at 1:30 PM EST
Website: https://zoom.us/j/340781916
Meeting ID: 340 781 916
Phone number: 1-929-436-2866

Shepherd Center

SCI and COVID-19 information: https://news.shepherd.org/what-you-need-to-know-coronavirus-and-people-with-spinal-cord-injuries-brain-injuries-or-ms/

Staying Prepared: https://news.shepherd.org/staying-prepared/

A Conversation with Alex Jackson

With his contagious smile and positive personality, Alex Jackson is the type of person who leaves a lasting impression on you. Injured at the C5-C6 level when he was just 9 months old, Alex does not let his injury hinder his dreams, and he advocates for others, as well.

Alex, can you tell us a little more about yourself?
I am a double graduate from the College of Charleston. I received my BA degree in Media Studies Communication in 2010 and graduated with my Master's in Corporate Communication in 2014. I am a public affairs specialist for Naval Information Warfare Center Atlantic (SPAWAR). When I'm not at work, I enjoy spending time with family and friends, traveling and trying new restaurants.

How did you get involved in the SCI community and what is the most rewarding part? One of the first ways I became an SCI advocate was when Dr. Susan Newman conducted a community-based, participatory research study called Photovoice. It was a group of folks with SCI who took pictures of barriers and facilitators of accessibility that impacted our daily lives. Examples of facilitators included ramps, elevators, and family members who were our support system. Barriers were stairs, grocery carts blocking access aisles in parking lots, and doors without automatic buttons.

How do you perceive research? Is it important to you?
Research is important to me because it can show what is working well and what is not working. It also allows members of the community to share issues that are overlooked and not being addressed.

What resources can individuals in South Carolina with SCI utilize? There are several resources available throughout the state. The South Carolina Spinal Cord Injury Association, local Breeze peer groups within the association, MUSC Center for Rehabilitation Research, Roper Hospital Spinal Cord Injury Clinic, Encompass Health rehabilitation facilities around the state and other rehab hospitals including Roger C. Peace.

Research Highlights: Pain and SCI

Pain is a common issue for people with SCI, and is typically more severe in those with SCI than in the general population. Pain may include nociceptive pain, which is joint or muscle pain (e.g., aches, soreness) or neuropathic pain, which is nerve pain (e.g. burning, tingling, or shooting sensation) Pain can affect quality of life and function, and having more pain makes people more likely to take opioids to treat pain. Participants answered several questions about pain and how it affected them, and some of the findings are below.

Figure 1

Rating of pain on average (scale of 0-10)

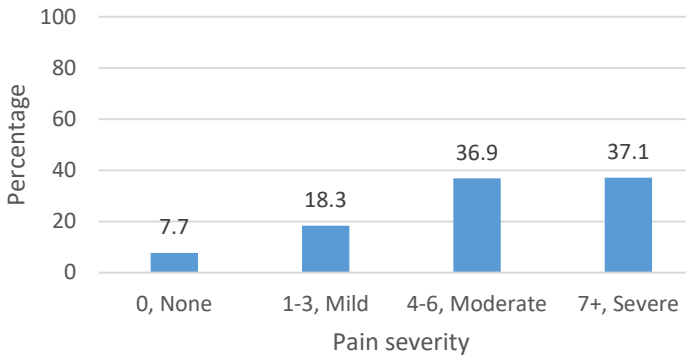

Figure 1 shows the portion or percentage of participants who reported different levels of pain on a scale from 0 – 10. We regrouped the pain severity variable into four categories: no pain, mild, moderate, and severe pain.

Most people reported moderate pain (4-6 on a scale of 0-10) or severe pain (7 or higher). Less than 1 out of every 10 participants reported no pain. Therefore, there is a large portion of people with SCI for whom pain is a major problem.

Portion of people using prescription meds for pain

Figure 2

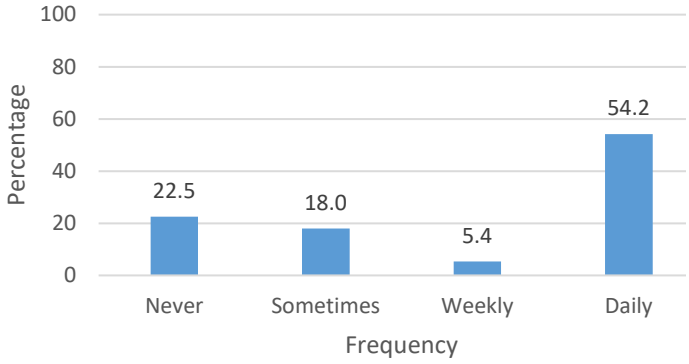

Figure 2 shows the portion of people who use prescription meds to treat pain and is broken down by how often they use them.

Over half of participants (54.2%) indicated they use prescription meds daily for management of their pain. 1 out of about every 5 people take no prescription medication at all for pain and another 1 out of 5 take it less than weekly.

Summary and Recommendations

The majority of participants (74%) reported experiencing moderate or severe pain, indicating that pain is a major problem. Of those participants who had at least one painful condition, over half reported daily prescription medication use to treat pain. To read more of our findings on pain, view our fact sheet here [https://chp.musc.edu/research/help/tools].

 This fact sheet is a product of grants 2017 SI-02 and 09-001 from the South Carolina Spinal Cord Injury Research Fund.

Research Highlights: Unintentional Injury and SCI

Unintentional injuries (UI) are injuries that happen as a result of some type of mishap, such as falls, motor vehicle crashes, and burns. They are one of the main reasons for people needing healthcare, including going to the emergency department or unplanned visits to the doctor. For many people, their SCI was due to UI. After SCI, people may be at risk for additional injuries because of the effects of SCI. Participants answered questions about their experience with UI, and some of the findings are below.

Walking status and the portion of people with 1 or more unintentional injury

Figure 3

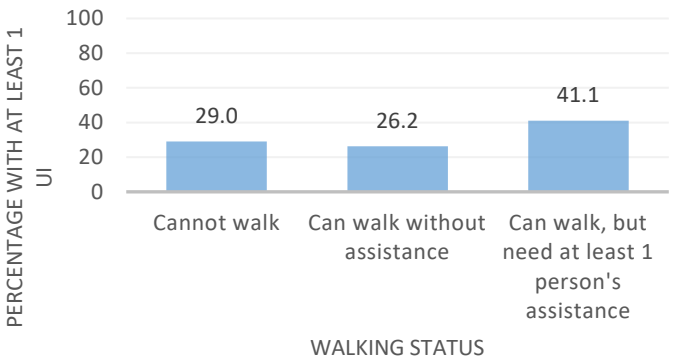

Figure 3 summarizes the portion of people with at least one unintentional injury (UI) based on whether somebody could walk and whether they needed help from another person to walk.

Those who can walk but need at least 1 person's assistance were at the highest risk for unintentional injuries. Over 4 out of every 10 people who could walk, but needed someone else's help, had at least 1 UI. Those who cannot walk or can walk without assistance had risk of less than 3 out of every 10 people.

How UI limited normal activities

Figure 4

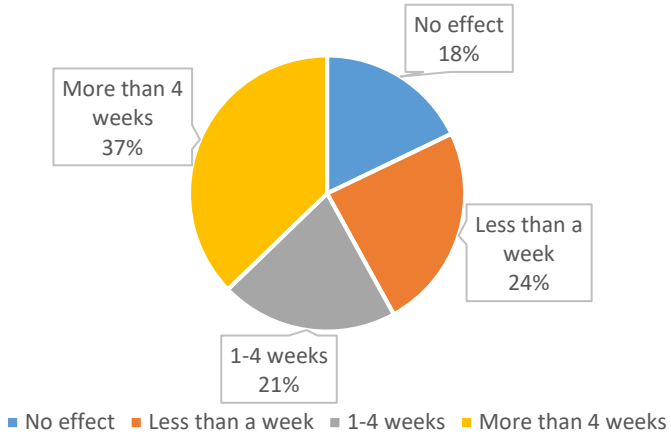

Figure 4 shows the relative portion of participants and how they were affected by UI over the past 12 months.

Among people who had UI, just under 4 out of every 10 people (37%) stated that their UI limited normal activities for more than 4 weeks. In contrast, nearly 2 out of every 10 people said that the UI did not limit their normal activities at all (18%). Therefore, when people do have UI, they typically have at least some effect on the individual's ability to continue normal activities and they have a major effect for just under 4 out of every 10 people.

Summary and Recommendations

Those who are ambulatory (can walk to some degree) are at a higher risk for UI, particularly related to falls. Injury prevention should target ambulatory individuals who cannot walk independently. Thirty-seven percent of the participants stated that their UI limited normal activities for more than 4 weeks. Further research findings on unintentional injury can be found here [https://chp.musc.edu/research/help/tools].

Message from Dr. Jim Krause

Dr. Krause serves as Scientific Director of the South Carolina Spinal Cord Injury Research Fund (SCSCIRF) and is the Associate Dean for Research in the College of Health Professions at the Medical University of South Carolina (MUSC).

As many of you know, our team has been doing research to help us understand the outcomes of people with SCI in South Carolina. We previously collected data on over 1,000 people with spinal cord injury (SCI). We continue to look at that data to see what we can learn that will allow us to better prevent some of the problems that occur most often.

In this newsletter, we share some of the basic findings on two different topics. The first is pain, which is a big problem for many people with SCI. The second is unintentional injuries. We present graphs related to these topics. We also provide links to more complete fact sheets on each topic.

We have **just started collecting new data**. To date, we have collected 43 assessments from newly injuries participants (1.5 years post injury) and over 300 follow up assessments (3, 4, 5, 10, 15 and 20 years post injury). This is a chance for us to partner with you. We ask that you help us by completing the surveys when we send them. In turn, we will analyze the data and share our findings with you. We will also publish findings in journals so that others with SCI may benefit and we will share our findings with people who will hopefully be able to allocate needed funds to help those with SCI.

We will send you newsletters once a year through email, if you have access, or by mail. We will post other newsletters and materials on the website: https://chp.musc.edu/research/help/tools.

Questions about SCI Please feel free to contact us! Phone: 843-792-2605, Email: aust@musc.edu . Thank you for your help!

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