Research Findings from the NWRSCIS

One of the missions of the Northwest Regional SCI System (NWRSCIS) is to conduct studies designed to improve care for people with SCI. Findings from two studies that our investigators conducted during the previous 5-year cycle of National Institute on Disability and Rehabilitation Research (NIDRR) funding were presented at the American Spinal Injury Association (ASIA) meeting in May 2013 and are summarized below.

**Venlafaxine XR for depression and pain after SCI**

By Charles Bombardier, PhD, Principal Investigator and Director of the NWRSCIS

**Why we did the study**

Depression and pain are two common conditions that make living with SCI that much harder. Though few like to admit they are “depressed,” the fact is that a group of symptoms that we call depression (including low mood, loss of interest in activities, sleep changes, appetite changes, poor energy, poor concentration, feeling worthless or guilty and thoughts of death or suicide) affect 20-30% of people with SCI (compared with about 7% in the general population). Pain affects even more people: 50-70% have chronic pain after SCI and for 20-30% that pain is severe. Treating depression and pain has been a major focus of our SCI Model System for years. Antidepressant medications have been used to treat depression and pain after SCI, but few if any high quality studies have been done to document what are the benefits and side-effects of this form of treatment.

**How the study was done**

With my colleague, Jesse Fann MD in the UW Department of Psychiatry and Behavioral Sciences, we led a team of six SCI centers in the first randomized, double-blind, placebo-controlled trial of the anti-depressant Venlafaxine XR (VFNXR) to see if it decreased depression and/or pain in people with SCI. Study participants were recruited from sites in Washington, Michigan, Texas, Alabama, Illinois and Florida. In the end, 133 people between 18 and 64 years old, at least one month post-SCI, and with a diagnosis of major depression participated in the study. Of those who participated, 94% also had chronic pain. Participants were randomly assigned to receive either a placebo (fake pill) or VFNXR for 12 weeks. They completed questionnaires periodically that measure depression and pain to see if any changes or improvements had occurred. Preliminary results show that while not all symptoms of depression improved more with VFNXR than with placebo, a subset of symptoms—including depressed mood, feelings of guilt, lack of pleasure and anxiety—did improve more with VFNXR. In addition, people who had non-neuropathic (or non-nerve related) pain improved significantly with VFNXR.

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Tips from the *Wheel World*
...wisdom and ideas for making life with SCI a little better, from individuals living with spinal cord injuries.

This is the second installment of our column featuring tips, ideas, fixes and modifications from other people living with SCI that help make life with SCI a little easier, healthier or more enjoyable. See previous tips at [http://sci.washington.edu/tips](http://sci.washington.edu/tips).

This installment comes from Aditya Ganapathiraju, a man with C5 incomplete tetraplegia and a member of our SCI Consumer Advisory Board.

**Sugru: Modify/adapt/fix (almost) anything**

**What is Sugru?**

Sugru is a moldable, silly-putty-like compound I use to make buttons and switches easier to grip on my camera, car, door locks and other equipment. Sugru dries overnight into a strong silicone rubber in any shape you need it. It bonds to most surfaces, including wood, plastics, most metals, glass, fabric and leather. It is waterproof, durable, removable, flexible when cured and stable at low and high temperatures (-50°C to +180°C).

**What do you use it for?**

So many things!

My first task was to make the buttons on my digital camera more tactile and easier to press with my nose or left index finger using only a small amount of force (Figure 1).

Once I discovered Sugru, I figured out many other uses that improve functionality of my “stuff”: twisting my doorknob lock (Figure 2); pressing the buttons on my car key remotes; pushing my phone charging cable into the phone; pressing the buttons inside my car that are a little tricky because they are flat and smooth (Figure 3); reinforcing electrical cables that are separating from the body of the device; and so on.

**Using Sugru**

The friendly and helpful Sugru website ([http://sugru.com](http://sugru.com)) tells you all you need to know about using this product.

Users share their ideas and photos online, and you can browse these different uses by category in their Guide ([http://sugru.com/guides](http://sugru.com/guides)). Directions, photos and videos provide instructions. You’ll be amazed at all the clever ideas and different uses—in the home, office, yard, car, boat, under water, in the wilderness, and much more.

**Where to get it:**

You can buy it exclusively on the Sugru website at [http://sugru.com/us/buy](http://sugru.com/us/buy). It comes in packets of different sizes and quantities. The smallest is three mini packs (5 grams each) for $10 (plus shipping). It is available in multi-color packs, black and white, or all black.

Often one pack is more than enough for many small fixes. It’s a good idea to make a mental list of all the uses you might want at once because after you open a packet you only have about a half an hour or so before it starts to harden up.

An unopened pack is good for six months if stored at room temperature or 18 months if refrigerated.

**Advice**

Go get some and let your Play-Doh-loving inner child out! (Note: Don’t eat it!)

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Do you have a tip to share with the SCI community? Please submit your ideas online at [http://sci.washington.edu/tips](http://sci.washington.edu/tips) and click on “Submit Your Ideas.”
What we learned

While the treatments we have are not yet as strong as we would like, they can be quite helpful. It is important to remember that both medical and behavioral approaches to treating depression and pain can help. For example, psychological counseling to learn relaxation skills, self-hypnosis, pacing, distraction and other coping strategies can help improve pain and reduce the amount pain interferes with life. The best results will probably come from using a combination of medical treatments and psychological counseling.

Next steps

We want to continue to get across to people that after SCI, depression and pain are common but not ‘normal’ or expected. These are treatable conditions. People with depression and/or pain should work with their doctors on achieving as much improvement as possible through the use of medications. We think additional improvement in depression can come by helping people find enjoyable and meaningful activities to become involved in and by helping them become more confident in their ability to manage the effects of SCI.

Scheduled telephone follow-up to improve outcomes after spinal cord injury rehabilitation

By Jeanne M. Hoffman, PhD, Principal Investigator and Co-director of the NWRSCIS

Why we did the study

Rehabilitation hospital stays after SCI have gotten shorter and shorter in recent years. As a result, people are often discharged without learning everything they need to know to take care of themselves and stay healthy. This not only causes distress to patients and families, but often leads to more medical complications and higher rates of clinic visits and hospital stays in the first year after injury. Patients and families have also told us that their first year after injury is a time of difficult adjustment and anxiety. We wanted to find out if we could improve this situation by having trained counselors regularly call patients during the first year to check up on the patients’ adjustment, answer questions and identify potential problems before they got serious.

How the study was done

We designed a randomized controlled trial comparing scheduled telephone follow-up with usual care during the first year after discharge from acute rehab. All newly injured patients at UW and Harborview Medical Centers were invited to join the study. Of the 168 individuals who enrolled, 85 were randomly assigned to receive scheduled follow-up telephone calls (the study group) and 83 to usual care (the control group) after discharge from the acute rehab unit. We asked them about clinic visits and hospitalizations at three, six, nine and 12 months and had them complete a questionnaire at one year asking about quality of life and adjustment.

What we learned

Our findings showed that scheduled telephone follow-up did not have the expected beneficial effect on health care utilization or medical complications compared to usual care. There are many possible reasons for this. For one, we know that not everyone needs help during this time, so our phone calls were not likely to make a difference in their situations. For those who do need help, many of them stay in close contact with their doctors and nurses during the first year and already get the help they need. For others, phone calls may not be enough. We may need instead to target individuals who have specific concerns and find ways to address those problems more effectively within the existing health care system.

Next steps

These findings and those of studies conducted by other SCI Model System centers have helped us design the SCI-CARE study we are now conducting for this current grant cycle. SCI-CARE enrolls individuals within the UW Medicine system who have requested help with specific problems that are typically difficult to manage in the current model of clinical care: depression, pain, and difficulty being active. It uses a collaborative care model in which a specially trained care manager works with the patient, his or her provider, and a team of experts to enhance health care delivery. This approach has been found to work well with patients who have chronic conditions such as diabetes and heart disease. If you currently receive your rehab care within the UW Medicine system and are interested in learning more about this study, see “SCI studies at the UW now recruiting” on the back page of this newsletter.
The 2013 SCI Wellness Summit on May 18 was an outstanding success, drawing upwards of 150 visitors—almost double the attendance of the first Summit in October 2011. The audience included individuals with SCI, family members and friends, caregivers, health professionals and students.

The free, half-day educational program was jointly presented by the Northwest Regional SCI System and the SCI Transitions and Wellness Program in the UW Department of Rehabilitation Medicine. Transitions is a health promotion program for individuals with SCI that was developed by the UW Medicine SCI Rehabilitation Core Group with initial grant funding from the Craig H. Neilsen Foundation. It has received ongoing support from the Kenny Salvini Fund for SCI Rehabilitation, the Unbroken Foundation’s Birdies for Brian charity event, and private donors. The Transitions program (http://sci.washington.edu/transitions) is located at both the UW and Harborview Medical Centers.

“We are thrilled not only with the attendance at this year’s SCI Wellness Summit, but the enthusiastic support of the symposium by the volunteers, artists and speakers that was critical to its success,” said Dr. Rina Reyes, medical director of UW Medicine SCI Rehabilitation. “The UW Medicine SCI Core Group, which oversaw the planning and development of the Summit, especially enjoyed the energy and engagement of the participants in the various presentations, and was pleased to be able to support educational enhancement, networking and mentorship opportunities in our local community. This is strong evidence of the Department of Rehabilitation Medicine’s commitment to serving the needs of consumers and health care providers in our community, and we hope to continue to have this level of impact in the future.”

A big draw this year was keynote speaker Daniel Lammertse, MD, an internationally recognized expert in SCI rehabilitation and the 2012 recipient of the prestigious American Spinal Injury Association (ASIA) Lifetime Achievement Award for his contributions to the world of spinal cord injury care. Dr. Lammertse is Clinical Professor of Rehabilitation Medicine at the University of Colorado.
Continued from previous page

Medical Director of Research at Craig Hospital in Denver, and co-director of the Rocky Mountain Regional SCI System.

In his talk “SCI Research and the Hope for Cure: Where Are We Today?” Dr. Lammertse lucidly explained the complex issues involved in SCI recovery research and provided a status report on these efforts worldwide today. This informative presentation was videotaped and is now available to watch on our website at http://sci.washington.edu/summit2013video.

Four additional presentations by UW professionals addressed a range of topics related to living with SCI: phone and computer access for people with limited arm and hand function; a new surgical procedure to improve sexual function in men with paraplegia (the TOMAX procedure); wheelchair maintenance; and emergency and disaster preparedness for people with SCI. (These presentations were not videotaped, but handouts are available for download on our website. See sidebar “Missed the SCI Wellness Summit?”)

During the breaks attendees enjoyed refreshments, viewed an art show of work by artists with SCI, and visited the displays of equipment manufacturers, distributors and others who provided underwriting for the Summit. Certificates of continuing education hours were given to physical and occupational therapists who attended presentations. In their responses on the Summit evaluation forms, attendees praised the high quality of the speakers and stated that they learned new information that would benefit them or their patients.

More than 35 videos, dozens of articles and our popular series of educational pamphlets on SCI are available for free on our website: http://sci.washington.edu

We are grateful to the following companies for generously underwriting this year’s SCI Wellness Summit:

- Bellevue Healthcare
- Care Medical Equipment
- Coloplast
- The Comfort Company
- Pacific Healthcare Associates, Inc.
- Permobil
- Pushing Boundaries
- Quantum Rehab
- Restorative Therapies
- United Seating & Mobility

Missed the SCI Wellness Summit?

Watch the video of Dr. Lammertse’s talk and download his handouts here: http://sci.washington.edu/summit2013video.

Get the handouts and other printed materials from the Summit presentations at http://sci.washington.edu/summit2013. Handouts are available for the following presentations:

- **Phone & Computer Access for People with Limited Arm and Hand Function**, by Amy Cisler, OT & Kristine Osmond, OT, Harborview Medical Center:
  - Choosing a Phone
  - Choosing a Smart Phone
- **Surgical Innovation for Sexual Function in Men with Paraplegia: The TOMAX Procedure**, by Thomas Lendvay, MD, UW Department of Urology:
  - Article about the TOMAX procedure at the UW titled “Surgery establishes penile sensation in men with spina bifida.”
- **Wheelchair Maintenance**, by Dave Colescott, PT, Harborview Medical Center:
  - “Wheelchair Maintenance and Minor Repairs”—a 13-page guide to maintaining your manual or power wheelchair.
- **Emergency/Disaster Preparedness for Individuals with SCI**, by Rosemary Buchmeier, RN, Harborview Medical Center; Tracy Connelly, Office of Emergency Management, City of Seattle, and Capt. Donald deVerca, Seattle Fire Department:
  - Your Family Disaster Supplies Kit
  - Disaster Tips for People with Mobility Challenges
  - Your Family Disaster Plan
  - Emergency Preparedness Personal Assessment
  - Speak Up: My Medicine List (wallet card)
PAIN

- A randomized trial of pregabalin in patients with neuropathic pain due to spinal cord injury. A total of 220 participants with SCI and chronic neuropathic pain below the level of injury were randomly assigned to receive either 150 to 600 mg/d pregabalin or placebo for 17 weeks. The primary outcome measure was the amount of change in pain that occurred during the study period, based on participant pain diaries. Secondary outcome measures included sleep disturbance, anxiety and depression. Pregabalin treatment resulted in statistically significant improvements over placebo for all primary and key secondary outcome measures. Significant pain improvement was evident as early as week 1 and continued throughout the treatment period. Side effects—mainly sleepiness and dizziness—were mostly mild to moderate. This study demonstrates that pregabalin is effective and well tolerated in patients with neuropathic pain due to SCI.


- Acceptance of chronic neuropathic pain in spinal cord injured persons: a qualitative approach. This study explored the idea that acceptance may be a viable alternative to suffering when other treatments do not adequately reduce chronic neuropathic pain (CNP). Seven individuals with SCI were interviewed about their pain experiences. Six phases were identified from these interviews: “comprehending the perplexity of CNP,” “seeking pain resolution,” “acknowledging pain permanence,” “redefining core values,” “learning to live with the pain,” and “integrating pain.” Two driving forces, “increasing independence” and “evolving pain view,” helped move the process of acceptance forward. Acceptance of pain appeared to reduce suffering and lead to a more satisfying and fulfilling life in these individuals. A decreased emphasis on continued searching for a cure for the pain and movement toward a self-management approach increased their ability to cope with the pain. Patients may benefit from early intervention to help with coping and exploring the notion of acceptance of pain.


OUTCOMES

- Rehospitalization in the first year of traumatic spinal cord injury after discharge from medical rehabilitation. This study looked at rates of rehospitalization within the first year after injury among 951 individuals with SCI in six rehabilitation centers in the U.S. More than one third (36.2%) of participants were rehospitalized at least once in the 12-month follow-up period; 12.5% were rehospitalized at least twice. The average length of stay per rehospitalization was 15.5 days. The three most common reasons for rehospitalization were problems with the genitourinary system (e.g., urinary tract infection), respiratory system (e.g., respiratory failure), and skin (e.g., pressure ulcer). Odds of being hospitalized again were higher in women, younger people, retirees, the unemployed, as well as those with Medicare coverage and more severe injuries. Those who had more intensive physical therapy during acute rehabilitation had lower odds of being hospitalized again. The 6 SCI rehabilitation centers varied nearly 2-fold (from 27.8% to 30%) in rates of rehospitalization. Future research should examine the role of health system variables in avoiding rehospitalization.


- Relationship of nursing education and care management on outcomes following spinal cord injury: the SCIRehab project. The authors reviewed the medical records of and conducted interviews with SCI patients to examine the relationship between nursing care and patient outcomes. Results showed that more nursing activities were associated with better outcomes. More time spent by registered nurses (RNs) in coordination with other members of the care team, consultants and specialists, along with participation in physician rounds (team process) was associated with patient report of higher life satisfaction and better function at one year after injury. More time providing psychosocial support is associated with higher mobility and occupation scores and with greater likelihood of working or being in school at one year after injury.


RECOVERY

- Effectiveness of intense, activity-based physical therapy for individuals with spinal cord injury in promoting motor and sensory recovery: is olfactory mucosa autograft a factor? Twenty-three people with SCI received either intense PT alone or intense PT and an olfactory mucosa autograft (OMA). Mean therapy dosage was 37.3 total hours. The participants’ lower extremity motor scores improved significantly while sensory scores did not improve during the first 60 days from initial to discharge examination. Incomplete SCI or paraplegia was associated with greater motor recovery. Five of 14 participants converted from motor-complete to motor-incomplete SCI. Individuals who had the OMA and participated in intense PT did not have greater sensory recovery or greater magnitude or rate of motor recovery as compared with participants who had intense PT alone. This study provides encouraging evidence as to the effectiveness of intense PT for individuals with SCI.


CONTINUED ON NEXT PAGE
BLADDER MANAGEMENT

- Intermittent self-catheterization with hydrophilic, gel reservoir, and non-coated catheters: a systematic review and cost effectiveness analysis.

Eight studies were included in this systematic review comparing the effectiveness and costs of hydrophilic, gel reservoir, and non-coated intermittent catheters. Most studies were conducted in patients with spinal cord injuries, and most of the participants were men. People using gel reservoir and hydrophilic catheters were significantly less likely to report one or more urinary tract infections (UTIs) compared with sterile non-coated catheters. However, there was no difference between hydrophilic and sterile non-coated catheters when outcomes were measured as mean monthly UTIs or total UTIs at 1 year. There was little difference in the incidence of UTIs for people using clean versus sterile non-coated catheters. The type of catheter used for intermittent self-catheterization seems to make little difference to the risk of symptomatic UTI; however, clean non-coated catheters are most cost effective. Because of limitations and gaps in the evidence base and the designation of non-coated catheters as single use devices, the authors recommend that patients should be offered a choice between hydrophilic and gel reservoir catheters.


SKIN CARE

- Effect of durations of wheelchair tilt-in-space and recline on skin perfusion over the ischial tuberosity in people with spinal cord injury.

Nine power wheelchair users with SCI were randomly assigned to three protocols of wheelchair tilt-in-space and recline of various durations (3min, 1min, and 0min). Each protocol consisted of a baseline 15-minute sitting, a first of 0- to 3-minute reclined and tilted, a second 15-minute sitting, and a 5-minute recovery. The position at the baseline and the second sitting was no tilt/recline of the participant and at the reclined and tilted and recovery was at 35° tilt-in-space and 120° recline. Skin perfusion (blood flow to the skin) was assessed by laser Doppler. The results showed that mean skin perfusion during recovery at the 3-minute duration was significantly higher than that at the 1-minute duration. There was no significant difference in mean skin perfusion between the 1-minute and 0-minute durations. Skin perfusion during the second sitting was significantly higher at the 3-minute duration than at the 1-minute and 0-minute durations. In conclusion, performing the 3-minute duration of wheelchair tilt-in-space and recline is more effective than the 1-minute duration in enhancing skin perfusion of weight-bearing soft tissues.


WALKING AND STANDING

- Locomotor training for walking after spinal cord injury.

This systematic review examined 5 randomized controlled trials (RCTs) involving 309 people that looked at the effect of locomotor training on improvement in walking for people with traumatic SCI. The use of bodyweight supported treadmill training as locomotor training for people after SCI did not significantly increase walking velocity nor did it increase walking capacity. In all five studies there were no differences in adverse events or drop-outs between study groups. The authors conclude that no one locomotor training strategy improves walking function more than another for people with SCI. The effects especially of robotic-assisted locomotor training are not clear; therefore research in the form of large RCTs, particularly for robotic training, is needed.


- Lokomat robotic-assisted versus overground training within 3 to 6 months of incomplete spinal cord lesion: randomized controlled trial.

Eighty participants (3 to 6 months after SCI) were randomly assigned to receive 40 sessions using either a robotic-assisted Lokomat program with overground mobility therapy or overground therapy alone. Primary measurements of outcome were walking speed and the Walking Index for Spinal Cord Injury (WISCI III). Secondary outcomes were the 6-minute walk test and measures of functional independence, motor scores, pain and spasticity. No significant differences were found at entry between treatment groups. After the walking training sessions, walking speed for Lokomat and overground therapy groups did not differ. However, the need for orthotics and assistive devices was reduced with Lokomat, perhaps because of greater leg strength in the robotic group.


- The effect of supported standing in adults with upper motor neuron disorders: a systematic review.

This review examined 17 studies involving 540 participants that studied the effect of assisted standing on lower limb muscle length, spasticity, bone mineral density or function of adults with upper motor neuron disorders from stroke, multiple sclerosis, traumatic brain injury or SCI. High-quality evidence suggested tilt-table standing has a small effect on preventing loss of ankle dorsiflexion. One high-quality study found a low-dose standing program did not change bone loss early after spinal injury. There was limited evidence that standing improves spasticity or function. Supported standing can prevent small losses of ankle mobility, but the clinical importance of these effects is uncertain. Low-dose standing is unlikely to protect bone health.


BREATHING

- Abdominal binder improves lung volumes and voice in people with tetraplegic spinal cord injury.

Breathing, vocal function and blood pressure were measured in 14 acute rehab inpatients with ASIA A (complete) or B (motor complete) SCI above the T5 level at 6 weeks, 3 months and 6 months after commencing daily use of an upright wheelchair. Measurements were taken both with and without an abdominal binder (AB) on. All breathing measurements improved at each time point with the use of the AB compared with no AB. Overall, using an AB significantly improved forced vital capacity, forced expiratory volume in 1 second, peak expiratory flow, maximal inspiratory pressure, and maximum sustained vowel time. There was no significant improvement in maximal expiratory pressure, mean arterial pressure or sound pressure level. Further study is needed into the effect of the long-term use of the AB on total lung capacity, functional residual capacity, breathing mechanics, rate of pulmonary complications, and overall respiratory health. Other factors to consider are whether a person with SCI will continue to use an AB and its impact on comfort, skin integrity, and likely postural changes during the initial years after injury.

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Editorial Board of Advisors: Charles Bombardier, PhD; Stephen Burns, MD; Chris Garbaccio; Barry Goldstein, MD; Jeanne Hoffman, PhD; Cathy Warms, PhD, ARNP, CRRN.

To add your name to the mailing list, contact the editor, Cynthia Salzman, at the University of Washington, Department of Rehabilitation Medicine, Box 356490, Seattle WA 98195-6490; 206-685-3999; csalzman@uw.edu.


SCI-CARE Study

The Northwest Regional SCI System is seeking participants for a study designed to improve care for people with SCI who are dealing with pain, low mood, or being less physically active than they want to be. You may qualify for this study if you have a traumatic SCI, are at least 18 years old, and receive care at either Harborview or UW Medical Center Rehabilitation Clinics.

Participants will be randomly assigned (50/50 chance) to receive either usual medical care or usual care plus a health assistant who will:
- Strengthen the connection between you and your doctor or nurse practitioner.
- Monitor your progress and assist with any problems that keep you from reaching your goals.
- Relay information to and from your health care provider in between appointments.
- Offer non-medical alternatives to pain, mood, or becoming more active.

Study participation will take place over four months. Most study activities will take place over the phone or at regularly scheduled clinic visits so extra trips to Harborview or UW will not be necessary. Participants will complete three questionnaires by phone. There is payment of up to $50 for participation.

Learn more about this study and find out if you qualify by calling Missy at 206-744-3608 (Toll Free 866-495-7015) or send an email to scicare@uw.edu. (Note: we cannot guarantee confidentiality of information sent via email.)

Read the newsletter online at http://sci.washington.edu/info/newsletters