Department of Rehabilitation Medicine

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INSIDE:
• SCI publications by UW faculty .......................................... 3
• SCI Forum: Pressure Ulcers ................................................... 4
• Literature review: 12 abstracts of SCI research ................. 6

SCI-CARE Study: Finding better ways to care for SCI patients

The Northwest Regional Spinal Cord Injury System (NWRSCIS) is starting an exciting new study that hopes to improve the lives of individuals with spinal cord injuries (SCIs) by doing a better job of managing three common, inter-related health problems: chronic pain, physical inactivity and depression. “We know from our clinical experience, consumer feedback, and the research literature that these three conditions are widespread, difficult to treat, often chronic, and can have a very negative effect on quality of life,” says Chuck Bombardier, PhD, professor and psychologist in the UW Department of Rehabilitation Medicine and director of the NWRSCIS. Bombardier is the lead investigator for this new study, called SCI-CARE. “These problems are interwoven,” he adds. “Individually and together they can create a downward spiral toward poor quality of life. But we are betting that if we treat them in a more coordinated way, we can create an upward spiral toward better quality of life.” (See Figure 1.)

About 63% of individuals with SCI have chronic pain, and research has shown that pain is related to poorer quality of life. Pain also seems to trigger depression and frequently keeps people from being more active. Standard medical treatments are beneficial but often not a cure. Non-medical treatments have been found to help but are underutilized. For example, cognitive-behavioral therapy for chronic pain can be very effective in decreasing pain and improving mood, but few people actually receive this type of treatment.

Figure 1.

Physical inactivity is also a major problem after SCI. Prior to injury many people with SCI were physically active, but after injury about 50% of people with SCI do not engage in any leisure time physical activities. That is, they never go for a walk, don’t play a sport, don’t exercise at home or go to a gym. Inactivity contributes to poor quality of life as well as obesity, diabetes, heart disease and accelerated aging. Many studies have shown that exercise improves strength, endurance and mood in SCI. There are now published physical activity guidelines for people with SCI. However, within the standard rehabilitation care system, we have limited capacity to help people meet those guidelines.

Depression is not something that people with SCI talk a lot about, but it is there in the background for about one in five people. Depression often lasts for years and is associated with poorer satisfaction with life. Few people receive adequate treatment for depression through medications or counseling. Physical exercise can be an effective treatment for depression but is rarely used.

As illustrated above, interventions for pain, depression and inactivity exist, but many patients do not receive them. “Lack of resources, inconvenience and limited transportation likely contribute to under-treatment,” Bombardier explains. “But the way medical care is organized also plays a role. Most medical care is set up to treat acute medical problems that can be ‘cured’ with medications

CONTINUED ON PAGE 2
or surgery. We are not organized as well to help people manage chronic conditions or make lifestyle changes.”

**Innovative approach**

For this reason, Bombardier and his colleagues decided to study an alternative way of organizing how we provide treatment for pain, inactivity and depression called “collaborative care.” Collaborative care has been used successfully in people with heart disease, diabetes and chronic pain but has not been tested in SCI. Collaborative care produces better medical outcomes (e.g., blood sugar control, blood pressure), better patient outcomes (e.g., lower depression and pain scores and higher satisfaction with care) and in some cases, lower costs. With this in mind, “we decided on a ‘real world’ experiment that tests the effectiveness of providing collaborative care within our outpatient SCI rehabilitation clinics compared to usual care,” Bombardier says.

The collaborative care approach used in the SCI-CARE study was developed here in Seattle by Dr. Wayne Katon and colleagues (http://www.teamcarehealth.org). Collaborative care uses a team of expert clinicians with complementary skills working closely together to care for patients with complex medical conditions, such as persons with SCI.

Central to the SCI-CARE team is a care manager who works with each patient along with his or her regular multidisciplinary rehabilitation team to ensure that the patient gets state-of-the-art care for these three conditions. (See Figure 2.) The care manager assists the patient and medical team in several key ways:

1. Identifying specific goals the patient wants to achieve, such as reducing pain by at least 50% or exercising for 20 minutes three times per week.
2. Checking in with patients to measure progress and identify any problems that arise between doctor visits. This information is fed back to the physician so treatment adjustments can be made more quickly and with less hassle for the patient.
3. Acting as a counselor and coach to help patients achieve their goals.
4. Receiving weekly supervision from experts in pain, exercise and depression to ensure the patient receives optimal care and meets his or her goal. These experts suggest treatment adjustments to the care manager and to the physician to help the patient meet the goal.

**Study procedures**

The study is a 16-week randomized controlled trial comparing collaborative care to usual care for improving physical activity, chronic pain and depression. Study participants will be randomly assigned to one of two groups. The first group will receive the same care that they would normally receive in our rehabilitation clinics (the “control” group). The second group will receive follow-up from a care manager (the “intervention” group).

Participation involves visits with the patient’s doctor or nurse, in-person and telephone contact with the care manager; and answering questions from a research study assistant. At the end of the 16 weeks, the care manager will help participants develop a plan to maintain health improvements that have been made.

**Who can participate**

To be eligible for the study, participants must be outpatients at the SCI clinics at Harborview or University of Washington Medical Center, at least 18 years old, and have significant problems in one or more of the three areas of pain, depression or inactivity.

**Results**

Since improvement in quality of life (QOL) is the goal of this study, the researchers will use QOL questionnaires specifically designed for the SCI population to determine whether the SCI-CARE intervention is better than usual care for managing pain, depression and inactivity in persons with SCI. Questionnaires will be administered to participants over the phone or in person before and after the 16-week study period, and again at 32 weeks to see if improvement has been maintained.

If results show that the collaborative care method is better than usual care, is it likely to be adopted by SCI providers and the health care system in general? Bombardier is hopeful, but some of it will depend on the bottom line. “We will look at the costs versus benefits of the intervention as one of the outcomes,” he says. “If the benefits outweigh the costs, there is a greater likelihood that this model could be adopted and paid for by insurers.”

**Find out more**

If you are interested in participating or want to learn more, call 206-744-3608 or send an email to scicare@uw.edu. (Study staff cannot guarantee the confidentiality of information sent via email.)

**References**

1. Jensen MP, Barber J, Romano JM, Hanley MA, Raichle KA, Molton IR, Engel JM, Osborne TL, Stoelb BL, Cardenas DD, Patterson DR. Effects of self-hypnosis

**CONTINUED ON BACK PAGE**
Recent SCI-Related Publications by UW Faculty

A selection of articles, books and chapters in peer-reviewed publications. Names of University of Washington faculty are highlighted.


Pressure Ulcers Can Wreck Your Life!
Preventing & Managing Skin Problems after SCI

Part 1: Risks, Causes and Prevention

By Deborah Crane, MD, MPH, assistant professor, Department of Rehabilitation Medicine, University of Washington. Presented at the SCI Forum on January 10, 2012 at the UW Medical Center.

What are pressure ulcers?
The National Pressure Ulcer Advisory Panel defines a pressure ulcer as “a localized area of tissue necrosis that tends to develop when soft tissue is compressed between a bony prominence and an external surface for a prolonged period of time.”

In other words, tissue death results when the soft tissue gets squeezed between a bony or firm body area and something external to your body. The area of damage is the pressure ulcer or sore.

How common are pressure ulcers?
About one-third of people with new spinal cord injuries develop pressure ulcers during their initial hospitalization.

A study that used the National Model Systems SCI database reported new pressure ulcers among 7.9% of persons in the first year after SCI and 8.9% in the second year. A study of 219 veterans reported only 19.6% had no history of pressure ulcers. Another study of 800 veterans found that 62.4% of participants had pressure ulcers within one to 52 years after SCI. According to the 1998 National Spinal Cord Injury Statistical Center Annual Report, 2,971 (73%) of 4,065 persons with SCI developed pressure ulcers over a 20-year period.

Why are we so concerned about pressure ulcers?
A common cause of hospitalization
Most people with SCI, once they go home after rehab, never want to be in a hospital again. But 39% of people rehospitalized in the first year after their SCI are admitted for pressure ulcers. And about one-third of people with an SCI end up requiring three or more hospitalizations throughout the rest of their lifetime for treatment of pressure sores. If you want to stay out of the hospital, you definitely want to prevent a pressure sore.

Increased care needs—decreased independence
Having a pressure sore means you are likely to need more help with your personal care. You may go from being mostly or completely independent with your care to suddenly needing a lot of help and losing your independence.

Expense
About 25% of the total lifetime cost of medical care for a person with SCI is related to pressure sores. Unfortunately, SCI is an expensive situation to be in, and we all want to reduce that cost as much as possible.

Personal costs
Perhaps most important of all, pressure sores can have multiple negative consequences, including loss of income because you’re on bed rest and can’t go to work, increased care costs, the negative health effects of prolonged bed rest and inactivity, and loss of your usual activities and sources of life satisfaction. There is a lot of personal suffering when dealing with a chronic sore, and it certainly can contribute to depression.

Death
About 7–8% of deaths in the SCI population are related to a pressure sore. These deaths most likely result from sepsis, an infection that spreads throughout the body in the blood and tissues.

Risk factors
There are several factors that put a person with SCI at risk for pressure ulcers. Some are a direct consequence of the SCI, and some are not.

SCI-related risk factors
- Paralysis and sensory impairment. If you are unable to feel things normally, you won’t know if something is hurting your skin.
- Changes in collagen metabolism (the way your skin and connective tissues are able to build new tissue and heal). Wound healing may take five times longer below the level of SCI due to these changes.
- Muscle atrophy (shrinking) can leave the bony prominences on your backside (or other areas) less padded, so that there is less protection over these areas.
- Altered circulation can reduce the blood supply to tissues. This not only increases your risk for skin problems, but slows the healing process if you do develop a pressure sore.

Risk factors not related to SCI
- Hypogonadism (low testosterone) can inhibit or slow wound healing. Since it is more common in men with SCI than those without, it’s important to get your testosterone level checked at least every couple of years. Ask your provider to do this if he or she isn’t aware that this is a problem for people with SCI.
- Diabetes.
- Fevers or illnesses.

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Positioning
- Abnormal or less than ideal positioning in your wheelchair, vehicle, or other equipment can increase pressure over specific bony areas.

Skin moisture and maceration
- Skin that is exposed to moisture (from urine, feces or sweat) for extended periods can become macerated (softened and weakened) and vulnerable to breakdown.

Prevention
Monitor your skin
- Inspect your skin twice daily; every morning when you wake up and every night before you go to bed.
- Use a mirror if you are able. If not, designate a caregiver to check your skin.
- Know your own skin. Your caregiver may change, but your skin is always with you.
- Contact your provider if you notice changes or have concerns.

Pressure
- Perform pressure reliefs every 15 to 30 minutes. (Learn how to do pressure reliefs properly on our website at http://sci.washington.edu/info/pamphlets/msktc-pressure_relief.asp.)
- Turn frequently in bed. The usual recommendation is to turn every two hours in bed, but this can sometimes be stretched out to longer periods (usually up to four hours) eventually.
- Use wheelchair cushions and mattresses that distribute pressure well and are inflated and maintained correctly.

Shear
- Keep clothing and linens wrinkle-free.
- Maintain good transfer technique. Make sure you aren’t dragging your lower limbs or back side across a surface.
- Protect hands, legs, feet and arms from trauma.

Positioning
- Make sure your positioning, posture and seating are correct. Consult your health provider or a seating specialist if you aren’t sure.

Moisture
- Maintain clean, dry skin.
- Maintain bowel and bladder continence.

Mental status
- Many medications commonly prescribed for individuals with SCI can cause sedation (sleepiness) or even confusion. Talk to your health provider about managing your medications so these kinds of side effects do not keep you from maintaining good skin care.

Alcohol and recreational drugs
- Alcohol or other drugs used for recreation or abuse can reduce your alertness, judgment and attention to doing pressure reliefs and good transfers.

Smoking
- There are lots of reasons not to smoke. Skin health is definitely one of them.

Anemia and nutrition
- Make sure you’re eating a diet that’s high in protein, iron, and vitamin C. (Learn about nutritional guidelines for persons with SCI on our website at http://sci.washington.edu/info/forums/reports/nutrition_2011.asp.)

Part 2 of this SCI Forum report is available online. (See below.)

Go to our website to watch the video or read the full report of this SCI Forum presentation:
CARDOVASCULAR


Ten SCI patients with paraplegia performed two rowing techniques in this study. The first technique used a fixed seat with rowing achieved using only upper extremity movement (fixed rowing). The second used an automatically moving seat, facilitating active upper extremity movement and passive lower extremity movement via the motorized seat (motor rowing). Each patient performed two randomly assigned rowing exercise stress tests 1-3 days apart to measure cardiopulmonary responses such as work rate (WRR), time, respiratory exchange ratio (R), oxygen consumption (VO2), heart rate (HR), metabolic equivalents (METs), and rating of perceived exertion (RPE). WRR, VO2, and METs were significantly higher and HR was significantly lower after the motor rowing test than after fixed motor rowing test. Motor rowing has an advantage of allowing natural rowing motion and passive leg movement as well as providing the significant change of cardiorespiratory exercise variables for individuals with SCI and no lower extremity motor function.

Jung DW, Park DS, Lee BS, Kim M.

Increased risk of stroke after spinal cord injury: a nationwide 4-year follow-up cohort study.

This study used a comprehensive national database in Taiwan to investigate the incidence of stroke in a group of 2,806 chronic SCI patients with moderate to severe disability compared to a group of 28,060 non-injured individuals. Every subject was followed for 4 years (unless they died or had a stroke by December 31, 2006). The incidence rate of stroke in the SCI group (5.96 per 1,000 person-years) was higher than that of the comparison group. In the SCI group, the incidence of ischemic stroke was higher than that of hemorrhagic stroke. SCI patients with disability are at a higher risk of stroke, especially the ischemic type. Strategies to prevent stroke are suggested.


MANAGEMENT OF CARDIOVASCULAR DISEASE RISK FACTORS IN INDIVIDUALS WITH CHRONIC SPINAL CORD INJURY: AN EVIDENCE-BASED REVIEW

A review of the medical literature revealed that almost all risk factors for cardiovascular disease (CVD) are higher in individuals with SCI, including physical inactivity, dyslipidemia, blood pressure irregularities, abnormal glycemic control, and chronic inflammation. Studies have also shown that these risk factors occur at an earlier age in persons with SCI. However, not enough studies have been done regarding treatment outcomes in SCI-specific study populations to allow for the development of evidence-informed clinical practice recommendations. Nevertheless, health care providers need to be aware that patients with SCI have a higher risk for CVD than the general population and should be offered screening and prevention strategies accordingly.

Cragg J, Stone J, Krasiovkov AV.

MUSCULOSKELETAL

Incidence and predictors of contracture after spinal cord injury-a prospective cohort study.

A total of 92 consecutive patients with acute SCI in two Sydney spinal cord injury units were assessed within 35 days of injury and 1 year later. Incidence of contracture at 1 year was measured in the wrist, elbow, hip and ankle. At 1 year, 66% of participants developed at least one contracture. Incidence of contracture at each joint was: shoulder 43%, elbow and forearm 33%, wrist and hand 41%, hip 32%, knee 11% and ankle 40%. Incidence of contracture determined by standardized torque measures of range was: elbow 27%, wrist 26%, hip 23% and ankle 25%. The incidence of contracture in major joints 1 year after spinal cord injury ranges from 11-43%. The ankle, wrist and shoulder are most commonly affected. The authors could not determine which factors accurately predict which individuals are more susceptible to contracture soon after injury.

Diong J, Harvey LA, Kwah LK, et al.

Acromioclavicular joint arthrosis in persons with spinal cord injury and able-bodied persons.

This was a retrospective analysis of medical records and magnetic resonance images (MRIs) of 68 persons with SCI and 105 able-bodied persons who visited an outpatient orthopaedics clinic because of shoulder pain. AC joint arthrosis was found in 98% of the SCI group and 92% of the able-bodied group. Within the SCI group, 72% had paraplegia and
28% had tetraplegia; 80% had ASIA A (complete) injury; and the average time since injury was 23.3 years. Both groups in this setting had a high prevalence of AC joint arthrosis, but it was more severe and more advanced in the SCI group. The authors recommend routine assessment during check-ups, which includes assessment of shoulder pain, physical examination, and diagnostic imaging (X-ray and when necessary MRI), in order to help to diagnose AC joint arthrosis at an earlier stage. Early diagnosis increases the likelihood that conservative interventions (e.g., optimizing transfer techniques, technique of wheelchair propulsion) can be used to successfully avoid further shoulder deterioration.


PRESSURE ULCERS
Effects of electrical stimulation-induced gluteal versus gluteal and hamstring muscles activation on sitting pressure distribution in persons with a spinal cord injury.

Muscle contractions induced by electrical stimulation (ES) might help prevent pressure ulcers (PUs) by reducing atrophy (muscle shrinking) and improve blood flow, oxygenation, and improve sitting pressure distribution. In this study, ten participants with SCI underwent two ES protocols applied using a custom-made electrode garment with built-in electrodes. In one protocol, both the gluteal and hamstring (g+h) muscles were activated, in the other gluteal (g) muscles only. In all participants, both protocols caused a significant decrease in ischial tuberosities (ITs) or sitting bones pressure. IT pressure was significantly reduced by 34.5% after g+h muscle activation and by 10.2% after activation of g muscles only. g+h muscle activation showed a decrease in pressure relief over time compared with g muscles only. While both protocols gave pressure relief, activation of both g+h muscles resulted in better IT pressure reduction in sitting individuals with a SCI than activation of g muscles only. ES might be a promising method in preventing PUs on the ITs in people with SCI.


SPASTICITY
Spasticity changes in SCI following a dynamic standing program using the Segway

Eight individuals with SCI ASIA (American Spinal Injury Association) A–D participated in a 4-week dynamic standing program of three 30-minute sessions using a Segway. The main outcome was spasticity as measured by the Modified Ashworth Scale (MAS). Secondary measures included the SCI-Spasticity Evaluation Tool, Pain Outcomes Questionnaire, and Fatigue Severity Scale. The dynamic standing sessions were associated with immediate improvements in spasticity and pain. Fatigue levels decreased, however this was not significant. Dynamic standing on the Segway may be effective for short-term spasticity reduction and decreased pain and fatigue.


WHEELCHAIRS
Increases in wheelchair breakdowns, repairs, and adverse consequences for people with traumatic spinal cord injury.

A survey of 723 participants with SCI who use a wheelchair for more than 40 hrs/wk treated at a SCI Model Systems center was conducted. Subjects were asked to indicate the number of times in the past 6 months the wheelchair they used most had been repaired. Those who reported repairs were asked to indicate which of the following five consequences occurred because of a wheelchair breakdown: (1) no consequence, (2) been stranded, (3) been injured, (4) missed work or school, or (5) missed a medical appointment. Significant increases were found in the number of participants reporting repairs (7.8%) and adverse consequences (23.5%) in a 6-mo period (2006-2011) compared with historical data (2004-2006). When examining current data, minorities experienced a greater frequency and higher number of reported consequences. Power wheelchair users reported a higher number of repairs and consequences than did manual wheelchair users. Wheelchairs equipped with seat functions had a greater frequency of adverse consequences. Repairs did not vary across funding source, but individuals with wheelchairs provided by Medicare and Medicaid reported a higher frequency of consequences than did the combined group of the Department of Vocational Rehabilitation, Worker’s Compensation, and the Veterans Administration. The incidence and consequences of repairs are increasing from what was already a very high statistic in this U.S. population. Further investigation into causality is required, and intervention is needed to reverse this potential trend.


UROLOGICAL
Effectiveness of aerobic physical training for treatment of chronic asymptomatic bacteriuria in subjects with spinal cord injury: a randomized controlled trial.

Forty-two participants with SCI between C8 and T12 were randomized to receive a physical activity program (intervention group) or to maintain their current activities (control group). The intervention consisted of 16 weeks of moderate intensity aerobic physical conditioning for one hour, two or three times per week. It included cycloergometer of upper limbs (Cybex), performed distance with a wheelchair, and general exercises to gain muscle power with progressive loading of residual muscle and muscle stretching. All participants performed a baseline stress test, urine analysis and urine culture at the beginning of the study (pre-training tests) and after 16 weeks. The intervention group showed an increase of estimated peak oxygen consumption and a reduction of chronic asymptomatic bacteriuria, with no adverse effects. The regular practice of physical activity of moderate intensity may be an effective and safe method for the treatment of chronic asymptomatic bacteriuria in persons with SCI.


TESTOSTERONE DEFICIENCY
Prevalence of testosterone deficiency after spinal cord injury.

Sixty male veterans with SCI in this study underwent testosterone blood tests for this study in addition to annual evaluation laboratory examination. A low serum testosterone level (<325 ng/dL) was detected in 43.3% of participants. The prevalence of testosterone deficiency was significantly greater in participants with motor complete (ASIA A and B) injuries compared with those with motor incomplete (ASIA C, D, and E) injuries. Testosterone levels also were significantly lower in participants who were taking narcotic medications for pain management. These findings reveal a substantial prevalence of testosterone deficiency in men with chronic SCI and confirm a significant association between injury severity and testosterone deficiency. Testosterone provides many potential health benefits, including increased bone mineral density, improved muscle mass and strength, increased sexual desire, increased energy, decreased irritability and depression, and improved cognition. Measuring serum total testosterone levels should be included in standard screenings for patients with SCI, particularly those with motor complete.

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Continue from Page 2


