spinal cord injury

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> NW REGIONAL SPINAL CORD INJURY SYSTEM



Setting Your Zzz's: *Sleep and Spinal Cord Injury*

Adapted from the SCI Forum presentation on February 14, 2012, by Don Fogelberg, PhD, Assistant Professor of Occupational Therapy in the Department of Rehabilitation Medicine, and Stephen Burns, MD, Associate Professor and physiatrist in the Department of Rehabilitation Medicine and Director of the SCI Service at the VA Puget Sound Health Care System in Seattle.

Why is sleep important?

We often take sleep for granted, but sleep is essential for health and quality of life. Poor sleep can seriously affect your mental abilities, causing problems with alertness, attention span, memory and judgement. Sleep loss increases a person's chances of getting in a motor vehicle crash or having an industrial accident.

Sleep loss also has many negative health consequences, including increased

pain, depression, disruption of immune and endocrine system function, diabetes, cardiovascular disease (CVD), and even obesity. The fact that diabetes, CVD and obesity are among the top causes of death in the U.S. highlights the critical importance of sleep.

Sleep disturbances can be a minor inconvenience with a small effect on quality of life, or it can be a big problem that overwhelms a person's whole life.

To be refreshed and alert in the daytime, we need both enough hours of sleep and minimal interruption so we can go into the deep phases of sleep that are most restful, including the dream—or REM—phase. When we sleep well, we can be alert during the daytime, have enough energy to participate in activities, not fall asleep as we're driving our cars, and stay alert until bedtime, at which point we start to wind down and fall into some nice, restful sleep. That's the ideal.

How does SCI affect sleep?

Sleep problems aren't unique to individuals with SCI, but having a spinal cord injury can affect your sleep in unique ways. There

are many barriers to getting a good, restful sleep if you have a spinal cord injury:

- Pain that interferes with falling asleep and staying sleep.
- Spasticity.
- Lack of physical activity.
- Needing to awaken a number of times during the night for care, such as doing intermittent catheterization or turning yourself in bed to protect your skin.
- Melatonin, the hormone that regulates the sleep-wake cycle, is often reduced in persons with high-level SCI. If you're not making enough melatonin, it may be more difficult for your internal clock to reset.
- Antidiuretic hormone (ADH) normally increases at night, suppressing urinary output. But in people with SCI, ADH levels often don't increase at night, so urinary output remains at daytime levels. If you need to go to the bathroom more at night, your sleep gets interrupted.
- SCI can disrupt the body's temperature regulation system, and since the internal thermostat determines timing of sleep onset, you may not be sleepy at the normal bed time.
- Depression can interfere with your ability to fall asleep and stay asleep for the full night.

Types of sleep problems

There are dozens of recognized sleep disturbances, but three major types are most relevant to SCI: circadian rhythm sleep disorders, insomnia and sleep apnea.

UPDATE

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

Welcome to our new column. Recognizing that the best SCI advice often comes from other people living with SCI, we have started this new column featuring tips and ideas from peers who have figured out ways to make life with SCI a little easier, healthier or more enjoyable.

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

Tips for Keeping Warm

Wool socks

Many people with SCI get cold feet of the literal kind by wearing cotton socks, which perform poorly in temperature control, wicking, cushioning, and wear. I made the switch to wool and immediately noticed the difference in warmth, or rather, less pain in my feet from being cold. (I am an incomplete quad and have sensation in my feet and other places.) Whether you feel cold or not, letting your feet get cold is a good way to lose body warmth or even cause skin damage due to poor circulation. And having cold blood pool in your legs all day can chill your whole body when you lie down in bed. A good pair of wool socks can be pricey, so be sure to check out closeout and clearance sales both in stores and online.

Where to find:

Soft, seamless, machine-washable wool socks by SmartWool and other brands are available in many styles, sizes and prices at retail stores and online, including REI, Sierra Trading Post and Amazon.com (\$10-\$25).

for the roller who doesn't want to sit on another layer of fabric, which can wrinkle and cause skin problems. I've noticed a huge difference in overall warmth when wearing let warmers, and even though I don't actually feel coldness in my legs, the pain caused by cold is significantly lower, especially when I've been rolling around town in frosty weather. I have two different kinds I bought online at REI closeout sales, one made of synthetic stretchy spandex (Perl Izumi) and another of fancy wool (Ibex); both zip at the ankles for easy on-off. Cyclists wear their leg warmers tight, but you should order them a size or two larger so they are easier to get on and don't constrict your flesh. Even though leg warmers stop at the ankles, they also help to keep my feet warmer. And since they're so formfitting, you can still wear discreet accessories under your pants (e.g., your leg bag,).

Where to find:

REI, Amazon.com and other retailers (\$30 and up).

Shoe gaiters

Winter gaiters are generally used by hikers and skiers for sealing the space between your pants and shoes in the vulnerable ankle/sock area, where Old Man Winter often sends his cold breath to rob you of your heat. Gaiters used by runners are shorter, lightweight versions that usually forgo the straps and bulkiness associated with full-size (see Figure 1). In addition to sealing out the elements, they also resemble old-timey spats—a once popular footwear accessory—and make a nice fashion statement.

Where to find:

Mountain Hardware Strapless Running Gaiters, sold on Amazon.com (\$23.97 - \$39.95).

Leg warmers

Bicyclists use leg warmers when riding out in the cold, but on the legs of the wellprepared wheelchair user leg warmers can make a huge difference in staying warm and comfortable in cooler temperatures. After all, your legs are not moving around too much, and even with a thick pair of corduroys or denim pants, they can lose a lot of heat without another layer of insulating fabric. That's where leg warmers are really handy (see Figure 1). Worn under your pants, they only go up to about mid-thigh. This is ideal



Figure I. Black ankle-to-thigh cycling leg warmers and gray shoe gaiters are worn underneath pants for warmth.

Do you have a tip you would like to share with the SCI community?

Please submit your ideas using our online form. Go to http://sci.washington.edu/tips

and click on "Submit Your Ideas." We will contact you if your idea is chosen to appear in this newsletter.

spinal cord injury

UPDATE

SLEEP (CONTINUED FROM PAGE 1)

Circadian rhythm sleep disorders (CRSDs)

These disorders occur when our internal body clock that governs our sleepwake cycle gets out of alignment with the normal 24-hour day. Our internal clocks normally run on a slightly more than 24-hour cycle but are constantly reset by visual cues of light and dark and our meal and exercise schedules.

CRSDs result in excessive sleepiness and lack of daytime alertness. Treating CRSDs usually involves resetting the internal clock by means such as light exposure, physical activity, or taking melatonin, a hormone that helps regulate sleep.

CRSDs can be brought on by jet lag from flying to a new time zone or by working a shift during normal sleep time (graveyard shift, early morning shift, or rotating shift). A CRSD may also occur

Guidelines for better sleep ("sleep hygiene")

From the American Sleep Association:

- Maintain a regular sleep schedule—this will help in resetting your internal clock.
- Develop a comfortable pre-sleep routine to help calm down your nervous system before sleep.
- Avoid naps if possible so you're more likely to be sleepy at bedtime.
- Watch your intake of caffeine and other stimulants, especially in the afternoon.
- Hide or don't look at your clock. Being too aware of how late it's getting just makes you more anxious as the night goes on.
- Don't stay in bed awake and trying to fall asleep for more than 10 minutes. Get out of bed and do some nonstimulating reading, or simply sit in the dark for a while. However, if getting in and out of bed is difficult, as it might be for someone with SCI, this rule may be difficult to follow.
- Don't read or engage in any screen time (TV, computers, etc.) in bed. The American Sleep Association states that bed is for sleep and sex, and that's all.

if our internal body clock puts us out of sync with a normal daily schedule, creating a tendency to stay up and awaken much too early or much too late every day.These types of CRSDs can be very disruptive and difficult to change.

Insomnia

Insomnia is defined as difficulty falling asleep, staying asleep or both, resulting in insufficient or poor quality sleep and daytime sleepiness. This can be an acute, isolated case lasting only a couple of nights or a nightly problem that continues for years. Insomnia is a very common problem, affecting approximately 33% of the U.S. population.

Secondary Insomnia

Insomnia is often considered to be "secondary" when it occurs along with other medical conditions (pain, arthritis and chronic bladder infection) or psychological disorders (depression, anxiety or panic attacks). The idea with secondary insomnia is that if you treat the main condition, the insomnia will go away on its own.

Primary insomnia

Sleep researchers are now recognizing that insomnia should often be thought of as a disorder in its own right and treated as such. Symptoms and consequences of insomnia are similar regardless of what disorder it is associated with. Likewise, the same treatments are effective for insomnia regardless of what other problems may be going on. In some cases, treating the insomnia alone can improve depression, pain, or other co-occurring conditions.

Sleep apnea

Sleep apnea is the most important medical cause for poor sleep quality and excessive daytime sleepiness in people with SCI. Sleep apnea can lead to serious health problems, such as heart and lung disease. Fortunately, there are treatments available that can dramatically improve symptoms and avoid the negative health consequences.

Sleep apnea is defined as having numerous episodes during the night in which breathing stops for at least 10 seconds. No air is moving in or out, and this causes a drop in the oxygen level in the body. Breathing stops because the soft palate and tongue have flopped back and blocked the airway. Sleep apnea is worse when people sleep on their backs. Snoring is usually severe, due to vibrations from air trying to push through the floppy tissues.

When the airway is obstructed, the oxygen level drops. The brain senses this and wakes up just enough to take a deeper breath, open up those airway muscles and let some air pass through. More frequent and severe apnea tends to happen in the deepest phases of sleep, which are the phases you need to be well-rested.

In the general population, sleep apnea occurs in about three to four percent of males and one to two percent of females. Obesity is the main risk factor, primarily from excess fat compressing the airway. Abdominal fat makes it harder for the diaphragm to move.

Sleep apnea has serious consequences

- Extreme daytime sleepiness.
- Decline in mental abilities. If sleep apnea is not treated, this decline can become permanent.
- Cardiac and pulmonary diseases, including hypertension (high blood pressure) that is resistant to many medications.
- Greatly increased risk for motor vehicle crashes.

Sleep apnea in SCI

Sleep apnea is a common condition in SCI. In the few studies that have been done, 60 to 80 percent of people with new tetraplegia and between 35 to 60 percent of those with chronic (longstanding) SCI were found to have sleep apnea.

Why is sleep apnea so common after SCI?

- Obesity, which makes sleep apnea worse, is common in SCI. However, many non-obese individuals with SCI also have sleep apnea.
- Weakness of breathing muscles.
- Altered breathing mechanics (inward collapse of the rib cage when the diaphragm contracts to try and take in a breath).
- Sleep apnea is more common in males, and most people with SCI are male.

CONTINUED, SEE "SLEEP" ON PAGE 4

SLEEP (CONTINUED FROM PAGE 3)

- Medications that affect respiration are commonly prescribed for people with SCI. For example, baclofen relaxes airway muscles, making them less effective.
- Many people with SCI can only sleep on their backs, which makes sleep apnea worse.

Serious consequences in SCI

People with SCI experience the same negative consequences from sleep apnea as anyone else, plus additional problems specific to SCI:

- In acute rehab, problems learning and participating fully in therapies due to sleepiness, which can result in less independence when leaving rehab.
- Difficulty maintaining overall health because sleepiness makes you less attentive to personal care and safety.
- Poor wound healing or getting pressure ulcers due to low oxygen at night or to not doing pressure reliefs because you keep falling asleep in your wheelchair.
- Difficulty adjusting psychologically to your disability.
- Sudden death. There are many unexplained deaths in the first year after injury. The autopsy shows nothing, and we say it was probably something heart related; but it's very possible that it was something brought on by severe apnea and low oxygen levels.

How is sleep apnea diagnosed?

Oximeter or pulse ox

This is a simple fingertip sensor that measures the amount of oxygen in the blood. The reading shows the percent saturation of oxygen in red blood cells. If it is below 90, something is wrong.

Polysomnography (PSG)

Considered the Cadillac or "gold standard" of sleep studies, this test measures breathing effort, airflow through mouth and nose, eye movement and brain waves (for sleep staging), body position and movement, snoring, oxygen level, heart rate and arterial tone.

PSG studies take place in a sleep lab. The patient is wired up to various machines and told to fall asleep as usual. Measurements are taken all night long and recorded on a printout called a polysomnograph. PSG results show the number of apnea events per hour (more than 15 events per hour is considered a major problem), how low your oxygen level goes, and time spent in different sleep phases.

Other studies

Limited sleep studies, limited channel studies, or cardiorespiratory studies are less expensive and easier to do than PSG. They measure oxygen level, heart rate, chest movement and air flow throughout the night but do not record information about sleep phases.

Watch-PAT measures peripheral arterial tone (PAT) and pulse ox in a wristmounted device. PAT is controlled by the sympathetic nervous system, however, and since this is altered in people with SCI, we can't be sure how reliable the PAT test is for the SCI population.

Barriers to diagnosing sleep apnea in persons with SCI

- Hospital staff don't always suspect sleep apnea. Sleepiness is common among inpatients for many other reasons, such as medications.
- If patients are not obese, providers may rule out sleep apnea because it is so closely associated with obesity. In the SCI population, however, thin people are also likely to have sleep apnea.
- It is difficult to get sleep studies done in the hospital because of other medical conditions, tracheostomies, etc.
- Providers may be reluctant to add another complicated treatment to the patient's life.
- SCI specialists may not be familiar with sleep apnea and its treatments.
- Sleep medicine specialists may not have experience with SCI patients.
- Sleep labs are not set up to deal with SCI and may not be accessible.

Treatment

Continuous positive airway pressure (CPAP) therapy is the most common treatment (see photo this page). A mask is positioned over the nose or nose and mouth. A bedside pump provides pressurized air, which keeps the upper airway "inflated" so it does not collapse while breathing. There are many different varieties of masks, and a person may need to test several before finding one that is

tolerable. CPAP is very effective, but it usually takes some getting used to.

- Bi-level positive airway pressure (BiPAP) alternates between high and low pressure and may be used if there is weakness of the breathing muscles.
- **Oral appliances** designed to pull your jaw forward and tug your tongue and other structures forward to give more room in the upper airway.
- Sleeping on your stomach can help if you are able to breath in that position.
- Surgical options such as UPPP (uvulopalatopharyngoplasty) to remove excess tissue obstructing the airway and jaw lengthening surgery that pulls the tongue forward.



What to do?

- If you have problems getting to sleep or staying asleep, make sure you are following the "sleep hygiene" guidelines (page 3) as much as possible.
- If you snore loudly or have problems with attention, alertness, staying awake during the day, and just feeling "foggy" a lot of the time, talk to your provider about sleep apnea. Bring this article if your provider is unfamiliar with the special problem of sleep apnea among people with SCI.
- If you are having symptoms of depression, see your provider. There are many causes of depression, and sleep apnea is one of them.

Watch the video of this presentation at: http://sci.washington.edu/sleep

It Happened to Both of Us: Conversations with Couples

When a person sustains a spinal cord injury, the impact is felt by the whole family, especially the spouse or partner. How does a partner cope and adjust? How does the relationship and each partner's roles within it change? How can a couple survive the stresses and challenges of such a life-altering event and go on to lead a satisfying life together?

At our March 2012 SCI Forum we invited four couples who were married at the time of the injury to talk about their experiences and the things they do to stay connected and maintain a healthy relationship. Although the particulars were very different for each couple, they all had to see their way through the unthinkable shock of their world turned upside-down and discover a path to go forward and thrive as a couple and family.

Watch the video of this conversation on our website at: http://sci.washington.edu/couples

Here' a preview:

Kate and Bruce

Kate and Bruce were 14 years into their marriage, with two pre-teen daughters, when Bruce had a skiing accident that resulted in C6 incomplete tetraplegia (quadriplegia). When Kate

got the call from the Ski Patrol saying Bruce had been injured and airlifted to Harborview Medical Center, her first reaction was, "He must have broken his leg or something. Bruce was an expert skier...it didn't even cross my mind that he had a serious injury." Hours later when she was told Bruce was paralyzed from his chest down, "The shock was overwhelming," she says.

As Bruce struggled to breathe in the ICU, Kate struggled to maintain traces of normalcy for her two daughters. "I made a commitment," Kate says. "I was going to be at home every day when the girls got home from school, just like I used to be before he got hurt." In order to make that happen and be with Bruce at the hospital as much as possible, a network of friends took turns staying at the house after the girls went to bed until late at night, when Kate came home from the hospital. In the

mornings, she saw the them off to school and then went back to the hospital until school was over. "We did that every day for months."

Today it is 12 years since Bruce's injury. His daughters are young adults. "We went through this whole experience as a family," Bruce says now. "We bonded in a way that I don't think we would have otherwise."

Laura and Lan

Laura and Lan had been married 25 years and enjoying their newly emptied nest in 2011 when Laura got a call while Lan was out on a bike ride. "His friends called to say Lan had been in an accident," she recalls. He was taken to Harborview Medical Center. "I thought, they'll just patch him up and we'll be out in two hours." When she learned instead that he had broken his neck and saw how bad he looked, "I didn't think he was going to survive. So after that, I was so thankful that he survived that I didn't think being paralyzed was a big deal."

One of the things that helped them both in the early days was that Laura was able to be with him in the hospital "virtually every day, and actually spend the night most times, so I didn't have to feel separated from her," Lan recalls. "That was reassuring to both of us. We sort of held each other up quite a bit during that time."

It's been about a year (since the injury), and they're still figuring things out, Laura says. But they both feel the experience has pulled them closer and keeps them focusing on what's really important. "You cut the complaining and seek a clarity that you have a common commitment. I think there's a better marriage and a deeper level of love."

Eddie and Ann

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Ann and Eddie had only been married three years when Ann became paralyzed. It was a third marriage for both of them, and

they both had adult children from earlier marriages. Unlike the others on the panel, Ann's spinal cord injury was not due to an accident. Eddie brought Ann to the emergency room with back pain one day in 1996. No cause was found, but she was kept in the hospital overnight. Eddie came back the next day expecting to take her home, but instead learned that she was paralyzed from the hips down. Understandably, "it was a huge shock," Eddie says. "But I immediately told her that we would go through this together, and that's what we did." That was 14 years ago, and today they both feel their marriage is very much stronger due to the shared experience.

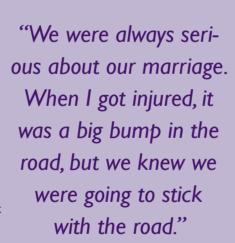
Stacy and Joe

At the time Joe was injured in 2004, he and Stacy had been married about nine years, had two preschool-age children, and were living in the southern California mountains. Joe was an expert class dirt bike racer, and on the day of his injury, he and Stacy had planned to meet

up after one of his races and take a trip into the desert with the kids. When she arrived at the race site, friends told her Joe had been injured and airlifted to a hospital in Palm Springs. It didn't occur to her that it might be serious.

When she arrived at the hospital, however, "they took me aside, sat me down and looked me in the eye, and I knew it was going to be bad," Stacy recalls. "They explained that he broke his neck and was going to be quadriplegic." Like many people who get this kind of news, she calls the experience "surreal." The life she and Joe had built together was suddenly turned upsidedown.

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literature review

The articles previewed below were selected from a recent screening of the National Library of Medicine database for articles on spinal cord injury. In the judgment of the editors, they include potentially useful information on the diagnosis or management of spinal cord injury. You may obtain copies of the complete articles through your local medical library or from UW Health Sciences Library Document Service (http://www.lib.washington.edu/ill).

WALKING

Training to achieve over ground walking after spinal cord injury: a review of who, what, when, and how.

A review was conducted of published findings about different training methods for over ground walking after SCI in order to understand who best responds to what type of treatment, how that treatment should be delivered, and at what stage after injury. Individuals with motor incomplete SCI (ASIA Impairment Scale C and D) are most likely to regain walking over ground. The effective methods of training all involved a lot of walking, and if assistance was provided, partial assistance was more effective than total assistance. Walking training resulted in an increase in over ground walking speed. The effective training schedules ranged from 10 to 130 sessions, with sessions ranging from two to five per week. Earlier training led to superior results both in the subacute (<6 months) and chronic phases (>6 months) after injury, but even individuals with chronic injuries of long duration can improve. *Yang JF, Musselman KE.*

| Spinal Cord Med. 2012 Sep;35(5):293-304.

■ The ReWalk powered exoskeleton to restore ambulatory function to individuals with thoracic-level motor-complete spinal cord injury.

This was an open, non-comparative, nonrandomized study of the safety and performance of the ReWalk powered exoskeleton in 12 participants with motor-complete paraplegia who used wheelchairs for mobility. Participants underwent gait training using the ReWalk for three 60- to 90-minute sessions over 8 weeks. By completion of the trial, all subjects had walked under their own control, without human assistance while using the ReWalk, for at least 50 to 100 meters continuously and for a period of at least 5 to 10 minutes. Some participants reported improvements in pain, bowel and bladder function, and spasticity during the trial, and all reported emotional/psychosocial benefits from the use of ReWalk. Most subjects achieved a level of walking proficiency close to that needed for limited community ambulation. ReWalk holds considerable potential as a safe ambulatory powered orthosis for individuals with motor-complete thoracic-level SCI.

Esquenazi A, Talaty M, Packel A, Saulino M. Am J Phys Med Rehabil. 2012 Nov;91(11):911-21.

EXPERIMENTAL TRIALS

• Expectations of benefit and tolerance to risk of individuals with spinal cord injury regarding potential participation in clinical trials.

This 46-item questionnaire asked 224 individuals with SCI about their receptivity to participating in clinical trials of drug therapies or stem cell therapies, their anticipation of therapeutic benefits, and their tolerance to risk. The average age of respondents was 42 years; average of 5.5 years since injury; 74% were male; and 62% had cervical injuries. Respondents reported their ASIA Impairment Scale (AIS) levels as: 33% AIS-A, 12% AIS-B, and 55% AIS-C/D. Receptivity to neuroprotective drug trials in the acute setting was very high, but somewhat less so for stem cell trials in the subacute or chronic (current) setting. About one third of the respondents indicated that they would want a 5-25% chance of achieving some functional recovery if enrolling in a stem cell trial in the current, chronic injury state. Whereas the majority said the risk of spinal cord damage, cancer, infection, and nerve pain from cell transplantation trials would need to be less than 1%, 15-30% of respondents said they would participate regardless of the risk of these complications. Those who accepted risks were male, older, and had

more self-reported knowledge of SCI research than those who did not accept those risks. These data underscore the need for careful communication with individuals with SCI to avoid unrealistic expectations and therapeutic misconception in experimental trials. *Kwon BK, Ghag A, Dvorak MF, et al.*

Neurotrauma. 2012 Dec 10;29(18):2727-37.

BLADDER MANAGEMENT

Treatment satisfaction and improvement in health-related quality of life with onabotulinumtoxinA in patients with urinary incontinence due to neurogenic detrusor overactivity. In this double-blind, placebo-controlled study, patients with urinary incontinence due to neurogenic detrusor overactivity from multiple sclerosis or SCI were randomized to three different treatment groups: 92 patients received placebo (sham treatment); 92 received onabotulinumtoxinA 200U; and 91 received a higher dose of onabotulinumtoxinA 300U. Patients who received onabotulinumtoxinA 200U or 300 U had significantly greater improvement in quality of life and greater treatment satisfaction compared to the placebo group. There was no difference between the different doses of onabotulinumtoxinA. Sussman D, Patel V, Del Popolo G, et al. Neurourol Urodyn. 2012 Sep 10.

BONE FRACTURES

Treatment of lower-extremity long-bone fractures in active, nonambulatory, wheelchair-bound patients.

A retrospective review found 11 surgically treated lower-extremity long-bone fractures in nine wheelchair-bound patients in an orthopedic department between October 2000 and July 2009. Mechanism of injury for all patients was a low-energy fall that occurred while transferring. Four patients who sustained a distal femur fracture, one patient who sustained a distal femur fracture and a subsequent proximal tibia fracture, and one patient who sustained a proximal third tibia shaft fracture underwent open reduction and internal fixation with plates and screws. Three patients with four midshaft tibia fractures underwent intramedullary nailing. At last follow-up, all nine patients had returned to their baseline preoperative function. All fractures achieved complete union, and no complications were reported. This study's findings demonstrate that operative treatment in active, long-term wheelchair-users can provide an improved quality of life postinjury and a rapid return to activities.

Sugi MT, Davidovitch R, Montero N, et al. Orthopedics. 2012 Sep;35(9):e1376-82.

PSYCHOSOCIAL

Trajectories of resilience, depression, and anxiety following spinal cord injury.

This was a longitudinal study of 233 SCI patients in six European countries who were assessed for depression and anxiety symptoms at four time points: within six weeks of injury and then at three months, one year, and two years after injury. Different patterns of trajectories for depression and anxiety symptoms emerged, but each model revealed a resilient trajectory of low symptom levels and a delayed trajectory of worsening symptoms. The resilient pattern was most common, observed in more than half of the patients. Chronic high depression was also observed in some individuals but not chronic high anxiety. The best-adjusted patients viewed major stressors as challenges to be accepted and met with active coping efforts. Results demonstrate CONTINUED FROM PREVIOUS PAGE

that SCI patients are likely to show different but observable patterns of long-term outcome. Although many SCI patients adjust remarkably well, some will fail to recover psychologically, and some (approximately 10%) will experience increased symptoms over time. The authors recommend early psychological interventions that target how patients perceive and cope with their injury.

Bonanno GA, Kennedy P, Galatzer-Levy IR, et al.

Rehabil Psychol. 2012 Aug;57(3):236-47.

Social networks and secondary health conditions: the critical secondary team for individuals with spinal cord injury.

In-depth semi-structured interviews with 14 community-dwelling individuals with an SCI (six men, eight women) in Canada were conducted in order to understand the nature and role of informal social networks in the prevention and management of secondary health conditions (SHCs). Participants were asked: (1) What have been your experiences with your health care in the community? (2) What have been your experiences with care related to prevention and/or management of SHCs? and (3)What has been the role of your informal social networks (friends/family) related to SHCs? Participants described their informal networks as a "secondary team" and a critical and essential force in dealing with SHCs that fills the gaps that exist within the formal health care system.

Guilcher SJ, Casciaro T, Lemieux-Charles L, et al. | Spinal Cord Med. 2012 Sep;35(5):330-42.

WHEELCHAIR SKILLS

Manual wheelchair skills capacity predicts guality of life and community integration in persons with spinal cord injury. This study looked at the relationship between proficiency in wheelchair (WC) skills and outcome measures of independence and quality of life. Participants were 214 individuals with SCI who used a manual WC for their primary mobility, had injuries between C3-L5, and averaged 8.6 years post-injury. Thirty-one WC skills were tested, including descending and ascending a 15-cm curb, holding a wheelie, and rotating a wheelie . Findings showed that better performance of WC skills was significantly related to better self-perceived health, higher life satisfaction, and more community participation. The ability to descend a 15-cm curb significantly predicted four of the outcome measures, more than any of the other individual WC skills. Factors contributing to low WC skill rates need to be investigated, and interventions to improve these rates are needed.

Hosseini SM, Oyster ML, Kirby RL, et al. Arch Phys Med Rehabil. 2012 Dec;93(12):2237-43.

Most essential wheeled mobility skills for daily life: an international survey among paralympic wheelchair athletes with spinal cord injury.

A sample of 49 male and 30 female elite manual wheelchair user athletes with SCI (64 with paraplegia; 15 with tetraplegia) at the Beijing Paralympic Games completed a survey in which they rated the importance of 24 predefined wheeled mobility (WM) skills on a 5-point scale (1=not essential; 5=extremely essential). They also were asked to state where, when, and with whom they have learned to perform each skill and to mark the level of WM they gained during and after their rehabilitation. Rated as the most essential skill was transfer into and out of a car. Of the respondents, 57% had learned the most essential skills in clinical rehabilitation, while 40% claimed to have learned those skills afterward in a community setting. Three percent never learned to perform the most essential skills. Of the very essential skills, 40% were self-taught. The authors recommend that the skills rated as very essential and extremely essential should be taught during inpatient rehabilitation or post-rehabilitation WM workshops.

Fliess-Douer O, Vanlandewijck YC, Van der Woude LH. Arch Phys Med Rehabil. 2012 Apr;93(4):629-35.

BOWEL MANAGEMENT

Transanal irrigation in the management of neurogenic bowel dysfunction.

Eleven individuals with SCI who did not have satisfactory results using a conservative bowel management program were trained to use transanal irrigation (TAI) to empty their bowels. Participants ranged from 27 to 72 years old; nine had SCI and two had spina bifida; and there were seven males and four females. The Peristeen TAI system (Coloplast, Denmark) was used in this study, which allows patients to perform irrigations independently or, if necessary, by a patient's carer. TAI was performed every second or third day. Severity of symptoms at initiation of TAI was measured using three questionnaires about bowel function and compared with severity of symptoms at follow-up (3-28 months). There was a significant decrease in bowel problems as measured on all three questionnaires, indicating a significant improvement in bowel function from using TAI. No serious adverse events occurred during the study. TAI is an effective treatment option for the management of neurogenic bowel dysfunction.

Loftus C, Wallace E, McCaughey M, Smith E. Ir Med J. 2012 Jul-Aug; 105(7):241-3.

PRESSURE ULCERS

Potentially modifiable risk factors among veterans with spinal cord injury hospitalized for severe pressure ulcers: a descriptive study.

Investigators examined knowledge, risk factors, skin protective behaviors, health beliefs and practices in 148 veterans hospitalized for pressure ulcers (PrUs) in six VA centers. Most ulcers were stage IV (73%), and about half of the patients had two or more PrUs. Most patients also had an average of 6.7 other medical conditions, including respiratory, gastrointestinal, renal disease/urinary tract infection, autonomic dysreflexia, diabetes, and bowel/bladder incontinence. Potential intervention opportunities include proactive assistance with management of multiple chronic conditions, substance abuse, nutrition, adherence to skin protective behaviors, readiness to change, and access to resources. Overall knowledge about PrUs was low, especially for how to prevent PrUs and what to do if skin breakdown occurs. These issues need to be addressed in order to reduce PrU incidence and recurrence in persons with SCI.

Guihan M, Bombardier CH. J Spinal Cord Med. 2012 Jul;35(4):240-50.

ACTIVITY-BASED INTERVENTIONS

Basic concepts of activity-based interventions for improved recovery of motor function after spinal cord injury. A number of advances have been made in the strategies used for rehabilitation, resulting in marked improved recovery, even after a complete SCI. Several rehabilitative interventions— assisted motor training, spinal cord epidural stimulation, and/or administration of pharmacologic agents, alone or in combination-have produced recovery in motor function in both humans and animals. The success with each of these interventions appears to be related to the fact that the spinal cord can use ensembles of sensory information to generate appropriate motor responses without input from supraspinal (above the spinal column) centers, a property commonly referred to as central pattern generation. This ability of the spinal cord reflects a level of automaticity, that is, the ability of the neural circuitry of the spinal cord to interpret complex sensory information and to make appropriate decisions to

generate successful postural and locomotor tasks. In this article, the authors review of some of the neurophysiologic rationale for the success of these interventions.

Roy RR, Harkema SJ, Edgerton VR. Arch Phys Med Rehabil. 2012 Sep;93(9):1487-97.

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MD; Chris Garbaccio; Barry Goldstein,

(OSERS), to the Northwest Regional Spinal Cord Injury System, one of 14 model SCI care systems nationwide. Project Director: Charles Bombardier, PhD. **Editorial Board of Advisors:** Charles Bombardier, PhD; Stephen Burns,

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It soon became clear that the home they had been living in was too remote for their new circumstances, and they would need to be closer to medical care and family support. Seattle was the best option, and over the next four months, with the help of many friends and relatives, Stacy sold their California house, bought and remodeled a home in the Seattle area, and found a new job."I was lying on my back in bed through all of this," Joe says now. "Stacy was phenomenal."

What held them together as a couple through the ordeal? "We were always serious about our marriage," Joe says. "That was the thing. Getting married, having kids, this is something we're doing together. And when I got injured, that was a big bump in the road, but we were going to stick with the road. So in that regard, it was just continuing to be a couple through whatever came along."

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