

spinal cord injury

UPDATE

Department of Rehabilitation Medicine

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Building a Life After Teenage SCI

Tammy Wilber was an athletic, outgoing 17-year-old on the summer day in 1993 when her life changed in an instant. While driving with friends to soccer camp, a distraction—a bee flew in the car, causing shrieking and commotion among the passengers—took her attention from the road. The road curved, the car flipped, and, not wearing a seat belt, she was ejected.

“I remember being on the ground, wide awake,” she recalls. “I knew something was wrong. I told people, ‘Don’t move me. Get help.’”

Soon after arriving at the hospital, she had emergency surgery to remove her kidney (damaged when her body was thrown against the steering wheel). Two days later she underwent spine stabilization surgery. She had sustained a complete spinal cord injury at the T5-6 level, but the fog of operations and medications kept full awareness of her situation at bay for a few days.

“I started realizing things were serious about the time I was moved from the ICU to a regular hospital room,” she remembers. “When they brought me a big blue wheelchair, I thought, ‘This is real? This is really happening?’ This was the moment I knew I was paralyzed and had my first big cry.”

For most people, the adolescent years are turbulent enough without adding trauma and permanent disability to the mix. Suddenly the path toward independence and identity takes a detour. The vision you had for yourself no longer looks like the person in the mirror.

Understandably, Wilber’s return to high school in her senior year was difficult. “People were shocked to see me,” she recalls. “I had lost a lot of weight. My hair had fallen out while I was in the hospital (a reaction to medications) and was just starting



Northwest Regional SCI System Consumer Advisory Board member Tammy Wilber was crowned Ms. Wheelchair Washington in 2006.

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Reader Survey Results

Thank you to all our readers who took the time to complete the newsletter survey from the last issue. We heard from 85 of you (so far; responses are still trickling in) and are grateful for your feedback on how the newsletter is serving your information needs and what we can do to improve it.

We were pleased to learn that most respondents (93%) said they learned new information from the newsletters, and that the information has been useful to them (87%) and has helped improve their health or quality of life (62.5%). A total of 57% reported they had changed a behavior or taken some action based on information they learned in the newsletter.

The majority of respondents (92%) gave the newsletter a favorable overall rating, with 80% reporting that the content and writing are “about right” (not too technical nor too basic).

The top ten issues of greatest interest to readers were: pain (51%), recovery or cure (47%), aging (46%), assistive technology (42%), bowel management (40%), equipment (39%), fitness/exercise (36%), profiles of persons with SCI (33%), skin care (31%) and bladder management (29%). Many of these topics have been covered in recent issues, and we will be sure to continue addressing these and other topics you identified in our various education activities (SCI Forums, newsletters and pamphlets) in the future.

Building a Life

CONTINUED FROM PAGE 1

to grow back, so I looked really different. To me, I looked and felt like an unhealthy person.” This was a dramatic change from pre-injury, and her self-image took a beating.

Gradually, the stares and awkward questions from peers diminished, and she eased back into a subdued version of her previous social life. “I was limited in my activities because of accessibility reasons, bladder and bowel issues,” Wilber says. “It took so long to do everything. So it was just easier for my friends to come over to my house.”

After graduation, “My friends went off to college, and I started feeling left out,” Wilber says. So she went to the Shriners Hospital in Philadelphia to take part in a functional electrical stimulation (FES) program for walking. “I lived at the hospital for six months. It was very therapeutic because it was a transition, going away from home like my friends who went to college, and because for the first time I was around a lot of people with disabilities. I made friends with people all around the country. My roommate was a paraplegic. It was kind of fun.”

The FES program involved implanting electrodes in her legs to stimulate her muscles to walk. While it provided good exercise, strengthened her muscles, and allowed her to stand to reach for things, it was too exhausting for regular ambulation and required occasional repair surgery trips to Philadelphia. Once Wilber started at the University of New Hampshire, these trips became too disruptive. She had the electrodes removed three years after their initial implantation.

Meanwhile, college life had plenty of its own challenges. “I had a hard time adjusting,” she admits. “That first winter was horrible—the snow, dorm life.” Self-conscious about her personal care needs, she did her bowel program in the middle of the night, when no one was in the bathroom. Having given up her childhood dream of becoming a nurse, she was at loose ends, switching majors often, transferring to Florida State in her sophomore year, and then dropping out as a junior.

That turned out to be an empowering move, however. She wanted to try working but wasn’t sure of herself, so she started volunteering at a recreation organization for people with disabilities. “It was a great way for me to gain job skills and the confidence that I could work,” she says. She was soon hired as a part-time administrative assistant.

Wilber had come a long way—she was independent; she could drive and play sports—but at the five-year anniversary of her injury, depression began undermining her equilibrium. She went to a counselor, who offered this observation: “You never really mourned the loss of the use of your legs.”

“It suddenly hit me how right she was!” Wilber recalls. “I had been all ‘go, go, go!’ I felt I needed to be superwoman, to prove myself.” Counseling helped her come to terms with her loss and let go of her compulsion always to overachieve.

Fast-forward to the present day, and Wilber is a Seattle resident and full-time marketing manager for VARILITE, a wheelchair seating company. “This job is something I have been working toward,” Wilber said. “Although I never became a nurse,

I am still connected to the medical and disability communities. I feel very fortunate to be working for such a good company.”

She doesn’t kick back during her off-work hours, however. “Volunteering has been my passion since high school,” she admits, especially when it involves helping others with disabilities. In addition to serving on the boards of PROVAIL (a non-profit service agency for individuals with disabilities) and the Northwest Regional Spinal Cord Injury System (NWRSCIS), she has been a longtime peer mentor to newly-injured SCI patients at the University of Washington. “Peer mentoring is so important,” she says. “So many people helped me the first few years. Being able to see someone who’s been injured 14 years and see that it’s not the end of the world, it’s huge.”

Wilber helped start an online women’s wheelchair support group that connects women with SCI throughout the Northwest. They share information and experiences about the nuts-and-bolts of living with SCI and even manage to convene periodically in person for social activities. Since only 25% of the SCI population are females, Wilber feels it is especially important for women to find ways to support each other. “It was almost six months after my injury before I talked to another girl with SCI. She was a huge influence. There are so many female issues. To be able to share that information and support is really important.”

In the same spirit of reaching out, Wilber was crowned Ms. Wheelchair Washington in 2006, a title that is more about community service than ball gowns and makeup (although they do have fun! See photo.). She made volunteering her platform for the year: “I called it ‘VolunteersAbility,’ because everyone has the ability to be a volunteer and make a difference.” This year she is the (volunteer) Washington State pageant coordinator and mentors the current title-holder.

Somewhere in the midst of all these major volunteer commitments and working 40-plus hours a week, Wilber still makes time for other community service opportunities that arise, such as helping gather medical equipment for persons with disabilities in third-world countries through The Mobility Project; participating as a study subject in SCI research projects (see the Spring 2005 SCI Update article at http://sci.washington.edu/info/newsletters/articles/05sp_arm_shoulder.asp); and speaking about disabilities to businesses and schools.

Wilber’s most recent accolade comes from the Washington State Governor’s Committee on Employment and Disability: She was awarded the 2007 Governor’s Trophy for “empowering leadership, removing barriers to employment, and improving access to programs and services.”

As a member of the NWRSCIS Community Advisory Board, Wilber helps plan and coordinate the monthly SCI Forums, serves as a forum greeter and frequent panelist, and advises staff on ways to improve the UW’s SCI services. Fellow board members and NWRSCIS staff agree that her insights, enthusiasm and energy are invaluable.

Her advice to others with SCI? “Patience,” she says. “Take one day at a time. For me, it’s been 14 years. I didn’t get to where I am overnight. Take one step at a time—one wheel at a time—focus on now. Don’t worry so much about the future.”

*It’s so important to
be able to meet someone
who’s been injured 14 years
and see that it’s not
the end of the world.*

Experimental treatment for SCI: *Watch out!*

Many people with SCI read about experimental treatments (for the spinal cord injury itself, or for its consequences such as chronic pain or problems in sexual functioning) and wonder why they are not being offered in the U.S. They may ask themselves whether they should consider traveling to distant places—usually at their own expense—for a chance to be cured. Sometimes these “innovative” treatments are offered as part of research, sometimes not even that.

Professionals who follow SCI treatment research at times have grave concerns about the safety of some of this research, especially some of the foreign trials. To help patients understand the maze of SCI research and make informed decisions about treatments, the International Campaign for Cures of Spinal Cord Injury Paralysis (ICCP) published a 2007 booklet called *Experimental Treatments for SCI: What you should know if you are considering participation in a clinical trial. A guide for people with SCI, their families, friends and caregivers*. Read or download it for free at www.icord.org/iccp.html.

The 40-page booklet provides guidelines and a checklist of questions to ask if you are considering a new treatment—any new treatment, but especially one that claims to offer radical improvements. It clearly explains what a clinical trial is and why it is difficult to know whether a treatment is really beneficial if there has not been a clinical trial. The booklet also describes the status of several experimental treatments currently being studied or used around the world.

People desperate for a cure are vulnerable to untested, unproven procedures. They owe it to themselves to become fully informed about the procedure and all the possible risks and outcomes of a treatment before deciding whether to participate. There is always a chance that an intervention (treatment) might make your condition worse rather than improve it. Only you can decide whether the risk is worth it.

Some issues you should consider before consenting to treatment:

- Is the proposed treatment part of a formal study (also known as a clinical trial)?
- Has the study been approved by the appropriate Research Ethics Committee or Institutional Review Board? This is essential in a clinical trial.
- If it is part of a properly controlled clinical trial, has it been explained that you might be one of the ‘control group’ patients? This means that you have a 50% chance of not getting the treatment being studied, but a comparison treatment instead (a placebo or sugar pill, a sham operation, or at best the traditional treatment, not the new one).
- Have all the known and potential risks been fully explained?
- Have details of the treatment (and its risks and benefits) been published in respected medical journals? Stories or “hearsay” from other patients are not normally considered strong evidence.
- What follow-up is available after the treatment? Will you be monitored and re-evaluated regularly?
- Has an independent expert agreed that the treatment is safe and worthwhile for you? Will the predicted benefit improve your daily life?
- What costs are involved before and during treatment, and in the follow-up period? It is considered unethical in the U.S. to charge patients for experimental treatments.

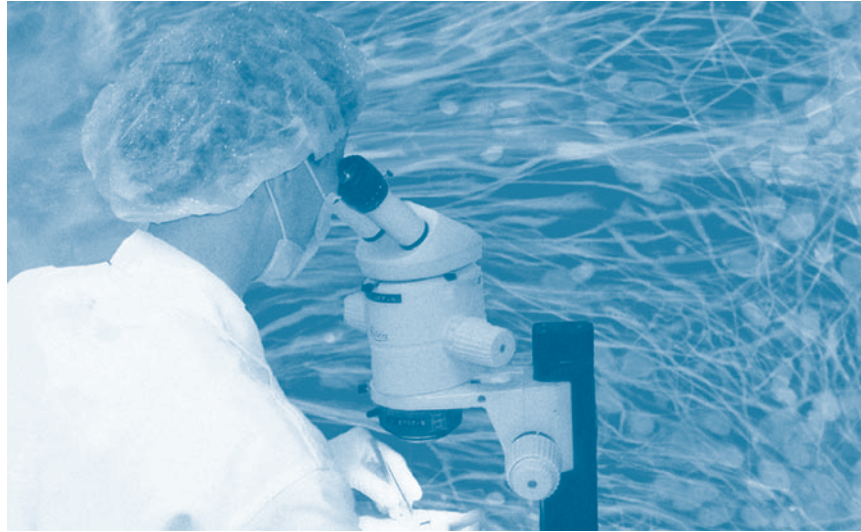
For more information:

International Collaboration on Repair Discoveries

(ICORD) (www.icord.org) — research and training to accelerate the discovery of more effective strategies to promote functional recovery after SCI, located in Vancouver, B.C.

International Campaign for Cures of Spinal Cord Injury

Paralysis (ICCP) (www.campaignforcure.org/) — an international coalition of non-profit organizations whose mission is to expedite the discovery of cures for spinal cord injury paralysis.



- Be aware that participating in one procedure might exclude you from receiving other procedures in the future.
- Be aware that regulations differ throughout the world. Strict regulations in the U.S. and other developed countries have been put in place to protect the research study participants.
- Be aware that some effects of treatment might be negative. For example, there is a chance that some interventions might increase pain.
- Be aware that any negative effects may be more harmful to patients with higher level injuries.

forum report

The SCI Forum is an evening presentation and discussion series on topics of interest to persons with spinal cord injury and their family members, friends, and caregivers, held monthly at the University of Washington Medical Center. To learn about upcoming SCI Forums, read reports of past forums, or view forum videos, consult our Web site at <http://sci.washington.edu/info/forums>. Contact Cynthia Salzman (email: csalzman@u.washington.edu; phone: 206-685-3999) if you wish to be added to the SCI Forum mailing list.

Universal Fitness

By Cathy Warm, PhD, ARNP, CRRN, Department of Rehabilitation Medicine, University of Washington

This is excerpted from Dr. Warm's presentation. Read the complete report or view the video on our Web site at http://sci.washington.edu/info/forums/reports/universal_fitness.asp.

Fitness isn't just about exercise and sports; it includes physical activity of any kind, and for that reason, almost anyone with a spinal cord injury can become more fit. What counts as exercise for the individual varies depending on the amount of active muscle.

Research has shown that exercise after SCI has many benefits: improved breathing ability, muscle strength, circulation, body composition (more muscle, less fat), blood lipid profile, self-esteem and self-confidence. Exercise can decrease depression and anxiety; help prevent secondary conditions (such as pressure ulcers, UTIs and respiratory infections); slow the rate of bone loss; improve the immune system; improve digestion and bowel activity; and decrease the risks of heart disease, high blood pressure, diabetes and colon cancer.¹

How exercise effects you will depend on your level and completeness of injury.

- **Blood pressure:** Some people with SCI, regardless of level, may experience low blood pressure during and after vigorous exercise, partly due to less efficient return of blood from the legs. This should not be a barrier to exercise. Keeping exercise to moderate intensity, or wearing support hose, ACE wraps, or an abdominal binder can help. There also are medications that your health care provider can prescribe.

- **Heart rate:** At T-6 and above it is harder to increase pulse in response to exercise. A maximum heart rate for someone with tetraplegia might be as low as 120 or 130. "Rate of perceived exertion" (see sidebar) is an alternative to heart rate as a way of measuring how intensely you are exercising.

- **Temperature regulation:** The higher the level of injury, the less able the body is to regulate its temperature. With cervical injuries, the temperature of the external environment will be the major determinant of body temperature during

exercise. Exercise in a cool place, drink water frequently, and use a spray bottle and a fan to help prevent body temperature increase.

Before starting out

- **Shoulder and arm pain.** While this can often be improved with appropriate regular exercise, anyone with pain or an overuse condition should consult a PT to avoid worsening the problem.

- **Skin breakdown.** Sometimes due to improper positioning or lack of cushioning during activity. Do frequent, complete skin checks when first starting a new activity and make adjustments as needed.

- **Autonomic dysreflexia.** If you're prone to it, avoid activities that irritate skin, and make sure your bowel and bladder are empty.

- **Spasticity (high muscle tone).** Some types of exercise may worsen spasticity. To avoid this, stretch the spastic muscle groups before exercise and avoid the exercises that tend to worsen or cause the spasms.

- **Spinal rods or fusion.** Individuals with spinal hardware or a fusion should be cleared for all activities by the spinal surgeon.

- **Medications can change the way your body responds to exercise.** Most common medications taken by people with SCI will not cause any difficulty. But people on medication for high blood pressure or breathing problems should check with their health care provider before starting an exercise program.

Guidelines and principles

- **Public health guidelines call for 30 minutes of moderate intensity exercise "most days" (5-7 days/week),** keeping in mind that your plan is based on doing as much as you reliably can rather than as much as you possibly can. Three 10-minute exercise sessions in a day works as well as one 30-minute session.

RPE: Rate of Perceived Exertion²

- 0 = Nothing at all
- 1 = Very Light
- 2 = Light
- 3 = Moderate*
- 4 = Somewhat hard*
- 5 = Hard
- 6,7,8 = Very Hard
- 9 = Very, very Hard
- 10 = Maximal

* goal

Hint: With light intensity, you can sing while you exercise; with moderate intensity, you can talk with someone else; with vigorous or hard intensity, you can't carry on a conversation.

- Exercises like wheelchair pushing or arm ergometry provide both cardiovascular conditioning and improved muscle endurance. Aerobic exercise is more difficult with the higher level injury, but not impossible. I read a case study of an individual with C-4 level injury who was able to increase heart rate during shoulder shrugging alone.

- **Aerobic exercise requires continuous, rhythmical motion.** Physical activity does not have to be strenuous to provide health benefits. Start slowly; fitness gains without injury are more likely if the duration and frequency are gradually increased, but the intensity is kept at a moderate level.

- **Use the rating of perceived exertion, or RPE, (above) rather than heart rate, to measure exercise intensity.**

Try to stay between levels 3 and 4 when you're working out. It may take a few exercise sessions before you get a feeling for knowing how hard you're working and how to adjust it.

- **An exercise program should include:** 1) cardiovascular conditioning (aerobic exercise); 2) muscle strengthening and endurance; and 3) flexibility.

Cardiovascular endurance (aerobic conditioning)

Activities that can provide aerobic conditioning include wheelchair pushing; seated aerobics (class, video, or invent your own); arm ergometry; swimming; circuit training (on machines in a

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gym); handcycling; adaptive sports (skiing, rowing, basketball); functional electrical stimulation (FES) walking or cycling; even housework and gardening. People with C5-C6 quadriplegia can exercise using an arm ergometer with pedal adapter, or by doing wheelchair endurance runs or wheelchair aerobics.

Varying aerobic activities decreases your chance of injury, makes exercise more enjoyable and gives you a contingency plan for good days, bad days, high pain days, or high stress days.

You can increase cardiovascular endurance by doing daily activities in a rhythmic manner and maintaining the effort for at least ten minute sessions. Even doing something like gardening for at least ten minutes at a time, three times a day, will give you fitness benefits.

Functional Electrical Stimulation (FES) Exercise

Functional Electrical Stimulation (FES) involves applying electrical stimulation to the paralyzed muscles via electrodes placed on the skin, causing muscle contractions that can provide functional movement of the limbs. Repetitive motions of the limbs can provide cardiovascular and muscle endurance training, increase muscle bulk, and provide that “exercise high” feeling. FES systems for cycling, standing and ambulation are available for home use.



Individual with C6 SCI uses an FES cycle for cardiovascular and muscle strengthening exercise.

FES technology works only for people with spastic muscles (injuries above T-12). People with cardiac pacemakers cannot use FES. People with joint contractures, autonomic dysreflexia and good sensation may not be able to use FES successfully.

Muscle strengthening (resistance training)

Free weights, wall weights, elastic bands and tubing, machines, even pulling weeds or pushing uphill, can be used to increase strength. Exercise elastic bands and tubing are an effective low-cost resistance training method, and they can provide varying degrees of resistance that can be done almost anywhere. They can be purchased with handles and can be fastened to wheelchairs or doors with loops or clip-ons. Try carrying a band with you so you have an instant exercise program during “down” times, even during your bus commute. Activity mitts and wrist

cuffs can be used to grip weight machines or dumbbells. For those who have difficulty with balance and stability, straps and gate belts can aid in proper positioning in a wheelchair.

Start with lighter loads while mastering technique, and find a weight or level of resistance that causes your muscles to fatigue after 10 to 15 repetitions. If you can do more than 15 reps, the weight is too light; less than 10 and the weight is too heavy. Rest at least 48 hours between workout sessions. Start your program in consultation with a PT or a personal trainer so that you can learn proper technique to get better benefits and avoid injury.

To prevent shoulder overuse injury from exercise, use good seating posture, wheelchair pushing mechanics and transfer techniques; avoid frequent reaching and overhead activities; don't sleep directly on your shoulders; and stretch your anterior (front) muscles and strengthen posterior (back) muscles of the shoulder (by pole-wheeling (using a pole to push your chair instead of pushing the wheels) or wheeling backward).

Some strength training equipment manufactured for the general public can be used by people with injury levels as high as C-5, although they may not be able to do all of the exercises available on a specific machine. Try out the equipment before buying it, preferably with advice from a physical therapist.

Flexibility Exercise

Everyone needs to stretch, and people who have little ability to move need to be stretched regularly and gently. Do it daily, and know the limits of your joints. Teach caregivers, and pay attention to what they do.

- Range of motion. Extremities are moved within their capacity. See Rehab Center of Ontario in Resources, below.
- Wheelchair yoga. Usually done in a group setting and can easily be adapted to differing abilities.
- Adaptive pilates. Combines stretch and flexibility using specific exercises.
- Watsu. The individual is floated and stretched in the arms of another person in warm water.

References (see back page)

Resources

- National Center on Physical Activity and Disability (NCPAD), www.ncpad.org, 1-800-900-8086: Excellent resource for information about exercise, recreation and physical activity options. Continually updated. Monthly newsletter available. SCI-specific guidelines and program descriptions including photos and videos.
- Videos: “Exercise Program for Individuals with Spinal Cord Injuries” has a version for tetraplegia and for paraplegia. Cost \$14.99 for DVD or VHS video. (To order: go to <http://www.ncpad.org/videos> or call 800-900-8086.
- United Spinal Association, USA Tech Guide, “Exercise Equipment,” <http://usatechguide.org/techguide.php?vmode=1&catid=41>: Links to sources for exercise equipment appropriate for people with SCI.
- Rehab Center of Ontario, www.rehab.on.ca/mobile/rom/index.html: Range of motion instructions and videos free online. Good for caregiver education.
- Rehabilitation Research and Training Center (RRTC) on Spinal Cord Injury: Promoting Health and Preventing Complications through Exercise, at the National Rehabilitation Institute (<http://www.sci-health.org>; 202-877-1038).

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 Delivery Service (call 206-543-3436 for fee schedule).

BOWEL

The pattern of colorectal dysfunction changes with time since spinal cord injury.

A total of 159 individuals with SCI belonging to the Danish Spinal Cord Injuries Association completed a questionnaire on colorectal function in 1996 and 2006. There were significant increases over the decade in the percentage of respondents reporting that colorectal dysfunction had some or a major impact on their quality of life (25% in 1996 to 38% in 2006); that they defecated less than every second day (11% to 19%); and that they spent more than 30 minutes at each defecation (16% to 25%). Digital anorectal stimulation or evacuation was performed at least once every week by 48% in 1996, increasing to 56% in 2006. Fecal incontinence was reported at least once a month by 22% in 1996, decreasing to 17% in 2006. While the frequency and severity of constipation-related symptoms increase with time since SCI, there is a decrease in the frequency of fecal incontinence.

Faaborg PM, Christensen P, Finnerup N, et al.
Spinal Cord. 2007 Sep 25; [Epub ahead of print]

COMPLICATIONS

Complications following spinal cord injury: occurrence and risk factors in a longitudinal study during and after inpatient rehabilitation.

A total of 212 persons with a SCI admitted to specialized rehabilitation centres were assessed for medical complications at the start of active rehabilitation (n=212), 3 months later (n=143), at discharge (n=191) and 1 year after discharge (n=143). Most subjects reported neurogenic and musculoskeletal pain, or had spasticity at each assessment. During the year after discharge, urinary tract infections and pressure sores affected 49% and 36% of the population, respectively. The degree of pain decreased, whereas the degree of spasticity increased significantly during inpatient rehabilitation. Overall, increased age, increased body mass index, traumatic lesion, tetraplegia, and complete lesion all increased the risk of complications.

Haisma JA, van der Woude LH, Stam HJ, et al.
J Rehabil Med. 2007 May;39(5):393-8.

MALE FERTILITY

Higher Sperm DNA Damage in Semen from Men with Spinal Cord Injuries Compared to Controls.

The sperm chromatin structure assay (SCSA) was used to investigate sperm DNA damage in the semen of men with SCI compared to control subjects. Men with SCI had significantly higher DNA Fragmentation Index (DFI). There was no significant difference in the DFI of samples obtained after prolonged (two to four weeks) anejaculation (no ejaculation) than samples obtained three days later. There was no significant difference in the DFI of semen samples that had been processed to remove dead sperm and leukocytes (white blood cells) than in unprocessed samples. DFI is higher in semen from men with SCI versus controls, and while the cause is unknown, it does not seem to be due to prolonged anejaculation or to the presence of dead sperm or leukocytes. The relevance of these findings to fertility outcomes with SCI male partners remains to be determined.

Brackett NL, Ibrahim E, Grotas JA, et al.
J Androl. 2007 Sep 5; [Epub ahead of print]

PAIN

Pregabalin in patients with central neuropathic pain: A randomized, double-blind, placebo-controlled trial of a flexible-dose regimen.

This study evaluated the effects of pregabalin on pain relief, tolerability, health status, and quality of life in 40 patients with central neuropathic pain caused by brain or spinal cord injuries. At baseline and 4 weeks after the start of treatment, subjects were evaluated with standard measures of pain intensity, health status and quality of life. Subjects were randomly assigned to receive increasing doses of either pregabalin (150, 300, and 600mg/day) or matching placebo capsules. After four weeks, there were significant reductions in pain as well as improvements in health status in patients suffering from severe central neuropathic pain.

Vranken JH, Dijkgraaf MG, Kruis MR, et al.
Pain. 2007 Aug 17; [Epub ahead of print]

Acupuncture for chronic shoulder pain in persons with spinal cord injury: a small-scale clinical trial.

In this randomized, double-blind, placebo-controlled trial, 17 manual wheelchair users with SCI and chronic shoulder pain were randomly assigned to receive 10 treatments of either acupuncture or invasive sham acupuncture (light needling of nonacupuncture points). Changes in shoulder pain intensity were measured using the Wheelchair User's Shoulder Pain Index. Shoulder pain decreased significantly over time in both the acupuncture and the sham acupuncture groups, with no significant difference between the 2 groups. There was, however, a medium effect associated with the acupuncture treatment, which suggests that it may be superior to sham acupuncture. A more definitive randomized controlled trial using a similar design should be done.

Dyson-Hudson TA, Kadar P, LaFontaine M, et al.
Arch Phys Med Rehabil. 2007 Oct;88(10):1276-83.

PSYCHOSOCIAL

Depression in adults who sustained spinal cord injuries as children or adolescents.

A telephone interview on depression was given to 232 adults (age 25 or older) who had sustained SCI as children (age 18 or younger). Twenty-seven percent reported depressive symptoms ranging from mild to severe; 7% reported having suicidal thoughts within the last 2 weeks; and 3% reported symptoms consistent with probable major depressive disorder. Depression was significantly associated with incomplete injury as well as with many participation outcomes, health-related quality of life, life satisfaction, and medical complications. Depression is a significant problem among adults with pediatric-onset SCI and is associated with poorer outcomes and lower quality of life. These findings should be addressed as clinicians prepare children and adolescents with SCI to transition to adulthood.

J Spinal Cord Med. 2007;30 Suppl 1:S76-82.

Anderson CJ, Vogel LC, Chlan KM, Betz RR, McDonald CM.

Cognitions, coping, and social environment predict adjustment to pain in spinal cord injury.

A total of 157 patients completed surveys assessing physical and psychological functioning, as well as psychosocial, demographic, and injury-related variables. Greater catastrophizing and pain-related beliefs (e.g., the belief that pain signals damage) were related with increased pain interference and poorer mental health, while coping styles (e.g., resting, asking for assistance) were related only with pain interference. Alternatively, greater perceived social support was related with bet-

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ter mental health. The findings are consistent with a biopsychosocial model of chronic pain, in which psychosocial variables such as coping, catastrophizing, pain-related beliefs, and social support are related to adjustment in persons with SCI and pain. These results have implications for interventions designed to treat pain interference in persons with SCI.

Raichle KA, Hanley M, Jensen MP, Cardenas DD.
J Pain. 2007 Sep;8(9):718-29. Epub 2007 Jul 5.

Resilient, undercontrolled, and overcontrolled personality prototypes among persons with spinal cord injury.

A sample of 199 persons with SCI were assessed on personality dimensions (using the NEO Five-Factor Inventory) at admission to an inpatient medical rehabilitation program. The patients fell into three personality groups or prototypes: resilient, undercontrolled, and overcontrolled. The largest group was the undercontrolled type. The resilient and undercontrolled types were better adjusted than the overcontrolled types, showing lower levels of depression at admission and higher acceptance of disability at discharge. Those who were classified as resilient at admission showed the most effective social problem-solving abilities at discharge, and the overcontrolled showed the least. The authors discuss implications of these results for assessment and interventions in rehabilitation settings.

Berry JW, Elliott TR, Rivera P.
J Pers Assess. 2007 Dec;89(3):292-302.

A longitudinal analysis of emotional impact, coping strategies and post-traumatic psychological growth following spinal cord injury: a 10-year review.

Eighty-seven people with traumatic SCI were assessed at 12 weeks post-injury and followed up 10 years later using measurements of depression, anxiety, coping, functional independence and social support. Rates of anxiety and depression had changed little over the 10-year period. Two-thirds of the sample showed no signs or symptoms of depression, and coping strategies remained relatively stable over time. Rates of post-traumatic psychological growth were associated with higher levels of psychological distress, suggesting that many people living with SCI manage the consequences of their disability without significant levels of psychopathology. However, the coping strategies they employ remain critical in accounting for this adjustment. The relationship between post-traumatic growth and psychological well-being was found to be complex, raising many questions for future research.

Pollard C, Kennedy P.
Br J Health Psychol. 2007 Sep;12(Pt 3):347-62.

RESPIRATORY

Acute respiratory tract infection visits of veterans with spinal cord injuries and disorders: rates, trends, and risk factors.

In a Veterans Health Administration population of 18,693 veterans with spinal cord injury and dysfunction (SCI&D), investigators examined the rates of outpatient visits over 5 years (1998-2002) for acute respiratory tract infections (ARIs), including pneumonia and influenza (P&I), lower respiratory tract infections (LRI), and upper respiratory tract infections (URI). There were 11,113 ARI visits over the 5-year period, with a slightly decreasing trend for LRI visits over time but no significant change for other ARIs over time. There were 30 - 35 pneumonia visits and 21 - 30 acute bronchitis visits per 1,000 SCI&D veterans per year. Older veterans were more likely than younger to have P&I visits and less likely to have URI visits. Veterans with paraplegia had fewer P&I visits than those with tetraplegia. Identifying risk factors associated with ARI visits is an important first step to improve prevention and treatment of ARIs and to improve the health of veterans with SCI&Ds.

Smith BM, Evans CT, Kurichi JE, et al.
J Spinal Cord Med. 2007;30(4):355-61.

Survey of use of the insufflator-exsufflator in patients with spinal cord injury.

The insufflator-exsufflator is a device that pulls secretions out of the lungs by first inflating the lung, then reversing the flow with enough force to simulate cough. Although it has been shown to be effective in assisting cough in individuals with SCI, many institutions do not use it. A questionnaire with 4 categories of questions (knowledge of the device, type of facility, clinical practice with the device, and patient and provider satisfaction) was mailed to members of the American Paraplegia Society. Eighty-six questionnaires (16%) were returned. The device was being used in 49% of the institutions, most commonly with a tracheostomy. Use did not correlate with size or type of facility. Patient and provider satisfaction with the insufflator-exsufflator was high.

Schmitt JK, Stiens S, Trincer R, et al.
J Spinal Cord Med. 2007;30(2):127-30.

EXERCISE

The effects of upper body exercise on the physical capacity of people with a spinal cord injury: a systematic review.

In this systematic review of the medical literature, the authors identified 14 articles of acceptable quality for analysis. These showed that, following training, average increase in peak power output (PO(peak)) was 26.1% and oxygen uptake (VO₂(peak)) was 17.6%. While overall quality of the studies was too low to draw definitive conclusions, results of the few studies with acceptable quality seem to support the view that upper body exercise may increase the physical capacity of people with SCI. The magnitude of improvement, however, varies considerably among studies.

Valent L, Dallmeijer A, Houdijk H, et al.
Clin Rehabil. 2007 Apr;21(4):315-30.

OTHER

Traumatic brain injury is under-diagnosed in patients with spinal cord injury.

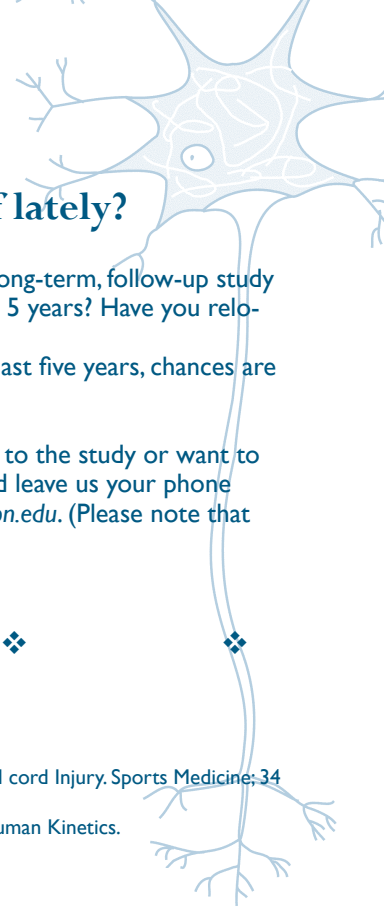
This was a cross-sectional study using prospective neurological, neuropsychological and neuroradiological (magnetic resonance imaging) examinations and retrospective medical record review. Thirty-one traumatic SCI patients on their first post-acute rehabilitation clinic visit were assessed for mild traumatic brain injury (TBI) using American Congress of Rehabilitation Medicine diagnostic criteria. Twenty-three (74%) met the diagnostic criteria for TBI, which was classified as moderate or severe in 17 patients and mild in 6 patients. The results suggest a high frequency of TBI in patients with traumatic SCI and stress a special diagnostic issue to be considered in this patient group.

Tolonen A, Turkkka J, Salonen O, et al.
J Rehabil Med. 2007 Oct;39(8):622-6.

The risk of bankruptcy before and after brain or spinal cord injury: a glimpse of the iceberg's tip.

The incidence of bankruptcy before injury and five years after was tracked in 3,527 adults admitted to hospital with brain or spinal cord injury from 1991 to 2002. The incidence of bankruptcy 5 years postinjury was 3.5%. Bankruptcy was more frequent in patients with commercial medical insurance than those insured by Medicaid. Bankruptcy was not consistently related to injury severity; patients with critical injuries tended to have a lower incidence of bankruptcy than those with mild injuries. Bankruptcy incidence was higher in younger patients and those with positive toxicology or moderately elevated blood alcohol concentration. Compared with preinjury, there was a 33% increase in bankruptcy incidence postinjury. The relative increase was highest in Medicaid patients. Better rehabilitation, workforce reintegration, and disability programs might reduce bankruptcy postinjury.

Hollingsworth W, Relyea-Chew A, Comstock BA, et al.
Med Care. 2007 Aug;45(8):702-11.



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Have you heard from our research staff lately?

Are you a participant in the Northwest Regional SCI System long-term, follow-up study but have not received a call or mailing for an interview in the last 5 years? Have you relocated recently?

If we have not contacted you for a follow-up interview in the last five years, chances are we have lost touch with you.

Please help us stay in touch. We want to hear from you.

If you want to continue to provide information about yourself to the study or want to be contacted about future studies, please call 1-800-366-5643 and leave us your phone number and address. You can also email us at nwrscis@u.washington.edu. (Please note that we cannot assure the confidentiality of e-mail.)

Thank you in advance for your continued participation!



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