

NeuroMatters

Connecting YOU to the Research

Under Pressure

To find pressure sore treatments that work

Chances are, if you have a spinal cord injury (SCI) you've had, or will have, a pressure sore at some point in your life. Most people will develop a sore within the first five years of their injury. Statistics show that 35% of the SCI population has a pressure sore at any given time. Up to 95% of people with SCI have had a pressure sore, and 13% have a recurring problem.

For the Ontario Neurotrauma Foundation (ONF), what these statistics represent needs to be addressed: loss of productivity, in addition to pain and suffering for people who have the sores and burden of care and associated costs for the health care system. Therefore, in 2007, ONF put out a call for submissions on research projects to treat and prevent pressure sores. ONF wanted to leverage the results of the projects to develop new, comprehensive prevention and treatment strategies that would advance clinical practice and improve quality of life for people with SCI.

Based on the recommendations of a review panel, ONF funded three projects on Ultraviolet-C radiation therapy, electrical stimulation therapy, and bioelectrical fields. Here's a description of these projects.

Ultraviolet-C Irradiation as an Alternative to Bed Rest for Healing Pressure Sores

Led by Dr. Ethne Nussbaum and Dr. Colleen McGillivray at Toronto Rehabilitation Institute, this project seeks to determine whether exposing pressure sores to Ultraviolet-C(UV-C) radiation

therapy, while still providing regular management of the sore, will result in less prescribed bed rest and faster healing. UV-C radiation is used to kill bacteria and to stimulate tissue and skin growth. UV-A and UV-B are more well-known as the radiant energies that we use sunscreen to avoid. The Earth's ozone layer normally blocks our exposure to UV-C, which is a band of energy on the electromagnetic spectrum that is safe when used properly. In this study, participants with pressure sores will receive UV-C therapy or a placebo therapy using a look-a-like lamp that does not produce UV-C. They will receive their treatments three times a week until the sores have healed.

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HAVING RELIEF FROM THE WORRY OF A PRESSURE SORE IS A HUGE STEP IN THE RIGHT DIRECTION FOR IMPROVING THE QUALITY OF LIFE FOR PEOPLE WITH SCI.



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The sores will be photographed every Monday to assess the progress. Participants have follow up telephone interviews one month, six months and 12 months after completion of the study to see whether their pressure sore has remained healed.

Researchers will see whether using UV-C therapy will:

- minimize the occurrence of infection
- shorten people's length of stay in hospital
- reduce secondary complications such as respiratory illness
- decrease time spent in bed
- and increase patient satisfaction with their quality of life (as measured by a "before and after" questionnaire completed by participants).

The project has already recruited half of its anticipated 20 participants.

Management of Pressure Ulcers in Community Dwelling Individuals with Spinal Cord Injury: Demonstration of a Community Care Access Centre Driven Model of Delivery of Electrical Stimulation Therapy

Led by Dr. Pamela Houghton at the University of Western Ontario, this study recruited 34 people with SCI who were living in their communities and dealing with long lasting pressure sores. All participants received, in their homes, the standard pressure sore treatment from health care professionals from their Community Care Access Centre (CCAC) or other health care programmes; and approximately half of the 34 participants also received electrical stimulation therapy (EST).

EST is a treatment that uses specialized electrodes and equipment to deliver low-level electrical current to a wound. Although pre-existing research shows that EST is

an effective treatment, there is a need to demonstrate that it can be used successfully within a Canadian health care model.

An interdisciplinary wound care team developed customized treatment protocol for each participant in the study. The team optimized the pressure sore environment for healing, promoted good eating habits, and reduced further skin damage from excess pressure or friction from movement.

The results were promising:

- On average, pressure sores were 75% smaller in the participants who received EST compared to those who did not receive EST.
- 69% of the pressure sores treated with EST healed completely, compared to 22% of those without EST.
- The pressure sores of those who received EST healed much faster than those of the other participants, whose sores were only 36% smaller after three months.

On average, participants with EST received wound closure after 17 weeks of EST, administered four and a half hours a day.

As an added benefit, EST was cost-effective - EST cost \$1,600 per person, which is 11% of the average cost paid out by CCAC to provide standard wound care to subjects enrolled in the study over the same time period (\$13,000 for 252 days).

Participants, as well as their family members, caregivers, and/or community healthcare professionals, received written instructions on how to administer EST. This patient-centred approach meant that not all participants received the EST treatment in the same manner, but it helped people to follow recommended EST treatment practices, and it enabled people in rural

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About Pressure Sores

- Also known as: bed sores, pressure ulcers, decubitus ulcers
- A pressure sore is an area of skin that breaks down when you stay in one position for too long without shifting your weight. This often happens if you use a wheelchair or you have to spend time in bed, even for a short period of time (e.g. post surgery).
- Pressure sores are caused by constant pressure against the skin reducing the blood supply to that area, and consequently the affected tissue dies.
- Although easily prevented and completely treatable if found early, pressure sores can be fatal - even if you are under medical care. As a common secondary complication of many medical conditions including SCI, pressure sores are one of the leading causes of death reported in developed countries, second only to adverse drug reactions.
- Prior to the 1950s, treatment was unknown until research showed that the primary prevention and treatment was to redistribute the pressure by using specialized surfaces on beds and wheelchairs and adopting a regular turning schedule for each patient every two to four hours.
- A pressure sore starts as reddened skin but gets progressively worse, forming a blister, then an open sore, and finally a deep crater. Pressure sores usually occur over bony areas, such as the buttocks, hips, heels, ankles, shoulders, elbows and the back of the head.
- Some complications of pressure sores are autonomic dysreflexia, bone and joint infection, systemic infection (blood poisoning), and even death.

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areas to participate in the study as well.

This project has been completed. Results were presented at the National Spinal Cord Conference in November, 2008. The results are presently being prepared for publication in a scientific journal.

Role of Bio-Electrical and Biochemical Fields in Chronic Non-Healing Wounds for People with SCI

This study also led by Dr. Pamela Houghton, is studying chronic pressure sores. In the first phase, the project team will compare the pressure sore wound fluid of people with SCI to the wound fluid of those who do not have an SCI. This study is based on the theory that the analysis of the chemical make-up of the wound fluid can predict pressure sore healing. The research team will collect samples of wound fluid from each of the 40 participants in the study (20 people with SCI and 20 without). Having an SCI impacts the ability for a pressure sore to heal. This could be because of one or both of the following reasons:

- Concurring health issues (e.g., a urinary tract infection, stress, chronic pain) may be interfering with healing and preoccupying the immune system.
- Healing in the part of the body that is below a spinal cord lesion is slower than in the part of the body above the lesion.

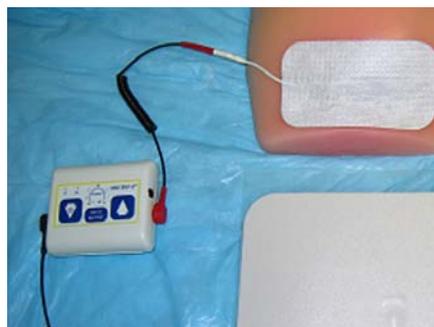
Since there is no research on whether an altered immune system affects the chemical make-up of a pressure sore and the healing process, the research team wants to investigate and identify what makes for successful healing in people with SCI.

In the second phase of the project, the research team will examine whether treatments using EST can restore normal wound chemical make-up to create an environment that is conducive to healing and more similar to that which is present in people who heal easily

and who do not have an SCI.

Previous research has shown that EST improves wound healing by:

- activating cells to form new tissue
- promoting cell growth and triggering key cells that help in the healing process
- improving the integrity and strength of the scar
- increasing circulation and the delivery of oxygen to the



Electrical Stimulation Therapy Treatment Device



UV-C Radiation Therapy Treatment Device

wound region

- preventing growth of bacteria
Researchers will examine changes in the wound (size, severity, appearance) due to EST treatments. The researchers will be able to assess what change a single and repeated treatments of EST bring to the pressure sore environment and examine how long these changes remain after EST has stopped.

By trying different electrical charges, the researchers hope to determine the best treatment schedule that EST needs to be applied, so as to develop best management practices and also to help predict whether the treatment will be effective. Evaluation of the wound's chemical make-up using a simple swab technique may also become a helpful tool in predicting who might best respond to an intensive course of EST therapy.

A combination of pressure sore wound fluid analysis and EST will be studied by three research teams in Toronto, ON, London, ON and Amherst, New York, USA.

All study sites are actively recruiting participants at this time. 20 of the study participants will have an SCI and 20 will not. In each of the two groups, ten participants will have wound fluid tested that predicts healing, and ten will not.

These three research projects show exciting promise for the management of pressure sores in people with SCI.

Pressure Sores Are Preventable

- Health care professionals must assess individuals who are at heightened risk for developing pressure sores, and then create an individualized care plan. A typical care plan will include: frequent rotation to discourage sitting or lying in one position for long periods, pressure relieving air mattresses, and wheelchair cushions, and nutritional diets.
- You can look after yourself, too. Check your skin regularly. Invest in a hand-held mirror so you can look at those hard-to-see places. At the first sign of trouble, relieve the pressure, and make sure you are giving your body what it needs to heal - rest, healthy food, and an early visit to a healthcare professional.

Research and You

Things to think about before entering a clinical trial

Clinical trials are an important part of research because they test medical innovations and discoveries in the real world, and help to determine best clinical practices. There are several reasons why consumers might want to participate in a clinical trial. It might be that you want to help - to play a part in a field of research that is exciting or that is looking for a medical breakthrough that will help you, as well as others, in the future. Another benefit to participating in a clinical trial is that while you are being well-cared for by healthcare professionals, you might find out more about new drugs, therapies or exercises that may improve your health.

Like anything in life, it's good to know what you are getting into before you participate in a clinical trial. You'll want to know: What is the purpose of the trial? Why does this trial matter? What are the potential benefits and the possible risks? What will happen to the findings? Right from the beginning, you'll want to know the kind of commitment that the researchers are expecting from you. How many times are you expected to come in for testing/treatment? How long does the trial go on for? In the long run, is the level of commitment going to be worthwhile for you? All of this must be explained properly to you to make an informed decision before you consent to participate.

Next, you want to make sure that the researchers/doctors are credible. Most clinical trials will be linked to a hospital or university. Be sure to ask which one. Clinical trials should neither cost you money to

participate nor make claims about the success of the trial.

Research studies often start with experiments on animals and then, if there is a marked success, the testing will begin with human clinical trials. The trials move through different phases starting with small groups of people who test whether a treatment is safe on humans; to a larger trial that compares the group that is having the special treatment with a group that is not; to an even larger trial with several tests going on doing further comparisons. After the treatment is a proven success many times over, it can then move to the status of an accepted best practice. For you, as a potential participant in a trial, you should ask what phase the trial is in. Generally, phases 2 and 3 are considered safer.

In a phase 2 or 3 trial, the group that is being compared to the group receiving the "special" treatment is called a "control group". If you are in a phase 2 or 3 trial, there is a chance that you will be in the control group because your placement in the trial is randomly selected. This isn't bad news because the special treatment might have negative side effects that haven't been discovered yet. Regardless of whether or not you are receiving the treatment, you are still getting great, individualized health care during the study. Furthermore, if a trial is successful, then the control group participants may be able to sign up first for the next trial. If you are considering participating in a phase 2 trial, ask whether or not you have first dibs on entering fur-

ther trials or whether you might be excluded.

No participant should be in a clinical trial without giving fully informed written consent. This means you have the right to ask all the questions you want about the trial and not move forward until you are satisfied with the answers. Ask questions about what to do if you are not happy with how the trial is going or if your health gets worse, who you can complain to, and how you can get the results of the clinical trial.

If you are seriously considering participating in a clinical trial, talk to others to get their opinion. Your doctor, other SCI and ABI organizations, and researchers will be able to give you feedback on the type of research being conducted. If you don't know who to talk to, ask the trial's researchers for references. Once you fully understand the trial and what is expected of you, then you are in a position to say "yes" if you still are interested.

Check out: www.icord.org/ICCP/Experimental_treatment_for_SCI-summary.pdf

Although written for people with SCI entering clinical trials, this questionnaire could also be used by people with ABI. The questionnaire includes good questions to ask researchers running clinical trials.



Finding the Pieces of the Puzzle

Looking at information that already exists to find out more about acquired brain injury in Ontario

In an effort to better understand and serve people with acquired brain injury (ABI), ONF has funded the ABI Dataset Pilot Project. The research team consists of Angela Colantonio (Senior Scientist, Toronto Rehabilitation Institute and Professor, Department of Occupational Science and Occupational Therapy, University of Toronto), along with Brandon Zagorski (Statistical Consultant), Rika Vander Laan (Consultant) and Daria Parsons (Consultant). The project aims to collect information about ABI in Ontario, and to build a comprehensive resource that will help to plan and deliver ABI hospital rehabilitation and community care effectively.

In the first phase of the project, which began in 2006, researchers collected information for the period between 2003 and 2006 from three existing databases.

What information is being studied?

The ABI Dataset Pilot Project uses information collected by or for Ontario's Ministry of Health and Long-Term Care (MOHLTC). This project makes use of administrative data from our public health insurance system. It is a cost-effective way to better understand



ABI information that is already collected through regular systems.

The first phase of this study collects and examines information from the following patient databases in order to get a better general "picture" of ABI in the province.

- National Ambulatory Care Reporting System (NACRS) - a database containing information about the use of outpatient services, clinics, dialysis, and emergency department visits
- Discharge Abstract Dataset (DAD) - a database containing information about people who are in acute-care hospitals
- National Rehabilitation Reporting System (NRS) - a database containing information about adults in rehabilitation facilities

Each of these databases represents a step in the continuum of care - from injury/diagnosis to rehabilitation to reintegration into the community. The project is interested in general trends, such

as different age groups or ABI occurrence in different regions, but is not focused on information about specific individuals.

Why do researchers want to study information in patient databases?

Patient databases have valuable information about health services and the people who use them. For example, researchers might find trends based on community size, geography, age, sex, or level of service. Awareness of trends can help governments to plan and make policy and can help those who serve people with ABI - all with a view to improving programmes and services.

What's new about this study?

This study is significant for several reasons:

- The information was pulled from existing databases, and was resorted in a way that has never been done before in Ontario.
- The information being collected is not available in other provinces in Canada.
- The information is based on people with ABI but, for the first time ever, it separates information about TBI and non-TBI.

What did the researchers find?

Here's what the researchers found with respect to the period between 2003 and 2006:

- The most common causes of TBI were falls, being struck

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by/against something, and motor vehicle crashes.

- The most common causes of non-TBI were injury to blood vessels in the brain (e.g. aneurysms), brain tumours, meningitis, and lack of oxygen to the brain.
- Visits to an emergency department and hospital admissions for people who already have an ABI increased.
- People with TBI are younger than people with non-TBI.
- TBI is considerably higher in males than females.
- Non-TBI is slightly higher in males than in females.
- The length of stay in hospital for people with ABI has decreased.
- 29% of people with ABI travelled outside of their community for treatment.
- Re-admission rates to hospital for people with TBI were lower than those for people with non-TBI.
- 11% of people discharged from acute care had days with an "alternate level of care" (ALC) designation, meaning they were cared for in an inappropriate setting, e.g. in acute care when they were actually ready for rehabilitation.

What are the next steps?

The project team has conducted an in-depth analysis of trends in health care use of ABI consumers by Local Health Integration Networks (LHINS) which are the 14 health service regions in the province. This analysis includes information on ALC days. Currently, the ALC days issue is of

great concern for policy makers and providers as people with ABI could be better served in another setting. This information is intended to help provide strategies to address this issue, to provide the appropriate health service when it is needed.

The researchers plan to move to a second phase of this project that will:

- share information on trends by geographical areas in order to assist LHINS in their planning
- direct researchers to areas that need attention or that have not been studied at all
- identify changes over time in trends relating to people with ABI

The second phase will also look at other databases, to find out even more about the services people with ABI use and need. There is a vast amount of information that is readily available. This will help researchers to better answer questions like:

- What services are people with ABI using after discharge from hospital, e.g. community services, physician visits, long-term and chronic care?
- What is the cost of ABI along the continuum of care?

The research has only just begun to scratch the surface when it comes to examining information about ABI. The findings from this phase of the project and fact sheets will soon be provided on the ONF website (www.onf.org) in the "What's New" section and the "ABI" section.

Upcoming Events

July 7-10, 2009: The 1st Annual Centre for Brain and Behaviour International Symposium - "Brain Injury in Children", Toronto, ON. A conference open to psychologists, psychiatrists, neurologists, surgeons, pediatricians, nurses, and rehabilitation service providers focusing on ABI in children and how ABI effects the developing brain. For more information, visit: <http://www.sickkids.ca/eventlistings/2009/cbb-international-symposium.html>.

July 10-12, 2009: The Brain Injury Association of Canada 6th Annual Conference - "Successful STEPS (Strategies for Education, Prevention and Support) - Celebrating Survival", Pierrefonds, Quebec. The conference will highlight informative sessions by brain injury professionals and survivors who have walked the walk. For more information, visit: <http://biac-aclc.ca/en/annual-conference/>.

October 28-30, 2009: The Provincial ABI Conference - "Harnessing the Power after Brain Injury", Niagara Falls, ON. Featuring key notes speakers, Dr. Abe Sniderman and Dr. Bryan Kolb. For more information, visit: <http://www.obia.on.ca/>.

Looking for Answers

Information from people with ABI helps to ensure better services

Since the late 1980s, the Ontario Brain Injury Association (OBIA) has been sending out two different questionnaires about life with an ABI: one to people with acquired brain injuries (ABI) (both adults and youth), and the other to caregivers. The questionnaires ask questions like: "How did you get your brain injury?" "Did you lose consciousness?" "Did you receive medical care?" They also ask about assistive devices, the impact of ABI on daily living, schooling, and living arrangements. OBIA receives much information and insight from the responses to these questionnaires. No other survey collects long-term data on the progress of people with ABI. To date, there is information about the impact of ABI on 625 individuals.



"These questionnaires are very useful," says Ruth Wilcock of OBIA "because we can identify trends, such as what services and resources a person with an ABI uses over a long-term period." The information is used in statistical reports that will benefit health care policy makers, insurers and researchers who are investigating ways that people with ABI can be better served. Personal data is never shared.

Last year, OBIA decided to improve these questionnaires. With ONF funding, an expert panel was

assembled in November to give input on the development of a new questionnaire. The panel consisted of people with ABI, caregivers, researchers, service providers, Ministry of Health representatives, insurance representatives, and other ABI stakeholders. The panel was asked to:

- review and discuss the current questionnaire
- discuss the potential benefits and utility of a revised questionnaire and database
- provide input into what key

information should be collected about the effect of ABI on adults, children and caregivers

- advise on redesign of the questionnaire to capture the key information

The group reviewed the questionnaire and then put together a report consisting of feedback and recommendations. Then, two researchers used this information to overhaul the questionnaire. Their changes were reviewed by OBIA and ONF and the expert panel, again. Now the questionnaire was ready to pilot.

"...we can identify trends, such as what services and resources a person with ABI uses over a long-term period."

OBIA will seek feedback on the questionnaire from 15 people who have filled out the past questionnaire, and 15 people who are answering the questionnaire for the first time using the new version. Once the results are in, the questionnaire will go back to the expert panel one last time. The panel will reconvene early in 2010 to discuss the results from the revised questionnaire and the feedback from the respondents. They will also discuss long-term planning for the questionnaire, including changes to the database that houses the information and what reports can be generated from it.

OBIA and ONF hope that an improved questionnaire will increase the quantity and quality of information, and that this in turn will improve services and supports for people with ABI and their families. To find out more about OBIA, please visit www.obia.on.ca.

Twice As Good

The Spinal Cord Injury Rehabilitation Evidence (SCIRE) Project

For some people with a spinal cord injury (SCI), going home after being in a rehabilitation hospital means returning to a smaller community or rural area, where resources are often limited and health care professionals, including family doctors and physiatrists, are often not abreast of the latest research on SCI. A person's health care can be compromised as can the on-going learning about living life with a SCI. It's a real challenge to have access to the latest research literature. As well, it costs the health care system between \$1.25 million and \$25 million to care for a person with an SCI over their lifetime. It stands to reason, then, that people with SCI, health care practitioners and the health care system would benefit from having access to resources and information on SCI.

This is one reason why researchers from GF Strong Rehab Centre at University of British Columbia, and St. Joseph's Health Care at University of Western Ontario, came together to build a collection of information about SCI rehabilitation. This initiative was funded jointly by the Ontario Neurotrauma Foundation and the International Collaboration on Repair Discoveries. The research team, comprised of investigators from both sites, selected and reviewed literature relevant to SCI rehabilitation and community re-integration. The project was named SCIRE - Spinal Cord Injury Rehabilitation Evidence.

SCIRE is a single document that contains over 1,200 pages of reviewed references of evidence-based research and best practices on SCI. This free resource is available online at www.icord.org/scire; it is also available in hard copy and CD format.

In the first phase of the project, a team of expert scientists, clinicians, people with SCI, and policy-makers determined which topics would be included in SCIRE. They searched major databases to

find information published between 1980 and 2005. To be included in SCIRE, the study had to (a) be in English, (b) be human studies (as opposed to animal), and (c) have people with SCI as at least half of its participants (with a minimum of three). 8,007 references were organized into 22 chapters on topics such as bone health, bladder health and function, sexual health, and pain.

The second phase of SCIRE added another 5,982 entries on literature that was published between 2005 and 2007, and added chapters on physical activity, wheelchair and seating equipment, and aging.

By pulling together this resource to inform people about the SCI research and best practices:

- healthcare professionals will be able to offer the best care supported by a strong SCI research community
- people with SCI will have evidence-based information on treatment and prevention strategies
- policy makers will be able to make more informed decisions

- clinicians will be able to use the evidence-based information to determine best practices and programmes

After reviewing all of the available information on SCI, the research team noted that there were knowledge gaps. For example, there is little research on women and SCI, especially in the area of sexual health. This is surprising because women are 25 to 33% of the SCI population. In addition, there is little information on best practices for reintegrating into the community after the injury. Knowing about the knowledge gaps will enable researchers and funders to identify where to target their future research and resources.

SCIRE's first phase was celebrated. It received awards, peer recognition through 20 published articles in peer-reviewed journals, and over 250,000 hits to its website. As well, SCIRE has been presented at over 50 conferences. The project team plans to update SCIRE regularly, and to introduce new topics so that this resource will continue to improve and be accessible to Canadians and virtually anyone worldwide, through the Internet.

The next time you are wondering about some aspect of your own health, check out the SCIRE website and see what research has been done and what are the best practices on your particular health issue. The information you find might help you ask informed questions when you meet with your healthcare professional. And who knows, you may even be able to share some knowledge that is news to your doctor.

