

# NeuroMatters

## Connecting YOU to the Research

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## Surprising Results

### *Primary care and rehabilitation for people with SCI in Northern Ontario*

Primary care and rehabilitation services are crucial for anyone who sustains a spinal cord injury (SCI). Gaining access to good quality primary care can be a challenge. For someone with a spinal cord injury (SCI) who lives in a relatively remote part of the province, it can be a very complicated process to access these much needed healthcare services.

The Ontario Neurotrauma Foundation (ONF) wanted to fill in the details about the particular challenges facing people with SCI in the northern regions of the province. ONF funded a research project designed to describe the patterns of healthcare utilization of inpatient rehabilitation and post-rehabilitation spinal cord injury (SCI) services, comparing Northern Ontario with the rest of the province. The years that the data were collected were 2002 through to 2005. The details, as furnished by

the research led by Primary Investigator Susan Jaglal, Senior Scientist at Toronto Rehab, may surprise you.

#### Primary Care

Primary care is the diagnosis, treatment and management of common health problems. Primary care is everyday health related care and community support through contact with a health care professional, i.e. physician, nurse, pharmacist or physio-therapist. Access to these

healthcare professionals is critical for maintaining health and wellness as well as for the timely management of common secondary medical complications resulting from an actual disorder or injury. For people with SCI, it means the treatment of medical conditions such as urinary tract infections, pressure sores and respiratory infections. It also includes appropriate referral to specialist care when needed.

Barriers exist for anyone with an SCI who needs access to primary healthcare. These barriers can include:

- physical accessibility
- provider attitudes
- information and knowledge gaps
- poor communication, especially among various healthcare providers
- limited and unreliable wheelchair accessible transportation
- limited attendant services.



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### Goals and Methodology

The first and most important component of the project was an analysis of administrative data collected by the province. The data were scrutinized to identify utilization patterns in the north as well as in the rest of the province. The other geographical areas in Ontario were studied in order to facilitate comparisons with the northern regions. In addition to the data analysis, five interviews were conducted with key informants identified by the Canadian Paraplegic Association and the Lyndhurst Centre of the Toronto Rehabilitation Institute, premier service agencies providing SCI specific community-based services and rehabilitation services respectively. The third and final component of the project was a review of related websites and printed materials.

### Local Health Integration Networks

The provincial regional analysis was conducted using data furnished by the Local Health Integration Networks, or LHINs. The establishment of the LHINs in 2006-7 transferred more healthcare decision-making power into the hands of local administrators. Part of the thinking behind the transfer was that people in the community would be better positioned to tailor healthcare services to local needs. While the provincial government maintains responsibility for overall leadership and system-wide initiatives and policies, the LHINs manage health care provision on a more local level in each of fourteen regions of Ontario.

LHINs do not provide services directly; rather, they are responsible for integrating services within a geographic area. When a patient requires a service that is not offered within the LHIN in which he or she resides, the patient is sent to

another LHIN. Three LHINs make up the province's northern region. They are called the North West, the North East and North Simcoe Muskoka LHINs.

### Surprising Findings

Jaglal's findings reveal that, statistically at least, it's not just people in the north who have limited access to local rehabilitation treatment.

"Well, it wasn't surprising that access in Northern Ontario was poor, so poor in fact that often clients faced a five hour or longer drive to get to Toronto for care. But what was shocking was that clients in Northern Ontario are not worse off than clients in Kitchener-Waterloo," Jaglal said.

Spinal cord injuries in the North of the province represent approximately 10% of the spinal cord injuries in Ontario. In the province, excluding the northern regions, two thirds of people who sustain an SCI usually undertake rehabilitation in their own LHIN. In the North, by contrast, only half of the people with an SCI receive rehabilitation treatment locally. The numbers are even starker when one looks at just traumatic SCI. In this case, while two thirds of people in the rest of Ontario receive treatment in their LHIN, in the North, two thirds have to travel for care.

But the problem is not confined to the northern regions. In fact, a person with an SCI in the North has the same sort of access as a person with an SCI living in the Mississauga Halton region. But here's the really startling finding: a person in the North has better access than someone with an SCI in the more heavily populated southwestern region of Kitchener-Waterloo and significantly better access than someone living in the central regions of the province.

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People with an SCI in Central, Central East and Central West LHINs are more likely to receive their initial rehabilitation outside their LHIN than individuals in the North. In fact, for the years studied, not one person with an SCI in the Central West LHIN (which includes the cities of Orangeville, Brampton) received their initial rehabilitation locally.

### Conclusions

Access to rehabilitation care has to improve across the province, but the areas that need to be targeted first include the following LHINs: Central West, Central East, Central, Waterloo Wellington, Mississauga Halton area and then, the three LHINs in the North. The rest of the province has pretty good coverage for people looking for rehabilitation within their local area. The Champlain LHIN which includes Ottawa and the Ottawa Rehabilitation Centre, had the highest rate of local provision at nearly 100% coverage, with the centres of Toronto, Hamilton and London Ontario not far behind.

## Living at home after a brain injury: A comparison of two CCAC models of service delivery in Ontario

Community Care Access Centres (CCACs) provide homecare all over Ontario to people with a variety of conditions and service needs. This includes rehabilitation services, nursing, dietary assistance, personal support and many other services – all provided in the person's own environment. People with acquired brain injury (ABI) often receive CCAC services when they return to their home following their injury and may need these on an ongoing basis.



The Ontario Neurotrauma Foundation (ONF) funded a project to compare outcomes and costs for two models of service delivery provided by CCACs for people with ABI. The two models are currently in use in and around two small cities in Ontario.

In one model, the generalized and contracted service model, the care is not specialized for people with acquired brain injury. A case manager assigns contracted service providers to ABI clients, as would be done for any community-based client with a service need. This is the standard of care in the majority of CCACs.

In the second model, the specialized service model, a multi-

disciplinary ABI team made up largely of CCAC staff members delivers care to clients with ABI living in its geographical catchment area.

The research was conducted by Kathryn Boschen, Research Scientist at Bridgepoint Health and Adjunct Scientist in the Graduate Department of Rehab Science at the University of Toronto, Gary Gerber, Clinical Director of ABI Behavioural Services at West Park Healthcare Centre, and Judy Gargaro, Research Coordinator at Toronto Rehab.

Research interviewers met with clients and family members in their homes at the outset of the study and then again after one year

and after two years. Standardized scales and rating tools were used to make comparisons and measure progress. Service use and costing information were obtained from CCAC databases. Data for the study was collected over the course of four years.

Two-year follow-up information showed that clients receiving ABI-specialized team services had increased the level of their community integration, their health status had improved, and the family burden was reduced. Non-specialized service clients, on the other hand, were assessed to have

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greater disability. ABI Team clients received more rehabilitation therapies, while non-specialized service clients received more personal support services. Services provided within the ABI Team model were tailored to the individual clients by providing the service frequency, intensity and coordination required to meet the clients' needs. The CCAC case manager had more contact with clients in this model. Services provided within the non-specialized model were delivered using service package guidelines that were applied to all clients, regardless of their diagnosis. In this model, case managers were restricted in terms of authorizing care beyond these service packages.

The ABI team approach produced more favourable client outcomes at a lower cost per client than the non-specialized service approach. Gerber identified this finding as the most surprising. Gargaro indicated that even when she compared both

models using the higher pay rates of contracted staff (as compared with employees), the ABI Team model was still more economical than the generic standard-of-care service model.

"The difference is giving service on the one hand, and teaching

"The difference is giving service on the one hand, and teaching the client how to do it for themselves, on the other."

the client how to do it for themselves, on the other. The ABI team we studied had employees of the CCAC who were occupational therapists, social workers, a rehab assistant, and had consultants for speech language therapy and

behavioural work, and these people were all very specialized in working with brain injury clients," Gerber said.

"The focus of the ABI Team model is on rehabilitation," Gargaro said. "The generalized model is a care delivery model," she added. "It's that old adage: give a man a fish and he eats for a day. Teach a man to fish and he eats for a lifetime."

The researchers have presented their findings at numerous conferences, and are working on a paper to be submitted for publication in an academic journal.

ONF and the research team have engaged in talks with organizations including the Ontario Association of Community Care Access Centres (OACCAC). The Chief Executive Officer of the OACCAC said that these findings correspond well with models currently being tested that use a specialized approach as well as more team focused approach to providing care.

## ONF launches NeuroMatters Blog!

Coming  
this  
summer!

The Ontario Neurotrauma Foundation is committed to keeping you informed about the research it supports in the areas of spinal cord injury and brain injury.

- Featuring material from the print edition plus link to related sites and back issues
- Join the NeuroMatters online community by visiting the blog at: [www.neuromatters.org](http://www.neuromatters.org)
- And don't forget to bookmark the ONF website where you'll find news about ONF initiatives as well as information about ONF's partners and so much more! [www.onf.org](http://www.onf.org)

# The Power of Positive Thinking

***Belief is powerful medicine. Its power to heal is well established.***



Belief drives the placebo effect, which happens when a patient is told that a pill will help and it does, even though it's just a sugar tablet. A recent study conducted at McGill University found that 20% of doctors in Canada prescribe placebos for their patients.

The Ontario Neurotrauma Foundation (ONF) was interested to learn whether programs designed to harness the power of belief and positive thinking could be beneficial for people with a spinal cord injury (SCI) and other neurological conditions.

In Toronto last fall one of ONF's partners, the Canadian Paraplegic Association Ontario (CPA Ontario), funded a pilot project of a cognitive therapy workshop specifically designed for people with disabilities.

*Discovering the Power in Me*, developed by the Seattle-based Pacific Institute, is a twelve-unit workshop delivered over two or three days. Based on the techniques of cognitive

psychology, the program aims to teach participants how to control their thought processes and to understand the workings of the mind in order to maximize their success and satisfaction with life.

ONF funded an independent evaluation of the Pacific Institute's pilot program.

## **What the program was like**

The sessions were led by a Pacific Institute facilitator. Using audio-visual aids and a print workbook, the facilitator guided the participants through each of the twelve sessions studying topics like "How My Mind Works", "The Power of My Self-Talk" and "Stretching My Comfort Zones". A number of invited rehabilitation professionals observed various program sessions.

## **How the program was evaluated**

Kathryn Boschen, Adjunct Associate Professor at the University of Toronto and an expert in rehabilitation program

evaluation, conducted the evaluation. Boschen attended each of the three days of the pilot program in Toronto. In her evaluations, she used both quantitative measures, including questionnaires and life-satisfaction scales, as well as qualitative measures, such as interviews, talking informally with participants during breaks, and conducting a final large-group discussion session.

For the quantitative measures, Boschen administered standardized tests to arrive at initial scores for each participant. These scores measured self-esteem, self-confidence and life-satisfaction. She repeated these tests immediately after the program was completed and then again several months later.

For the qualitative assessments, Boschen initially interviewed each participant and then chatted informally with individuals during breaks over each day of the workshop. At the program's

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conclusion, she met privately with the entire group of participants for a final hour before they departed. Boschen wanted to give individuals the chance to speak freely about the program in a full-group setting, but without either the facilitator or other observers present.

### Results

Boschen reports that based on her qualitative findings the program appears to make people feel better and that participants self-reported that the program was worthwhile. Overall the individuals said they were very satisfied with the program and would recommend it. They also felt their lives had improved as a result of the sessions. But when Boschen compiled the data using the quantitative tools measuring self-confidence, self-esteem, and life satisfaction, the results were less clear, only mildly supporting the strongly positive self-reported assessments.

The before and after questionnaire scores for the majority of participants showed an improvement in the scores in most cases. However, those higher scores returned to initial levels in most cases when they were measured three months after the workshop. In a few cases the results were still somewhat elevated, but in one or two others there was no change or even a slight decrease in scores. Yet all but one of those same participants reported that they benefited from the program and would recommend it.

"It's a program that gives people the positive feeling that they're helping themselves and that they've had some attention given to them. So the participants said "yes", they would recommend it and "yes" they think they did improve. But the survey results may only bear that out over the short term," Boschen said. She attributes the difference between the quantitative scores and the

self-reports to what she terms the initial "halo effect".

"Participants feel good just for having participated. This is not unusual for programs of this kind, and there is nothing wrong with that, just like with the placebo effect. In fact, it may be where the strength of the program lies. But whether that halo effect can be later boosted or re-engaged to somehow last in the long term is another question," she said.

One session that participants especially enjoyed was the "My Perception versus Reality" unit which explored how the mind deals with conflicting beliefs (not well) and how we can unwittingly program ourselves to have a bad day by simply expecting a bad day and then perceiving the day's events through that "bad day" lens, rendering us blind to the good things that may happen.

Boschen thinks that the results are intriguing enough to warrant further research into the power of positive thinking for people with spinal cord injury.

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elements that assist in the diagnosis of a child with a TBI. The tool is being tested using CT scans that were collected for another ONF research project (the Young Traumatic Brain Injury (YTBI) data set )in 2003–6. These scans were of young children with TBI who were under the age of five and admitted to a intensive care unit for brain injury. Three hundred and fifty scans were retrieved from this collection along with information for each patient about their outcomes.

The team is using the YTBI scans

to test the effectiveness of the tool they are developing. In the study, physicians are provided with a CT scan from the collection and they are asked to make a diagnosis using nothing but the diagnostic tool. "We're evaluating the impact of this tool in the hands of ER doctors, neurosurgeons and radiologists. And we're trying to do it without them knowing what they're looking at because that's what it's like in real life," Guerguerian said.

The preliminary results indicate that the tool maximizes both

speed and precision in diagnoses of children with TBI. With this tool, the diagnosis process is not affected by medications, nor is there any need to consult the child or any witnesses. Additionally, the tool is specifically designed for assessing TBI in children and not adults. Finally, the whole process can be accomplished in a matter of minutes.

"The advantages for children is that this is a tool that will help tailor therapy to their immediate needs after injury" Guerguerian said.

# Rick Hansen 25th Anniversary Relay

The Rick Hansen 25th Anniversary Relay is an exciting and inspiring journey beginning on August 24, 2011 in Cape Spear, Newfoundland and Labrador. Retracing the Canadian portion of the original Man in Motion World Tour the Relay will travel westward and make its way across the country over nine months, before concluding in Vancouver, BC on May 22, 2012. This time one man in motion will be represented and celebrated by many in motion; engaging 7,000 participants from across Canada who have made their own difference in the lives of others.

As the Relay travels westward, each participant will pass the singular Rick Hansen medal-created by the Royal Canadian Mint – from one participant to the next, along the 12,000 kilometre journey. With a shared vision of celebrating everyday Canadian's contributions to their communities, McDonald's and Nike have joined as the Presenting Partners of the Rick Hansen Relay.

"Canadians across the country are being asked to join me in the celebration of the 25th Anniversary of the Man in Motion World Tour," said Rick Hansen,

President and CEO Rick Hansen Foundation. "The Relay will connect a nation of difference makers who are outstanding examples of everyday heroes having an impact on the lives of others through a vision of a healthy and inclusive world. This is the start of a movement for 7,000



Canadians to help inspire the nation and live by the credo that anything is possible."

To get engaged in this exciting event go online at [www.RickHansenRelay.com](http://www.RickHansenRelay.com) to enter to win a spot to participate in the Relay as a Medal-Bearer. To encapsulate the country's multi-faceted population, contest criteria will be broad and is

open to: individuals who are creating a more accessible and inclusive world, leading and encouraging others to live a healthy and active lifestyle, or persons who are contributing to the protection and sustainability of the environment. All Canadians (13 years and up) will be able to apply to become a

participant through this online contest. The contest closes on August 3, 2011 for those living in Ontario.

Each relay day will feature community celebrations that recognize local difference makers, raise awareness about accessibility, celebrate progress that has been made and

inspire a new generation to take action.

Celebrate the journey of one of Canada's heroes by getting involved in your community's events supporting the Relay or enter to become a medal bearer. "If one person can inspire many, imagine what 7,000 can do" Rick Hansen on his 25th Anniversary Relay.

## Developing a Tool... for diagnosing severe traumatic brain injury in children

The medical attention a child with a traumatic head injury requires is determined by the nature and the severity of the injury. If there is a generalized swelling of the brain, critical care, medication and occasionally surgery would be the treatments needed. If, on the other hand, the child has a brain haemorrhage, neurosurgery may be required.

The hard part is figuring out what's wrong and how severe the injury is. In an Emergency Room (ER) assessment, a child's medical history and details of the incident are taken and the child is observed. The trouble is that the kind of information revealed in an ER examination is not always that helpful in finalizing a diagnosis, especially in the first hours after an injury. And yet, it is precisely the hours immediately following an injury that are the most critical in terms of influencing the direction an injury will take.

Sometimes doctors rely on information provided by witnesses, but often this information is neither available nor verifiable until days after the event. Another complicating factor is that often medications will be given to a child to prevent a worsening of symptoms. But these medications can potentially blur the results provided by vital signs readings and scales such as the Glasgow Coma Scale (GCS) used to assess the level of consciousness after traumatic brain injury.

To make matters worse, some assessment tools like the GCS are not designed for children and their

effectiveness with preverbal children may be limited, even in the best of circumstances.

What is needed is a quick, safe and reliable method of determining the nature and severity of a child's TBI.

The Ontario Neurotrauma Foundation (ONF) is currently funding research into the development of a diagnostic tool designed to improve the medical assessment and outcome of a child with traumatic brain injury (TBI). The goal of the project is to create an easy-to-use, reproducible tool that can measure early visible brain imaging evidence of traumatic brain injury.

The research project draws on the expertise of paediatric brain surgeons, paediatric brain scanning specialists, engineers, and many other specialists under the guidance of primary investigator Anne-Marie Guerguerian who is a paediatric critical care physician at Toronto's Sick Kids Hospital as well as a researcher and Assistant Professor at the University of Toronto.

The project is focused on improving assessment of CT (computed tomography) scans. As a method of brain-imaging in the hours immediately following a head trauma, the CT scan is the most widely used tool and favoured over the MRI (magnetic resonance imaging) scan for a number of reasons. A patient needs to remain still for only one to two minutes in order for a CT Scan to be performed effectively. By



contrast, an MRI requires a patient to remain still for a full 45 minutes, which is very difficult for children. CT scans require less cooperation from the patient for an effective scan. CT scanning equipment is also more widely available in Canada than MRI equipment. Thus, in terms of speed, accessibility, and amount of cooperation required, a CT scan is preferable to an MRI immediately after injury.

A scan image needs to be interpreted in order to be useful in a diagnosis. "Some CT scan scales developed 20 years ago for adults are not suited for children," Guerguerian explains. "When a child's brain is injured, the injury doesn't develop in the same way as it would in an adult's brain. It can be difficult to evaluate the severity of injury on a child's brain on a CT scan," she said.

The Paediatric TBI CT Scan Tool developed by Guerguerian and her team combines several

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