

NeuroMatters

Connecting YOU to the Research

Making the Most of Information

Ontario Spinal Cord Injury Registry Pilot

In Ontario, health care planning for people with spinal cord injury (SCI) can be a bit of a guessing game based on partial information and anecdotal evidence. This is because in Ontario there is no registry, i.e. no collection, of health care information for people with SCI.

The Spinal Cord Injury Committee of the Ontario Neurotrauma Foundation (ONF) has long been concerned about the lack of information on the incidence and prevalence of spinal cord injuries (SCI) in Ontario. ONF initiated a pilot project to collect clinical data at five Ontario sites in support of the Rick Hansen Spinal Cord Injury Registry (RHSCIR), a national SCI registry. For the pilot, the team examined cases clustered around the Toronto and Hamilton areas looking at three acute care hospitals in Toronto (Sunnybrook Health Services Centre,

St. Michael's Hospital and the University Health Network) as well as the Toronto Rehabilitation Institute - Lyndhurst Centre and an acute hospital and rehabilitation centre in Hamilton (Hamilton Health Services). The pilot project included 124 acute care cases, 90 cases in traumatic SCI in rehabilitation and 27 cases in non-traumatic rehabilitation.

The Ontario Spinal Cord Injury Registry is a pilot project designed to determine the feasibility of collecting information about people with spinal cord injury in Ontario and of systematically arranging and storing that information in a database in order to improve the quality of care and the range of services offered to people with SCI and to support the national registry RHSCIR. The registry was based on clinical data about the health status of the participants in the study.

What was missing?

Until the OSCIR Pilot Project, there was no single comprehensive source of clinical SCI data. Relevant data are currently collected in databases including the National Ambulatory Care

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Reporting System, Discharge Abstract Database and the Ontario Trauma Registry, among others. But the current method provides no means to link records to track the care of people with SCI across the continuum of care, to determine treatment effectiveness, to conduct lifetime follow-up to better understand the obstacles to healthcare, to track the development and evaluation of prevention programs or to determine the best areas for further research.

"What was missing is the ability to combine appropriate data sources. The existing data collection methods fail to capture the richness of the clinical data that the pilot was able to reflect," said principal investigator Molly Verrier, Professor of Physical Therapy and Rehabilitation Science at the University of Toronto and Senior Scientist at the Toronto Rehabilitation Institute.



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Assembling the data

Collecting administrative data about people with SCI in the health care system is not as easy as it may seem. Because the information is collected, arranged and stored in a variety of ways by each hospital and rehabilitation centre, the data collection and retrieval methods had to be harmonized. "We needed to align data acquisition across the continuum of care. We took one area of Ontario, that was possibly least aligned, to establish a methodology to get the data collection coordinated," Verrier said. Together with ONF, Verrier assembled a team of experts to help oversee the project at its various participating sites.

There are several registries in Ontario including a joint replacement registry, a stroke registry, a trauma registry, and a cardiac registry. The OSCIR pilot specifically investigated the feasibility for a registry for people with SCI in Ontario.

Informing the National model

This pilot study is the attempt at a comprehensive database of health care information for people with SCI in Ontario. The OSCIR team added data fields about rehabilitation of people with SCI to inform the national registry. Other data elements added to the Ontario project included enhanced diagnostic imaging, neuropathic pain, functional outcomes such as ability to walk, and resource requirements on discharge.

These data elements were added based on a consideration of, among other things, the importance of the data to the participating institution, the feasibility for collecting the data, and the utility of the data to define best practices in order to address

specific Ontario-based research questions.

Looking Ahead

The goal of the pilot project was to lay the foundation for the development of a sustainable provincial SCI data registry to align with the national activity. One of the project's conclusions is that current methods of data collection will need to be redesigned to better capture the data for SCI with the ultimate goal being to optimize health outcomes for people with SCI in a time-sensitive manner.

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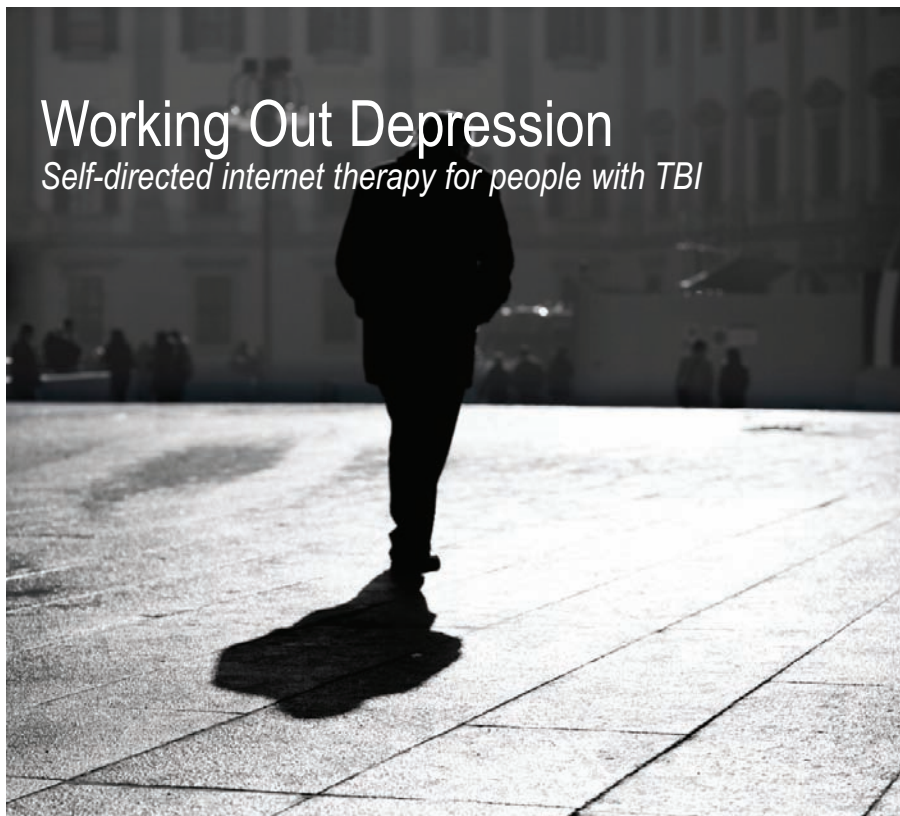
Among the achievements of the pilot was the development of a rehabilitation database for people with SCI. The database included categories on clinical outcomes, secondary complications, health service utilization, and quality of life post-discharge. OSCIR also collected information on non-traumatic SCI patients in order to understand the rehabilitation needs for this group and provide a comparison group for traumatic SCI. Non-traumatic spinal cord injuries are increasing in this province and the team wanted to look ahead to servicing this population.

People with SCI will benefit from a provincial informatics approach because it will provide better information about their status and needs and will also provide opportunities to influence service planning and to participate in research at the provincial, national and international level.

Of the many findings of the pilot, two were identified that impact functional recovery and future prevention measures. One finding indicates that the mean time from spinal cord injury to spine decompression or stabilization surgery was 62.7 hours. This finding could lead to a redirection of scarce funding to better support people with SCI in the acute setting by decreasing long waiting times and implementing early decompression protocol. A second finding indicates that driving all terrain vehicles and cycling each account for 19% of the sports and recreation injuries for people with SCI in the pilot project. The provision of such information could better further ONF's goal of improving prevention by better targeting prevention efforts to lower the rate of SCI incidence in the province.

But these results, while interesting, were not the main focus of this pilot project. Rather, this project sought to determine how best to get data, what data would be most helpful and what data could be extracted from existing administrative sources in Ontario. The actual results of the pilot project are useful as an example of what could be achieved with implementation of a provincial informatics strategy.

With such a strategy in place, the understanding of health service utilization can enable evidence-based decision making and planning to improve care and outcomes for people with SCI. At present, without the evidence, such decisions are, at best, based on opinion, partial information and a retrospective data analysis. With the development of a national registry, more effective and cost-efficient efforts can improve the health care provision for people with SCI in Ontario and Canada.



Working Out Depression

Self-directed internet therapy for people with TBI

The most frequently reported psychiatric symptom after traumatic brain injury (TBI) is depression. Some studies indicate that as many as three in four people with TBI have depression. Depression could, in some cases, affect a person with TBI for years, interfering with the ability to work, keep up with friends and enjoy leisure time. Depression can also disrupt rehabilitation for a person with TBI. Research has shown that people with TBI who experience depression benefit less in rehabilitation than those free of depression.

Recognizing how widespread and debilitating depression can be among people with TBI, the Ontario Neurotrauma Foundation (ONF) put out a call for proposals for innovative ways to address depression for people with TBI. One of the projects that ONF funded is a pilot project that uses the internet to help people with TBI deal with their depression.

Why the internet?

Many factors pointed to the potential of the internet to ease depression in people with TBI. One consideration is that the internet can be used at home, making a treatment delivered via the internet more accessible and less expensive than traditional therapies, with the added bonus

that such a program can reach people in remote areas. Accessibility is particularly important as many people with TBI have additional injuries which compromise their ability to get around. A depressed mood itself can also rob a person of motivation to leave home, even if it is to seek help with depression.

Another consideration is the young age of a significant proportion of people with TBI at the time of the initial trauma. As Jane Topolovec-Vranic, Clinical Researcher with the Trauma and Neurosurgery Program at St. Michael's Hospital and primary investigator of the project explains, "young people are internet-savvy and it was thought many would be more open to trying a therapy

for depression on the web than to trying more traditional psychotherapy treatments".

The pilot study

The project began in 2005 and was completed in 2008. For a 12 month period, people with TBI treated at the out-patient Head Injury Clinic at St. Michael's Hospital in Toronto were screened for participation in the project. 31 people met all the eligibility criteria and of those 22 agreed to participate in the study. That number was seen to be appropriate for a pilot project.

To be eligible for inclusion in the study, participants had to:

- be sixteen years old or older
- have a diagnosis of mild or moderate TBI
- be fluent in English
- rate a score of 12+ on the Patient Health Questionnaire-9, a tool that is used to screen for depression.
- have regular access to the internet
- be available for follow-up phone calls

Topolovec-Vranic indicated that people who experienced high levels of anxiety, had pre-trauma psychological conditions, or were viewed as suicidal were excluded from the study as they required other types of psychological therapy.

Shree Bhalerao, a psychiatrist who served as a consultant as well as a co-investigator on the study, was on hand in case any of the participants experienced increased depression during the project. "I think the internet is great for information and some people can self-teach themselves to use it properly. It has to be augmented with a professional to help with questions and concerns," he said.

For this study, the researchers decided to use cognitive behavioural therapy, a short-term

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treatment that helps change patterns of thinking that can be the cause of unwanted behaviour, moods or disorders. It has been shown to be effective in dealing with problems including mood disorders, anxiety, eating disorders, substance abuse, and depression. Cognitive behavioural therapy has also been shown to decrease emotional distress in people with acquired brain injury (ABI).

"Cognitive behavioural therapy looks at cognitive distortions like black and white thinking, catastrophic thinking, all or none thinking. The purpose is to have people identify these, challenge them and eventually change the thoughts when they occur. Following this, patients are taught relaxation techniques and behavioral approaches to coping with the emotional upheaval these thoughts may bring," Bhalerao said.

The cognitive behavioural therapy was delivered via the internet. Participants were asked to follow a web-based program called MoodGYM. The MoodGYM program consists of five cognitive behaviour training modules, a personal workbook (containing 29 exercises and assessments), an interactive game, and a feedback evaluation form.

Originally developed by the Centre for Mental Health Research at the Australian National University, the program, offered via the Internet, is not specifically designed for people with TBI. The researchers wanted to see if the program would be helpful to people in the study.

"We knew that the MoodGYM program in particular had been shown to be helpful in reducing the depression of young people who followed it," said Topolovec-Vranic. She referred to studies that showed reduced levels of depression in those following the MoodGym program compared

with people who did not.

For the ONF study, participants with TBI were asked to follow the MoodGYM program on the internet in their own time. Once a week during the initial six week period and then after six months and after 12 months, the participants were contacted and asked questions in order to assess their levels of depression.

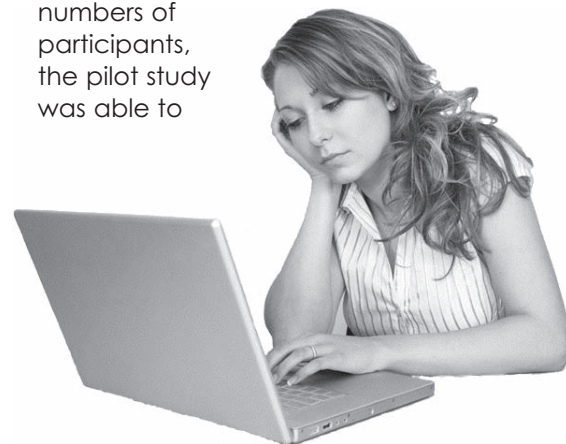
Feedback and results

Many participants reported benefits to following the program and scored lower on the depression scales after the program than they did before they started the program.

In a recently published paper, Topolovec-Vranic reports that one participant commented that the modules of the MoodGYM "take a lot of time, but they give me something to do". The participant also expressed motivation for sticking to it: "I hope that it will make me feel better, so I will continue using the website".

Some feedback from participants indicated that the MoodGYM program may not be ideal for all people with TBI. Many participants found that the program required too much reading and memory work, which can be challenging for people with TBI. Another concern was the program took too long to complete in each of its stages. Some of the participants found that the MoodGYM didn't speak to their situations as much as it did to those who are younger (15-25), single, and possibly still living with their parents. Also, there is a fair bit of Australian language in the program and this was also identified as a problem. Despite these drawbacks, the final assessments indicated that the internet-delivered program did prove valuable in lowering the participants' depression levels and this was repeated in the comments

of participants who indicated that they were happy they followed it, with some indicating they would continue. Due to the small numbers of participants, the pilot study was able to



deliver interesting but not conclusive evidence on the benefits of the internet cognitive behavioural therapy program.

Looking Ahead

The results of this pilot study indicate that self-guided therapy delivered over the internet could be helpful for people with TBI who experience depression. Based on the findings of the ONF-funded pilot study, Topolovec-Vranic has begun a new project using a different internet tool, one that she hopes will be more suitable for the cognitive needs of people with TBI.

In this new study, she has broadened the eligibility criteria in an effort to increase the number of participants and this has proven successful as she already has 100 people involved in the new study which has been running for less than 10 months. Meanwhile results of the ONF-funded pilot study have been presented at several conferences both in Canada and in Europe. The research was also recently published in the May issue of the professional journal *Brain Injury*.

ONF recommends that anyone who may be experiencing depression consult a psychology professional before trying the MoodGYM program.

Stem Cell Global Blueprint Conference

First steps towards a blueprint for stem cell research

On May 21st and 22nd, 2010, Dr. Michael Fehlings, Professor of Neurosurgery, University of Toronto and Krembil Chair in Neural Repair & Regeneration, Toronto Western Hospital, chaired the inaugural Stem Cell Global Blueprint Conference at MaRS in Toronto. Some of the goals of this conference were to discuss barriers to the advancement of stem cell technologies from the lab to the clinic and also to begin working on a blueprint for stem cell innovation, translation, and commercialization for spinal cord injury and related degenerative disorders of the central nervous system. Over 80 people attended this conference, from six continents. Many stakeholder groups were represented, including scientists, clinicians, government representatives, consumers,

research funders, experts in ethics among others. The conference was divided into eight sessions over two days. Each session involved a panel discussion with subject experts followed by an audience breakout session to encourage multi-stakeholder dialogue.

The results of these breakout sessions were enlightening and insightful and will provide a starting point for future engagement as we work towards a global blueprint for stem cell translation. Among many interesting comments, the majority of attendees felt that major barriers to this translation included the lack of funding, particularly for phase 1 clinical trials, and the lack of appropriate communication with consumers, which may lead to participation in stem cell tourism.

Moving forward, these working groups will collaborate on

specific tasks to address barriers to stem cell translation. The tangible outcomes of this conference and these working groups will include

- a website aimed at consumers and the general public that can compete with those of clinics involved in stem cell tourism,
- peer-reviewed publications describing the results of the conference and survey,
- the organization of a Delphi consensus process to address some of these barriers,
- and ideally another conference in one to two years.

ONF and other funders of the conference are supportive of the ultimate goal: to smooth the pathway for stem cell therapies from bench to bedside in a safe and efficient way.

Wired for Success

Towards an Ontario Brain Strategy

In our Winter issue of *Neuromatters*, we told you about the Ontario Brain Strategy. Work is being conducted by members of Neurological Health Charities Canada and the Health System Strategy Division of the Ministry of Health and Long Term Care.

The outcome of the work to date is a report entitled, *Wired for Success - Towards an Ontario Brain Strategy*. This report is an important first step in developing an integrated approach to addressing many of the important issues facing those living with a neurological disorder including neurotrauma. Five dominant themes emerged for the consultative work supporting the report. People expressed a need for having:

Personal Choice

- Direct control of decisions

regarding medical care, social supports and shaping their living environment

An inclusive culture

- An Ontario that has a focus on health over illness
- Reduced stigma achieved by shifting public values and attitudes
- Employment opportunities and flexible work arrangements

Enabling technology

- Assisted living technologies to enable better living
- Smart homes, accessible education and workplaces
- Flexible transportation systems

Supported caregivers

- Whose role is valued
- Who are supported sufficiently to maintain their own health and financial stability

Shared knowledge

- Commitment to research and to moving evidence into practice
- Reliable medical and decision support information
- An engaged online community

Secondary themes also emerged including integrating systems, designing the built environment, engaging the private sector and taxing and funding.

NHCC and the Ministry are continuing this work to examine these broad themes, develop them into specific strategies, engage key stakeholders, and develop breakthrough solutions that will be implemented and sustained.

For more information on the report and work of NHCC contact Shannon MacDonald, Shannon@mybrainmatters.ca

A Revolving Door?

Rehospitalization for people with SCI in Ontario

Rehospitalization is a fact of life for one third of all people living with a traumatic spinal cord injury (SCI). Studies in Canada, the US and Europe support this finding. A recent study funded by the Ontario Neurotrauma Foundation (ONF) into rehospitalization rates for Ontario residents with traumatic SCI confirms this result. Costly both to the healthcare system and to the individual, rehospitalization warrants research into the contributing causes to enable more effective prevention planning. The ONF-funded study, "Incidence, Healthcare Utilization, and Rehospitalization Following Spinal Cord Injury" found that 27.5% of participants with traumatic SCI were rehospitalized within one year of their initial acute care discharge.

Collecting the information

The data for this project was collected from several sources, including: the Canadian Institute for Health Information Discharge Databases, the Ontario Health Insurance Plan physician billing information for outpatient visits, and the National Ambulatory Care Resource System for visits to Emergency Departments.

The information in the databases was linked anonymously using encrypted individual health card numbers. From April 2003 until the end of March 2006, patients admitted to Ontario hospitals for a traumatic SCI were tracked for the study. The average age of the 560 study participants was 51 years old with roughly 75% of the participants being male, reflecting the gender split in the community of people with SCI.

Incidence

This project also looked at incidence of traumatic SCI and healthcare system utilization. Falls were found to be the leading cause of injury with motor vehicle crashes being the second biggest cause. Gaining insight about the causes of traumatic SCI can assist policy makers in targeting prevention measures and in anticipating the sorts of services that the health care system will need to provide.

While the incidence of traumatic SCI is not going up, it is not decreasing either. "The most interesting finding was that while rates of traumatic SCI remained stable over the last decades, the causes of injury have changed with falls responsible for twice the number of cases as motor vehicle crashes," said Susan Jaglal, primary investigator of the project and Toronto Rehabilitation Institute Chair at the University of Toronto.

Earlier studies both in Canada and abroad indicated that motor vehicle crashes were the primary cause of traumatic SCI. There are two main contributing factors which explain the shift in the leading cause of traumatic SCI from motor vehicle crashes to falls. The first is the increase in vigilance about seat-belt use in motor vehicles and the effectiveness of safety features such as the airbag in modern cars. The aging population is another factor that explains why falls have overtaken motor vehicle crashes. Fall-induced injury rates increased with age, the study found. In the age group of 18-39 years of age, 19% of injuries were due to falls, whereas in the 60+ age group, nearly 52% of injuries were due to falls.



Rehospitalization and Health Care Utilization

"Rehospitalization in many cases represents a failure of the primary care system," said Susan Jaglal. Looking at the reasons for rehospitalization is important in order to identify those people at greatest risk so that preventative strategies can be developed in the long term. The study found that certain factors seemed to predict rehospitalization rates. They included the length of short acute care stay, living in a rural area, and having more than 50 unscheduled visits in community healthcare facilities. The main reasons for rehospitalization were secondary complications, specifically for urologic, respiratory, gastrointestinal and musculoskeletal issues.

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Jaglal indicated that the rehospitalization rates as found by this study were “surprisingly high”. Although the rehospitalization rate is consistent with earlier studies both here and elsewhere, the ONF research confirms that the rate has not come down.

The healthcare utilization research found that on average, people with traumatic SCI had 31.7 unscheduled appointments per year. One of the main reasons this number is so high is the way the healthcare system is set up in Ontario. She explained that in Ontario, in order to see a specialist, one first has to have an appointment with a family doctor, even if one doesn't need to see the family doctor. This amounts to two appointments for one required visit. In other models of healthcare provision, people with

SCI can arrange required appointments by telephoning a designated person, a sort of healthcare system navigator, who books specialists' appointments, eliminating the need for a referral visit with a family physician and thereby lowering healthcare utilization rates.

Often when individuals with spinal cord injury are rehospitalized, they enter the system via the emergency departments. This process of reliance on emergency departments for medical care points to the inability of the system to meet the primary healthcare needs of people with SCI. The study found that people whose trauma had occurred in motor vehicle crashes had lower rates of rehospitalization. Jaglal suggested that the reason is that people whose trauma was the

result of a motor vehicle crash were more likely to have supplementary health insurance coverage for primary care and thus were likely to access more care in the community. With greater care in the community, rates of hospitalization seem to be lower as do emergency department visits. Given that the average cost of rehospitalization for people with traumatic SCI was found to be in excess of \$17,000 a person, this research finding points to a financial reason to better fund primary healthcare in the community.

The research has been presented at several conferences both in the US and in Canada. In addition, three articles based on the research have been published in the professional journal *Spinal Cord*.

One in Four

Rehospitalization rates for people with traumatic brain injury in Ontario

All too often, a person with a traumatic brain injury (TBI) returning home following discharge from hospital may find themselves checking into the hospital again within three years time.

The Ontario Neurotrauma Foundation (ONF) wanted to learn more about rehospitalization for people with TBI in Ontario and so it funded a project to address the following question: Of the people who sustain a traumatic brain injury each year in Ontario, who gets rehospitalized after discharge for the initial injury and why?

For this project, the researchers selected participants with TBI who were discharged from Ontario hospitals between April 1, 2003 and March 31, 2005. Over 6,000 people with TBI were included in this study. Although the majority of the

people with TBI who participated in this study were male, between the ages of 25 and 64, this study included people of all ages, male and female, living in rural and urban environments.

Falls were discovered to be the leading cause of initial injury with the average length of stay in hospital at one to two days.

Angela Colantonio, primary investigator of the project and Senior Research Scientist at Toronto Rehabilitation Centre, and Professor of Occupational Science and Occupational Therapy at the University of Toronto, reports that the readmission rates for people with TBI were 26.8%. That means that more than one in four people with TBI were readmitted to hospital within three years of their initial trauma.



Factors Associated with Readmission

The main reasons for readmission, based on codes used by the hospitals upon readmission, were additional types of injury (20%), circulatory system concerns (15%) and mental health issues (8%).

The researchers found that

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readmission rates were predictable based on considerations of aspects including age, where a person lives, and the mechanism of the initial injury. For example, the older the participant, the greater the likelihood of rehospitalization. Similarly, males were more likely than females to be rehospitalized and people who live in rural areas were also more likely to land in hospital a second time. As there are fewer support services for people living rurally, Colantonio suggested that one reason for the higher rate among rural dwellers could be that visiting a healthcare professional often involves a car journey of several hours because of the distances involved. She said that in such cases a readmission is more likely as often the person has to stay overnight away from home.

Another finding of the study was that the longer the length of stay in hospital, the greater the risk was for readmission. This is not surprising as an injury that is more severe often warrants a longer initial stay and may also require further care at healthcare facilities in the community after discharge. Without sufficient or appropriate care in the community, a person with a more severe TBI could find themselves back in hospital.

Another finding was that people whose injury resulted from a fall or another mechanism of injury had a higher risk of readmission than those who were involved in a motor vehicle collision. This can possibly be due to improved or more comprehensive availability of support services for individuals whose trauma is covered by supplementary (auto) insurance. With greater use of support services in the community, the likelihood of

rehospitalization decreases.

Having TBI together with another health condition (called a co-morbidity) is another factor that can lead to rehospitalization. The most significant co-morbidities affecting people rehospitalized with TBI are mental health conditions. This means that a person with TBI who also has mental health conditions is more likely to be rehospitalized than someone with TBI who doesn't. (Please see "Working Out Depression" in this issue.)

With each additional year from the initial injury, readmission rates fell, making the time immediately following discharge and for first year after, the riskiest for readmission. This finding highlights the need for greater access to support services in the community especially for the first year after discharge.

Conclusions

This study is the first to examine the risk of readmission among people with TBI across all age groups in a place like Ontario which offers publicly funded health insurance. The ONF-funded study found that readmission rates for people with TBI at 26.8% are higher than previously documented rates in reports from American rehabilitation centres. The findings of this report also reveal that rehospitalization rates have risen not declined, despite advances in medical treatments. The study has been presented at international conferences and will be published in peer reviewed scientific journals.

The findings of this report suggest that people who have access to more services are less likely to be readmitted to hospital. The research also indicates that those

people who are at greater risk of readmission - the elderly, people in rural communities and people with additional health concerns - require support in the community to keep them out of hospital. The fact that re-injury is the greatest cause of rehospitalization for people with TBI suggests that greater attention needs to be placed on a person's risk of re-injury after discharge, where problems with balance and concentration issues may contribute to further injury.

This ONF-funded study underlines the importance of comprehensive healthcare and social supports for people with TBI once they return home from hospital. Without adequate healthcare services in centres in the community, one in four people with TBI will return to hospital within three years of discharge.

Upcoming Events

October 28-30: Toronto Rehab presents: *Fourth National Spinal Injury Conference*. Niagara Falls, ON. In collaboration with ONF, financial support will be provided for people with SCI to attend this conference. To be eligible you must agree to attend the full conference and provide feedback to the conference organizers and your community members about the presentations. Applications are due August 2. More info: <http://www.torontorehab.on.ca/education/scic10index.html>.

November 8-9: Toronto ABI Network Bi-Annual Conference. Toronto, ON Info: <http://www.abi-network.ca/conference2010/index.htm>