

NeuroMatters

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Finding the Best in the World

New Acquired Brain Injury (ABI) Casebook Highlights the Most Exemplary Programs in the World

Regardless of culture or location, programs around the world that help persons with ABI regain a sense of well being share common characteristics: each one emphasizes community participation and self-confidence, and helps individuals feel they've exercised power back into their lives. This is the finding of the world's first *ABI Casebook*, which selected 14 examples of excellence located in five countries and on three continents, after reviewing over 130 programs.

"An individual with a brain injury is now a different person," explains April Ferguson, who sustained an ABI 16 years ago and was part of the Casebook reviewing panel. "You need to get to know who you are again, and how you fit in with others. Self confidence is a big part because you need to believe you are just as important as before — that you can still contribute in

an important way to the community around you."

The ABI Casebook is the result of an ONF-funded project to identify such programs and find why they are successful. Some use models that have been working over two generations and continue to inspire with their emphasis of self-sufficiency. Others are created out of goodwill and local capacity.

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But each one stands out as exemplary for helping individuals regain those elements that can make one of the biggest differences going forward: quality of life and purpose.

"These programs nurture individuals in a way that they gained strength they didn't know they had," explains Dr. Richard Volpe, Professor of Human Development at the University of Toronto and project director. "They show that the things that make a difference in people's lives are relationships, trust, and recognition that we're all able to adapt in very challenging circumstances."

What's working with these programs?

The key aspect of the ABI Casebook to appreciate is the criteria for selection. The social and psychological components, not just the physical components that affect a person's health and well being, had to be taken into



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consideration. These programs were considered to have “successful outcomes” if individuals, regardless of the severity of their injury, were able to participate once again in the community in new but still meaningful ways.

“These programs help get us away from a “cure view” of service,” says Volpe. “It’s not about making it better, or making it go away, it’s about doing the best we can, emphasizing resilience, knowing how to draw on personal and social reserves.”

As stated in the Casebook’s concluding “insights” chapter, “Being part of a community is how humans make and derive meaning in life.” The programs that the Casebook consider ideal are community-based, where individuals are helped to take responsibility for their own health and engage in their community. They clearly “walk the talk” of participation.

“These programs really help individuals be ready for the next

step, moving out of rehabilitation and into the community,” explains Ferguson. “We are all human beings. Yes, after a brain injury we need the physical rehabilitation to learn how to do things again, but we also have a need to integrate socially.”

Excellence in Ontario

Three of the fourteen programs are from Ontario, something that makes Ferguson particularly proud.

The Pediatric Acquired Brain Injury Community Outreach Program (PABICOP) for children and adolescents with an ABI and their families. PABICOP regards the child/family and their community as the real “experts”, encouraging and supporting as much community partnership as possible.

Cornerstone Clubhouse in London, Ontario, operates on a 70 year-old model for a network of community centres established around the world. There are no “patients” in the clubhouse, everyone supports each other in pursuit of personal goals. Emphasis

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again is on community participation, sense of purpose and self-sufficiency.

Community Head Injury Resource Services (CHIRS) started in 1978 as the first community-based brain injury rehabilitation program in North America. Two fundamental practices at CHIRS are: “Developing community participation strategies” and “measuring community participation”.

Stories of inspiration

The goal for the casebook was to help service providers, policy makers and researchers everywhere learn about exemplary programs by making the information easy to find and read so they might adapt all or some of the ideas. Volpe, a champion for the “casebook” format, describes it as a “collection of problem solving stories that are meant to stimulate thinking about what successful participation is”. “It stops us from trying to fit people into pre-determined categories, it shows instead the inter-disciplinary and holistic nature of all these programs.”



About the ABI Casebook

The global search identified over 130 programs designed for persons with ABI, representing all age groups and a diverse range of services and focuses. Programs were then reviewed and selected using pre-identified criteria: they had to be community based, not individual practices, evidence-informed, and most importantly, considered to be exemplary in fostering community participation and looking at the individual from a holistic perspective.

The Casebook is available for free download from the ONF

website, or alternatively, you can obtain an electronic copy by contacting us at info@onf.org

Ontario Context

With half a million people in Ontario living with ABI, and at least a third of those requiring ongoing supports in their life, community participation is essential to improving health. Previous ONF research has shown that too many people 'fall through the cracks' after sustaining a brain injury. In every one of Ontario's LHINs there is a need for more community-

based programs that help people with ABI to be productive and active members of their communities.

There are important lessons to be learned from this Casebook, for those providing programs for people with ABI, for policy makers who may be asked to support such programs, and for people with ABI and their families, and to see some remarkable successes in programs from around the world, and in our own backyard. ONF sees this Casebook as an important tool to demonstrate the ideal features of community-based programs.

SCI and TBI Combined

How much greater is the impact when you sustain both injuries?

Several years ago a physician approached scientists at Toronto Rehab with a serious concern, "I have patients with spinal cord injury (SCI) who I think have had a traumatic brain injury (TBI)," he said, "Someone has to do some research into this. Front line clinicians need help."

What the physician and other front line clinicians had noticed was that some patients who they'd thought had just sustained a SCI appeared to be "difficult" once they entered rehabilitation. They had emotional outbursts, a tendency to miss appointments, not remember their therapy. It was at this point that an astute therapist might suspect that the individual also might have a TBI. This led the team at Toronto Rehab to apply to a call for proposals issued by the Ontario Neurotrauma Foundation (ONF).



The first Canadian study to look at both injuries

The study was approved for funding to look at the prevalence of TBI in a sample of 100 persons with SCI, to determine the proportion of individuals for whom a TBI diagnosis was missed in acute care.

The results were conclusive. 40-50% of patients referred for SCI rehabilitation to a large SCI rehabilitation facility also had sustained a TBI. Only 39% of these patients were diagnosed with TBI in acute care; in a further 14%, a possibility of TBI was mentioned in their medical records. SCI is

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traumatic to the individual, but this went beyond the usual adjustment. These individuals were experiencing: 'difficulty setting goals', 'difficulty following instructions from therapists', 'difficulty staying focused on and benefiting from therapies', 'difficulty remembering therapies from one day to next', and planning and organizational problems regarding returning to their community'.

An important implication of these findings is that many patients with SCI are not receiving specialized care for this dual diagnosis as they move from acute care to rehabilitation. They may not get rehabilitation for their TBI, and moreover, their SCI rehabilitation may not take into consideration the cognitive and emotional challenges of TBI.

Why does TBI get missed?

It's not that the symptoms weren't there right from the very beginning — at emergency or in acute care," explains Robin Green, senior scientist at Toronto Rehab and Principal Investigator of the study.

"The problem is that if the TBI is at the milder end of the spectrum, the symptoms may be overlooked because they are subtle or they can be misattributed to other factors, like the emotional reaction to the SCI."

Both conditions are the result of trauma, i.e. a car accident, fall, assault, so it's not difficult to see why individuals that have

sustained a SCI may also have a TBI. But in the immediate aftermath of a traumatic event, unless someone is unconscious, SCI is usually more immediately apparent. Compounding the challenge, in some cases, the level of consciousness cannot be accurately measured if high levels of alcohol or substances are accurately measured or if the individual has been placed into an induced coma. If there's no obvious physical sign of head trauma, clinical evaluations such as a CT scan and neuropsychological assessment may not be done.

Mis-diagnosis of symptoms continues throughout acute care. This is because some symptoms of a TBI — apathy, agitation, emotional distress, compromised attention — can be attributed to the SCI or the effects of medication. And lying in a hospital bed, issues such as forgetting appointments or not fitting back into the community don't readily become apparent.

A typical example is someone in the construction industry who falls off a ladder and sustains an obvious SCI. Although the individual lost consciousness, by the time emergency team arrived, he was awake and talking. The ABI is completely missed until 2 ½ months into rehabilitation. Missing an ABI can seriously impact how well the young man re-learns skills for daily life, and has huge consequences when he has to retrain for a different career.

What the Study teaches us

For those who've sustained a traumatic SCI, Green says it's important not to "dismiss or disregard changes in your behaviour, or assume they are results of medication or an "emotional state of mind."

“They may not get rehabilitation for their TBI, and moreover, their SCI rehabilitation may not take into consideration the cognitive and emotional challenges of TBI.”

Requesting a neuro-cognitive assessment might be helpful, and in some cases a MRI might show that a TBI has occurred.

By getting treatment early, individuals with both SCI and TBI are able to get appropriate care. Toronto Rehab, for example, now has a program stream that deals with the dual conditions.

Next steps

Changes to health-care practices and policies are needed to bring about better care to improve short and longer-term outcomes for those who have sustained both SCI and TBI, but may not know it right away. With this study now complete, there are clearer answers to why this was the case, and best practice guidelines for front line clinicians are under development so they are better able to identify and manage patients with both conditions.

Prevalence of Undiagnosed and Untreated Traumatic Brain Injury in Individuals with Spinal Cord Injury, and the Implications for Quality of Life was funded by ONF.

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Taking Care of Your Bones After SCI

Gaining a Better Understanding of Fracture Risk

It's the activities of daily life that can put individuals with SCI at risk of a fracture, perhaps a twist during a transfer from one surface to another, bumping into something in the home, or a foot getting caught in a door frame. The result is a "fragility" fracture that creates more than just pain and obvious inconvenience. For an individual with SCI, these fractures can lead to immobilization, pressure sores, and a diminished quality of life.

Determinants of Fracture Risk Among Individuals with Spinal Cord Injury: A Case Control Study is the first of a series of studies helping to increase our understanding of bone health and fractures after a SCI. The research team is following a group of participants over two years, looking specifically at how bone and muscle changes after SCI. The research will help clinicians and individuals with SCI have a better idea of who's at risk, and what to do in order to protect bone health.

"By identifying those at higher risk, we can make better decisions about who we should target for prevention strategies," says Lora Giangregorio, who supervised the *Determinants of Fracture* study at the University of Waterloo.

Loss of bone mass

Normal, healthy bones can withstand light trauma, a gentle fall or twist, but when substantial bone loss occurs, bones fracture much more easily, resulting in a "fragility" fracture. The situation is similar for those with SCI. There is substantial loss in bone mineral density (BMD) following an injury, specifically in the lower extremities.

Studies have demonstrated that individuals with SCI can lose between 1.1% to 47% of BMD in the knee region, per year. The bones around the knee, the distal femur and proximal tibia, are the most vulnerable to fracture. A person with SCI has approximately twice the risk of suffering from a lower extremity fractures than an individual without SCI, regardless of their age or gender.

The challenge measuring bone strength

Clinicians measure BMD through a dual energy X-ray absorptiometry test (a DXA scan) to predict fracture risk for individuals over 50. But it may not be appropriate to apply the same risk assessment protocols for individuals with SCI because they are often younger, have different risk factors, and the regions of the body that are at risk of osteoporotic fracture are not the same as in the general population.

The research team has developed a method for measuring bone density around the knee so that clinicians can assess fracture risk in individuals with SCI. The team is also using new technology called "peripheral quantitative computed tomography (pQCT)" to assess bone geometry and structure. The study provides preliminary support for the use of the new knee BMD test. This was necessary because people who had sustained previous fractures were much more likely to have low BMD as measured with this test than people who had not had a fracture. Also, the study showed distinct differences in bone geometry and structure between individuals who had and had not had fractures.



What the study will do

By evaluating SCI-specific risk factors and changes in BMD, bone geometry and structure over time, the team hopes to design better risk assessment protocols for individuals with SCI. The research team also hopes to build on the research and help clinicians understand why some individuals with SCI experience multiple fractures while others experience only one or none.

"We hope to be able to put together some guidelines for assessing risk of fracture in individuals with SCI, so that fracture prevention strategies can be implemented," says Giangregorio.

Both studies, *Determinants of Fracture Risk Among Individuals with Spinal Cord Injury: A Case Control Study*, conducted by Deena Lala, University of Waterloo, and *Bone Quality in Individuals with Chronic Spinal Cord Injury*, are funded by ONF.

Canadian Institutes of Health Research

National Traumatic Brain Injury Research Strategy

April 12th and 13th marked an important milestone in traumatic brain injury research. CIHR's Institute of Neuroscience, Mental Health and Addiction, in partnership with Ontario Neurotrauma Foundation (ONF) and other partners welcomed close to 120 research stakeholders from across the country to a two-day invitational workshop.

Larry Carlson, Chair of the Brain Injury Association of Canada (BIAC) participated in the event to continue what ONF and BIAC had started—a National Traumatic Brain Injury Strategy. The enthusiasm and energy at the event was infectious, with representation from organizations such as the Institute of Neuroscience, Mental Health and Addiction, Hotchkiss Brain Institute, Fonds de recherche du Québec-Santé (FRQ-S), and National Departments of Veteran's Affairs and Defense. Opportunities for national collaborations were identified; research exchanges promoted and areas of national strength highlighted. In the final session key partners met to discuss how to sustain and advance this energy. As one of the country's prominent organizations in TBI research, ONF agreed to take the lead in advancing the next steps in the National TBI Research Network.

The engagement of the research community and the development of a Pan-Canadian strategy led by the Canadian Institutes of Health Research is a critical step in recognizing brain injury as a significant public health

issue and one that needs more attention from both public and private providers. We heard from speakers on topics such as the epidemiology of brain injury, clinical and pre-clinical research, best practices and implementation research, imaging research and national strategies around quality improvement.

Tony Phillips, Scientific Director for the Institute of Neuroscience, Mental Health and Addiction not only supported the Pan-Canadian activity, but also provided details on an emerging international traumatic brain injury research initiative in collaboration with the European Union and the National Institutes of Health and Department of Defense in the United States. He noted that

Canada has an important role to fill within the international community and can be a beneficiary of emerging research generated from our international colleagues.

The second day was devoted to putting together the beginnings of a national brain injury research strategy and discussing how a brain injury researcher network could be sustained.

Brain injury research is a catalyst for change in improving the quality of life for those living with a brain injury and their families, and its significance has now been raised to a national and international level. Much still needs to be done but April 12th and 13th saw the beginnings of what the future can and should be.



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“Changes in bowel function can be one of the biggest barriers persons with SCI face when reclaiming their lives”, explains Dr. Anthony Burns, Co-Primary Investigator for the research study and rehabilitation specialist in the Brain & Spinal Cord Rehabilitation Program at Toronto Rehab.

“Because of the issues and challenges associated with bowel management, persons can feel trapped and reluctant to leave their homes, unable to get back to work, afraid to start new relationships.”

“The problem, identified before the study began, was simply, a lack of clarity about what specifically determines one’s ‘bowel care experience’. In short, it was and is an issue that few want to talk about.”

A study unique in its approach

Others have tried to draw attention to the issue in the past. A 2004 study reported in the *Journal of Neurotrauma* that, “Recovery of bowel and bladder function has

also been rated as more important than walking by individuals with SCI”.

Why has NB waited so long to get the attention it deserves? The problem, identified before the study began, was simply, “a lack of clarity about what specifically determines one’s ‘bowel care experience’”. In short, it was and is an issue that few want to talk about. Scientists and clinicians need to understand the factors that shape the experience of those who live with NB. Otherwise, how can they effectively address the issue and help achieve outcomes that positively impact the quality of life following SCI?

ONF funded the study to explore and describe the experience of NB dysfunction and care from the perspective of affected stakeholders — individuals with SCI, families and care providers.

Study methods

The study used a qualitative methodology, phenomenology, to really understand the experience of the consumer. Phenomenology is an ideal methodology as it examines the lived experiences of humans from their own view of life situation. Through phenomenology, researchers were able to better capture the experience and nature of the condition for the person living with NB, and develop a richer insight into the associated challenges and concerns.

To date, interviews have been conducted with 19 persons with SCI and 10 care providers living in Ontario and Quebec. The individuals selected represented a diverse range, those over ten years and less than 10 years with SCI, as well as different injury levels. Questions were clear and straightforward, e.g. for the consumer: “How does your bowel care impact your life?” for the care

“Recovery of bowel and bladder function has also been rated as more important than walking by individuals with SCI”

provider, “What is it like providing bowel care to an individual with a spinal cord injury? What are your feelings about this?”

Getting the word out and next steps

The results of the study are now beginning to be shared with SCI healthcare practitioners, clinicians and community support providers. Dr. Burns presented preliminary findings at the Ontario Spinal Cord Injury Research Network Meeting in Niagara Falls this past April. Additional findings will be presented at the 5th National Spinal Cord Injury Conference, October 18 – 20, in Toronto, and plans are underway for initial publications. Future directions include developing interventions that target aspects of NB ranked as having the most impact, and looking at how best to measure outcomes.

“We’re starting to shed some light on the thing that no one wants to talk about,” concludes Dr. Burns, “We’ve done it by bringing visibility to it through the experience of the people living with it every day of their lives.”

The Topic that “No One Wants to Talk About”

Results of A Neurogenic Bowel Study



It's the topic that no one wants to talk about, until you start to ask the right questions in a comfortable setting. These are the findings of a recent study, which for the first time, looks at neurogenic bowel care from the perspective of the person with SCI and their care providers. Neurogenic bowel (NB) is characterized by impaired gastro-intestinal motility and a loss of voluntary control. Although the study's conclusions may not seem like new information to the family, care providers, or individual with SCI, it was the first time that their every daily experiences were documented in a way that helps scientists and clinicians understand what was most on their minds, and what affects quality of life the most.

Examples of issues raised as being important and negatively impacting quality of life included:

- The amount of time required for bowel care and its impact on work, school, recreation, social activities, etc.
- Planning involved to do activities that anyone else would consider routine.
- Loss of spontaneity and flexibility because of the need to make special arrangements, work around a schedule, prepare

and plan ahead.

- Loss of autonomy because you are reliant on family and other supports.
- Fear of eating, or eating the wrong thing.
- Fear of social situations, in particular, relationships and intimacy.

Preliminary findings drawn from the study, *Understanding the Factors that Shape the Neurogenic Bowel Experience Following Spinal Cord Injury: Identifying Important Themes from the Perspective of Stakeholders* are the following:

- NB impacts several life domains of people with SCI; which limits their ability to fully participate in the community and maintain their well-being.
- Because of NB, individuals with SCI and their care providers have to spend a great deal of time and resources planning, because social and community participation revolves around the bowel routine.
- The identified areas of concern provide specific targets for interventions and quality of life outcome measures.

Looking at issues of daily life

Despite the fact that NB negatively impacts 40 – 60% of individuals following SCI (Glickman, 1999), for too long, there has been limited research, advancement in knowledge or understanding of the consumers' experience.

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