The Cost of SCI

Improving quality of life by the numbers

86,000 Canadians live with a spinal cord injury (SCI). 95 percent experience pressure ulcers over their lifetime. For the individual, their family and caregivers, managing and treating this common secondary complication results in a lifetime of visits to clinics, therapists, doctors, hospitals and emergency departments.

The clinical and social impact of pressure ulcers is well documented. An individual’s quality of life is directly affected as well as that of the family. But only in recent years have researchers been interested in the cost of pressure ulcers in terms of dollars. Tracking the cost may seem like an accounting exercise to some, but for healthcare providers, researchers and funding partners, health economics is a very significant way of looking at value to the system. Once value can be calculated in terms of dollars and cents, a stronger case can be put forward for new treatments and interventions – not just for the pressure ulcers – but all secondary complications following SCI.

Dr. Nicole Mittmann is a scientist at Sunnybrook Health Sciences Centre in Toronto. She has worked with ONF and the Rick Hansen Institute for several years trying to determine an economic value into how care and treatment programs are evaluated in the SCI population.

“The healthcare economics,” explains Mittmann, “asks ‘if you have a pressure ulcer, what does it cost the healthcare system, and does a particular treatment have an economic value?’”

Three years ago Mittmann was awarded a mentor-training grant to look at Health Economics in Spinal Cord Injury. Her mentee, PhD student Brian Chan, spent the past 3 years gathering and analyzing Ontario healthcare administrative data in order to calculate cost of pressure ulcers in a SCI population. The first phase was identifying all incidents related...
to individuals with SCI from 2005-2011. Once identified, he looked at both short term costs, on average of a pressure ulcer (per incident) and the long term cost to the health care system (per year.)

Managing the cost of a pressure ulcer
Thanks to the work of Mittmann and Chan, the cost of managing a pressure ulcer can now be calculated as well as the factors that contribute to the cost. In the case of pressure ulcers, this is usually the grade of severity – which affects where the individual is treated, i.e. a hospital, and how long they remain there.

“We now can assign a value of adding a new product, intervention or treatment approach that has proven to reduce the number of medical appointments, amount of therapy, emergency visit or length of hospital stay,” says Mittmann. “It tells us that we can spend more dollars on an intervention because we know this will affect the final outcome and the costs.”

With the cost and cost drivers identified, researchers now have a better idea of what could be done better.

“If we can direct more resources to making an impact on severity,” she explains, “then we have a chance to impact the cost on the entire system.

Putting the research to the test
Another recent study by researchers at Sunnybrook (including Mittmann) put the advantage of health economics to the test. By treating pressure ulcers with electrical stimulation therapy, they proved that grade 3 and 4 wounds healed faster and thereby, reduced costs to the system.

The study, in Mittmann’s words, “added in an economic reason for early intervention... There is a cost up front for the device, but we are able to demonstrate the cost effectiveness of the treatment.”

Applying Health Economics to other secondary complications
Health economics provides a concrete way to compare costs for decision makers in funding, procurement of devices, products, drugs, as well as government ministries. It also makes it possible to see how alternative treatments might accomplish more, over the long term, with fewer resources, or free up resources for new programs.

Mittmann is enthusiastic that health economics can be applied to the other secondary complications of SCI such as fractures and heart disease.

“It starts us thinking about other cost drivers and asking, how do change these in terms of new interventions, therapies, programs, and more education.”

Health Economics is a growing field within the discipline of economics, particularly as healthcare systems struggle with funding issues and look for the more effective and efficient way to deliver healthcare services. In Ontario, the availability of Ontario health administrative data, now available through the not-for-profit research institute, ICES, has benefited this on-going study. See www.ices.on.ca

Health Economics is a branch of economics that is concerned with how resources are allocated and used in different health systems. Global Health Education Consortium
Surviving a TBI is one thing. Learning to live with its consequences once rehabilitation ends is another. Thanks to the work of an interprovincial team from Quebec and Ontario, research into the large and complex topic of community integration has increased over the past seven years. So have the number of programs to make life somewhat easier once the TBI survivor returns to the community.

“We are fighting for the individual at the core of this challenge – the individual living with brain injury,” says Dr. Deirdre Dawson, co-principal investigator of the team, in Ontario.

A team approach to moving research forward

CRRReATe (Community Reintegration Research Action Team) was formed in 2007; one of six teams jointly supported by ONF (Ontario Neurotrauma Foundation) and REPAR, the Québec Rehabilitation Research Network.

ONF-REPAR grants are not typical research grants. They are intended to encourage interprovincial collaboration by building a team and moving the research programs in a certain direction.

CRRReATe’s purpose is the promotion of reintegration of people with acquired brain injuries (ABI) into their communities. Combining the expertise of researchers in two provinces, CRRReATe focuses on long-term difficulties faced by individuals with ABI.

“Working in teams gives strength to our research and our commitment,” says Dr. Carolina Bofftari, co-principal investigator of CRRReATe in Quebec. “It also gets the research and the knowledge available to a much wider audience, and in two languages.”
Building capacity in brain injury research
Learning to develop meaningful goals and how to make plans to achieve them can be a significant challenge after a TBI. The team supported a series of pilot projects, which looked at innovative and creative programs to address these difficulties. These include the Personalized Community Integration Program, Communication through the Arts, Social Communication, Leisure Education and a program aimed at managing problems with higher-level cognitive deficits.

But the value of the team’s work reaches far beyond the above pilots. The strength of the combined research has led to increased funding for ABI rehabilitation and community integration from larger provincial and national agencies such as the Canadian Institutes of Health Research and the Fonds de Recherche du Québec - Santé. With more comprehensive studies underway, research has advanced in new directions.

“When the team first met seven years ago” Dr. Dawson recalls, “we were a disparate group of younger researchers, working on individual projects in two provinces and in two languages. The ONF/REPAR team building grants allowed us to build strength in this important area of brain injury research.

“It means we have a chance of making a bigger difference in people’s lives,” says Dr. Bottari.

Real progress
Over the past seven years, CRReAte has seen progress in several areas:

More collaboration: The team welcomed many more trainees from Canada as well as Australia interested in ABI rehabilitation and community integration. Under the supervision of either Drs. Bottari or Dawson or other senior members, they work on the various projects during their master’s or PhD programs, and post-doctoral fellowships.

National and international reach: Team research has been presented at national and international consumer, clinician and scientific meetings. “More people are seeing the benefits of our work,” says Dr. Dawson.

Greater understanding of ABI: In addition to increased research activity, the importance of community integration over a lifetime for the individual with ABI is now being better understood.

“An individual who sustains a brain injury at 16 faces different challenges at middle age,” notes Dr. Dawson, “People now are starting to think of brain injury as a chronic disease, that is, something an individual has through their life course.

“There is more recognition now of the importance of advocating for a model that addresses these needs.”

Value of interprovincial teams
CRReAte includes representation from the University of Toronto, Université de Montréal, Université du Québec à Trois Rivières, Community Head Injury Resource Services, Toronto Rehabilitation Institute and Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal.

“We combine the expertise of two of the largest provinces in Canada with the strength of brain researchers in those provinces, and engage in knowledge translation in two languages,” says Dr. Bottari. “The sharing of ideas has been tremendously stimulating and productive.”

Your Opinion Matters
It’s important to us to have a good idea of what our readers are interested in and what they think of NeuroMatters, so we’ve created a short, 5-minute survey.

Please go to http://onf.org/neuromatters-survey to share your thoughts with us.

This survey is anonymous.
Studies have been done to identify various needs of the individual with SCI. Until now, however, there has been a lack of evidence regarding the extent of met versus unmet needs, and their influence on social participation and quality of life.

But thanks to the SCI Community Survey, the first of its kind ever to be done in Canada, researchers, health practitioners and community workers now have a more comprehensive understanding of the needs for services in communities where people live. The survey identified the gaps in healthcare and social services. It helped answer how well these support systems meet SCI-specific needs and what could be done to improve the system.

"While needs such as attendant care, accessible housing and technical aids are met to some extent by more than 70 percent of people with SCI, needs that are unmet in the majority of people – healthy living, recreation, emotional counseling, income support – raise concerns," says Dr. Luc Noreau, professor at Laval University and principal investigator for the SCI Community Survey. "Unmet needs and secondary health complications are among the most significant contributors to a poor quality of life."

**Secondary complications**

The survey measured the frequency of 21 health complications over the last 12 months and their impact on daily activities. Results demonstrated a clear connection between such complications and daily living. Sexual dysfunction was highest in frequency and made the biggest impact on activities. It ranked as the least satisfying dimension in terms of quality of life.

While pressure ulcers were not among the most frequent complications, almost half of respondents ranked them very high in terms of limiting activities.

**About the Survey**

*Spinal Cord Injury Community Survey: A National, Comprehensive Study to Portray the Lives of Canadians with Spinal Cord Injury* was conducted from May 2011 to August 2012. It included 1,549 respondents (of which 1,137 were traumatic injuries). Highlights from the survey that studied traumatic injuries are listed below. Future issues of NeuroMatters will look at other specific topics.
The top 5:
- Sexual dysfunction
- Neuropathic pain
- Shoulder problems (pain from overuse)
- Urinary tract infections
- Pressure ulcers

Multiple challenges and health care utilization
Individuals with SCI face multiple health issues, known as “multimorbidity.” Multimorbidity requires frequent use of the healthcare services. In Canada, persons with SCI are 2.7 times more likely to contact physicians, 2.6 times more likely to be re-hospitalized, and require 30 times more hours of home care services compared to the general population.

Need for services in daily life
The survey measured the frequency of 13 needs for daily living and the level to which these are being met. An accessible home and adapted equipment were at the top of the list. Others in the top five were general healthcare, short distance transportation and specialized healthcare services. Although overall, financial support was in the lower five, for individuals with tetraplegia, the need for home care and financial support was much greater.

Changing needs through the years
The survey helped demonstrate how needs change over a lifetime. Mood disorders, for example, were more commonly reported by respondents as an issue in the early years post-injury. They tended to diminish with time, suggesting better adjustment to the situation. As individuals with SCI age, however, more develop needs for transportation, home accessibility and professional training.

Employment
Individuals with SCI continue to face difficulties finding and maintaining paid work. Survey findings showed that the low employment rate has not changed in four decades. This ongoing concern needs to be addressed. Employment is directly related to health and quality of life. Workforce participation provides economic and residential independence, builds self-esteem, gives individuals the opportunity to interact with others, and creates structure in daily activities.

The fall issue of Topics in Spinal Cord Injury Rehabilitation also presents the major findings.

The SCI Community Survey was created with input from people with SCI, experts in the field of SCI research and healthcare and SCI community advocates. Supported by the Ontario Neurotrauma Foundation and Rick Hansen Institute, the survey was created by a team of Canadian researchers, led by Dr. Luc Noreau at the Université Laval and endorsed by SCI Canada, MÉMO-Québec and other community groups.
But in cases where this is not possible, CBT by teletherapy should be considered. “CBT helps individuals uncover what would make a difference in getting their lives back,” explains Dr. Bradbury, “It also teaches techniques on how to become good self monitors of their own emotions.

“We strongly believe that people with ABI should be provided with this intervention regardless of geography, transportation or their ability to get around. The techniques of CBT work and in teletherapy can make it possible for more individuals to get the help they need.

Applying the research further
Going forward, Dr. Bradbury wants to find ways to further educate clinicians on the value of CBT as well as look at ways to extend the model to online tools, e.g. Skype or iChat. This will involve solving issues around confidentiality and general comfort level with the technology.

In addition, the model is now being considered for other situations where mood disorders affect quality of life. Dr. Robin Green, and several of the co-investigators are applying the findings to a research project on how teletherapy can help individuals who are older and have some degree of impairment.

The techniques of CBT work and in teletherapy can make it possible for more individuals to get the help they need.”

SCI Conference:
A Remarkable Experience

The 6th National Spinal Cord Injury Conference took place October 3 and 4, 2014, with the theme Bioinformatics Inform SCI Rehabilitation. Held every second year in Toronto, the event makes it possible for a group of consumers to attend and talk with professional researchers.

“The Conference was a remarkable experience,” says delegate Richard Ruest. “I learned so much and was able to network with many amazing individuals including the recipient of the Champion of Change Award, Doctor Serge Rossignol, MD PhD, of the University of Montreal.” (Dr. Rossignol dedicated more than 40 years of his life to SCI research.)

Brian McLean echoes Ruest’s enthusiasm, “There were some areas that the knowledge base and understanding, such as nutrition and how to improve the quality of life from what you eat can make a huge impact for various organs and on fatigue.

“This information was not available to me 25 years ago, and I really didn’t put much thought into that as being such a huge contributor to how we feel daily.”

MacLean also was fascinated watching a demonstration where a robotic suit was put on a patient, making it possible for the person to walk and do daily activities.”

ONF is proud to be a lead sponsor for the National SCI Conference. The more than 500 delegates from across Canada included six consumer delegates from different areas of Ontario. Delegates complete an online application, which is then reviewed by the selection committee.

Thank you, event attendees for your evaluations, which help shape the next conference in 2016.
TBI Treatment by telephone

Not Your Average Therapy Session

An acquired brain injury frequently causes emotional stress once an individual returns home. Just trying to cope with daily life affects the quality of the individual’s life as well as that of their family and/or caregivers. But in recent years, a specialized psychological treatment called cognitive based therapy (CBT) has been used as a way to help individuals improve overall psychological well-being and practice techniques to fight depression and anxiety.

A relatively new treatment option, CBT works on the premise that how one thinks affects how that person feels, which affects how he or she behaves. A therapist takes individuals through a process that helps them break down overwhelming problems into smaller pieces so they can see how each one is affecting their behaviour. Once individuals are able to identify their negative thoughts, anxieties and frustrations, they can begin to understand better why they act a certain way.

Traditionally, CBT means an appointment with a therapist face-to-face or treatment in a group setting. But what if the person lives where there isn’t a specialized therapist or enough individuals to form a group? Perhaps the brain injury or other physical injuries makes it difficult for that individual to leave the home or impossible to travel to appointments on a regular basis.

A surprising success
Two years ago, a research study was conducted to answer two critical questions. First, is CBT effective when conducted over a fairly short period of time? Secondly, does it make a difference if the CBT is administered over the telephone instead of face-to-face or in a group?

In order to do the study, two groups were monitored over a 3-month treatment period and then six months later to see if the effects lasted. The research team was led by principal investigator, Dr. Robin Green, Canada Research Chair in traumatic brain injury. It included psychologist, Dr. Cheryl Bradbury at UHN – Toronto Rehabilitation Institute. The study produced two promising results.

“Both groups benefited significantly from the therapy, regardless of the severity of the injury,” says Dr. Bradbury, “And we were happily surprised that both groups produced the same results, whether the therapy was administered face-to-face or by telephone.”

The power of CBT
Given the study results, Dr. Bradbury says that ideally, they would recommend having at least one face-to-face meeting before teletherapy begins and possibly one or two check-in times in person. “Establishing trust in your therapist is a large factor in how well the therapy works,” she says, “And when people share as much as they do in therapy, many like the idea of meeting who they are talking to.”

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