

NeuroMatters

Connecting YOU to the Research

Addressing Neuropathic Pain and Depression

Reducing Inflammation is the Key

There is a great deal being written these days about the dangers of chronic inflammation in the body. It is a health concern facing the Canadian population, but particularly, for individuals with spinal cord injuries (SCI) who are already susceptible to infections, weight gain and cardiovascular disease. Such chronic inflammation directly affects the severity of both neuropathic pain and mood.

The good news, however, is that inflammation can be reduced through interventions such as change of diet and exercise. For the first time, a team of researchers at Brock University is looking at a way of reducing inflammation for those with SCI through a specific diet and exercise and thereby helping to reduce both neuropathic pain and depression.



The inflammation study

Although diet isn't the only way to reduce inflammation, there was a scientific reason to believe it may provide an effective strategy while

avoiding the side effects associated with taking medications. The study was led by David Ditor and graduate students, David Allison and Hisham Sharif. Twenty individuals

with SCI took part in the study. Twelve followed a specific anti-inflammatory diet for three months while the remaining eight continued to follow their usual diet as members of the control group.

Blood tests were done every month to measure the amount of "pro-inflammatory cytokines" present before inflammation sets in – these are blood markers that indicate inflammation levels. Participants also self-reported the changes they experienced throughout the time period in neuropathic pain and mood by means of surveys and interviews.

Both studies showed remarkable results. "Through blood analysis we observed that inflammation was successfully reduced," reported Ditor. "We also found substantial reductions in the intensity of neuropathic

...continued on page 2

IN THIS ISSUE

- 1 Addressing Neuropathic Pain and Depression
- 3 You Are Not Alone
- 4 A Family's Challenge
- 5 Making Connections in Fall Prevention
- 6 You Are What You Eat
- 8 TBI and Financial Management



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...continued from page 1

pain and improvements in mood, which were related to the change in inflammation."

Impact on depression

As research shows, individuals with SCI are more likely to experience depression. The first study looked at the link between lowering inflammation and improving mood.

Among its many impacts, inflammation in the body has a direct effect on serotonin levels. Serotonin is a chemical in the brain that is known to act as a mood stabilizer.

"Results were apparent even after the first month," said David Allison, "Depression dropped 50 percent and by the end of three months, it had dropped more than 55 percent." Ditor also noted that of the five study participants who began with scores suggesting serious clinical depression, all five improved. Their scores suggested elimination of depressive symptoms by the end of the intervention.

Impact on neuropathic pain

The purpose of the second study was to examine the effectiveness of an anti-inflammatory intervention as a treatment for neuropathic pain. Neuropathic pain is common following SCI (an estimated prevalence of 20-70 percent). The cause of pain most often is related to nerve damage from SCI. Neuropathic pain is very difficult to treat, with many treatments showing little efficacy and many undesirable side effects. "Inflammation also plays a role in pain intensity," Ditor explains, "Chronic inflammation makes the pain pathways in our body hyper sensitive. By dropping the amount of inflammation, we hoped to reduce this effect."

The observed change was very encouraging. There was a 40 percent reduction in the intensity of the pain as well as a change in how pain affected daily living. One woman commented that getting up each morning used to be a challenge because of pain but after being on

the diet, she was waking up pain free and able to go about her day more easily.

The anti-inflammatory diet

Although the influence of inflammation on neuropathic pain and mood was the primary focus of the study, the substantial reduction in inflammation brought on by the diet is important to note. (See page 3 for details of the diet.)

Made up of healthy, tasty food, it was a diet that participants were generally able to stick with (adherence ranged from 70 to 100 percent). It also wasn't a calorie restrictive diet so no one was hungry. In fact, most lost weight even though some found it difficult to eat all that was required!

Outcome

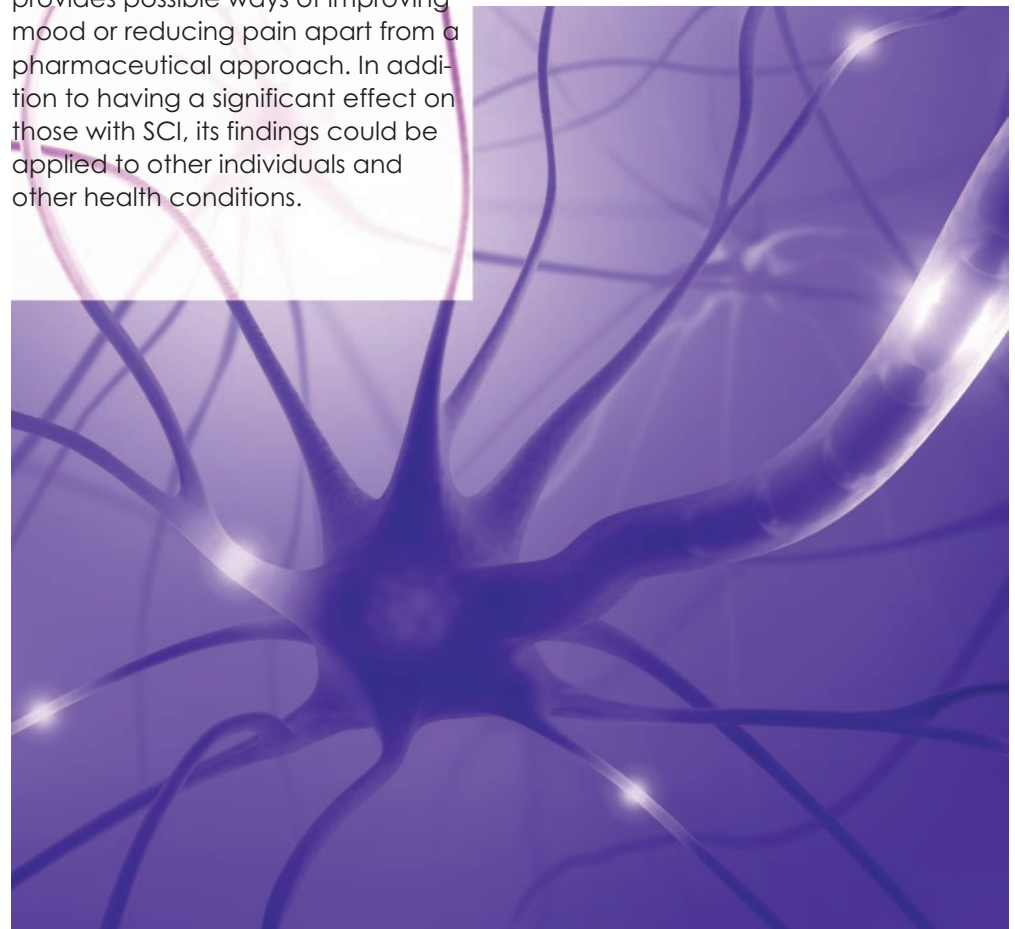
Individuals with SCI often turn to various medications, with limited success and in most instances, unwanted side effects. The study provides possible ways of improving mood or reducing pain apart from a pharmaceutical approach. In addition to having a significant effect on those with SCI, its findings could be applied to other individuals and other health conditions.

From Lab to Lives Lived

An important aspect of the study was the way the research connected directly with consumer's lives. Both Ditor and Allison had the opportunity not only to study results in a laboratory, but also hear the personal stories of those individuals affected by pain and depression.

"There was such value in getting away from the typical laboratory science and looking at a practical way of getting this kind of diet out into the world. It renewed our commitment to address barriers and teach people how to realistically work this into their life."

– Ditor and Allison



You Are Not Alone

New TBI Resource Supports Caregivers and Clinicians



Unfortunately, there are few services specifically designed to meet the needs of the roughly 1 in 4 individuals living with both a brain injury, and serious mental health and substance use problems. These “concurrent issues” make their lives particularly challenging. The families who care for them also struggle. There is no “how to” manual for a clinician to provide to families who are caring for a person with concurrent issues that explains what to expect, what to do, or even the diagnostic terms.

As a result, thousands of families have difficulty getting the right services and feel alone.

“The individuals dealing with complex needs have no where to land,” explained one service provider, “and neither do their families.”

Finding and filling the gap

“We often hear from family members that their loved one has not been accepted for care because their mental health problems are too great for brain injury providers, and mental health and addiction providers are reluctant to help

because of the brain injury-related issues,” says Dr. Carolyn Lemsky, Clinical Director at CHIRS and Principal Investigator for SUBI (Substance Use and Brain Injury Bridging Project). “Trying to advocate for a loved one across service provision sectors becomes an almost impossible task.”

Materials have been created through the ONF-funded SUBI project for clinicians to be trained across sectors, but there has been nothing provided for the families who must manage day-to-day.

“In my clinical practice,” Lemsky explains, “we do our best to address the needs of families and clinicians dealing with these complex conditions. Everyone was clear about the need for materials for families living with the long-term effects of brain injury with complex co-existing conditions.”

Building the resource

Judith Gargaro, Research Coordinator, worked with Lemsky to create an initial outline of such “family materials”.

The project began with focus

- **23 percent of people seeking addictions services at the Centre for Addiction and Mental Health in Toronto, over a three-year period, were found to have a history of brain injury with a loss of consciousness.**
- **Those identified as having a brain injury also report more severe consequences of substance use, more episodes of addictions care, and more mental health symptoms than individuals without a brain injury.**

groups with clinicians and families to find out what would be most helpful. The project team then continued to review excellent resources in order to extract the most appropriate therapeutic components, strategies and techniques for coping, problem solving and advocating. “There was no need to reinvent the wheel,” says Gargaro, who now is in the process of compiling the final document.

Right information at the right time in the right way

Every step along the way, the team was encouraged to make the materials a “one stop shop” resource so families could find the information they needed without having to visit countless printed and online sources. The information needs to be in a concise format, easy to understand and practical. One focus group advised that it had to be “conversational”, not like a textbook, with single page tip sheets on topics relevant to daily life, e.g., positive communication tools and tips for de-escalating a crisis.

...continued on page 4

...continued from page 3

Being able to advocate for a loved one or client is another major challenge. The materials will list the types of services and resources available so it is clear who to call, when and for what. Local service providers will be asked to add information relevant to each community.

Dealing with crises and emergencies

The section in the family materials that addresses emergencies and crises is particularly relevant to families of those with concurrent conditions. Topics address how to tell the difference between a crisis and an emergency, and what to watch for if the situation requires emergency intervention. A crisis planning tool is included that takes caregivers through the typical phases of a crisis, records the behaviour observed and recommended responses. There even is a list of what to put in a crisis kit.

Addressing self care

"We know that the road can be long for the caregiver and self-care is essential," says Lemsky. The materials include ways to cope; how to gain perspective and patience when times are difficult; and practical suggestions for getting a break.

An unexpected benefit of creating the resource has been the reaction from caregivers and service providers when they learn the project is underway.

"They tell us 'thank you for doing this – now we know we are not alone'," says Gargaro."

Family Materials is in the final stage of writing. The Ontario Brain Injury Association (OBIA) is assisting with its evaluation, including final testing. Once complete (Fall 2016), it will be promoted by both ONF and OBIA as a free resource, available in print or as a download.

A Family's Challenge

The following is a compilation of several case studies, submitted by Carolyn Lemsky, Clinical Director, Community Head Injury Resource Services (CHIRS) and Director of the Substance Abuse and Brain Injury Bridging Project (SUBI).



Daniel and his parents faced some real challenges in getting the supports that they needed.

Daniel sustained his injury at the age of 10 when he got sick with meningitis, had a seizure and a fall. Although he was lucky enough to survive without obvious physical difficulties, he struggled quite a bit with memory, attention and organizing himself. He needed help in school, and the transition to high school was very difficult.

By the age of 15, Daniel started to use marijuana regularly. At the age of 22, he developed signs of psychosis that included hearing voices and having unusual ideas. At first, the focus of his treatment was on the new psychiatric symptoms because his injury was so long ago. When he didn't respond like his peers to treatment, his parents started to talk to his care providers about his medical history. This is when they started to have difficulty getting services.

"When we talked to the mental health folks," his parents explained, "they suggested that we needed help from people who know brain injury. But when we asked for help for his brain injury, they told us his injury was too long ago to get services, and that they didn't really have supports for people who have schizophrenia."

His parents had a lot of questions. What was the cause behind Daniel's

problems? Was it really schizophrenia, or was it related to brain injury? What part did his marijuana use play? Did his mental health providers understand enough about brain injury to help him the right way? How could they get the help they needed?

It was clear to them now that they had to learn more about the impact of substance use, brain injury and mental health together so that they could get Daniel the care he needed and advocate more effectively for him.

After a wait, they were able to get a neuropsychological assessment and consultation about his cognitive impairments. This information helped his psychiatrist and the people at his day program understand his needs better. Outreach supports helped him to benefit more from the mental health services and work on strategies to stay organized.

His parents learned that complicated problems take a long time to get sorted out. They also found out that they were not alone. There were other families like them living with an individual with concurrent needs and facing similar challenges. Learning about concurrent conditions and how to advocate for a family member, as well as knowing how to pace themselves and take care of their own needs all made a difference in the quality of Daniel's care.

“Make Connections” in Fall Prevention

Cyber Learning for Healthcare Practitioners

Practitioners working in older adults' fall prevention are turning to YouTube to learn about the latest research and information on preventing falls. Whether the topic is bathroom safety for older adults and their caregivers, or exercise and balance training to prevent falls, the Fall Prevention Community of Practice (CoP), sponsored by ONF, has organized over 20 webinars.

The webinars are part of the Making Connections webinar series presented by the Seniors Health Knowledge Network (SHKN) and posted on their YouTube channel. On

average, 100 members of the CoP register to watch the free webinars live, allowing them to interact in real time with the presenter and other participants. The webinars are recorded and posted on YouTube afterwards for public viewing. To date, over 130 subscribers have signed up as regular viewers, and the webinar series boasts 17,516 views and counting!

“The webinar series is definitely making a positive contribution to older adults' health,” says Lindsay Toth, the ONF staff who coordinates the webinar series. “It is one of the

most popular services offered by the CoP,” she explains.

Topics covered in the Making Connections webinars emphasize key issues related to fall prevention in the home, in healthcare settings and the community. The information is practical and intended for practitioners, researchers, policy makers, caregivers and older adult groups. In the webinar on Bathroom Safety, for instance, getting safely in and out of a bathtub is presented from both the perspective of the older adult taking a bath, and the caregiver assisting an older adult.

Other webinar topics include:

- Successful Partnerships
- Fall Prevention in Hospitals
- Vision, Aging, Falls and Fall Prevention
- Exercise for Older Adults in the Community Setting
- Too Fit to Fracture: Exercises and physical activities for individuals with osteoporosis

The Fall Prevention CoP's webinars serve to increase knowledge and build capacity of practitioners and people working in fall prevention. SHKN provides the technology for the webinars while ONF staff facilitate the presentations, often with guest experts in fields related to older adults' health.

The Making Connections webinars (with descriptions) are posted on SHKN's YouTube channel, each with an overview of the webinar content. www.youtube.com/user/SHKNNetwork

“On average, 100 members of the CoP register to watch the free webinars live, allowing them to interact in real time with the presenter and other participants.”



Everywhere you look these days, someone is promoting a new version of a “healthy diet”. But is there a diet that is specifically suitable for persons with a spinal cord injury? The recent study (page 1) that looked at the consequences of inflammation in the body showed that diet can and did make a difference on both mood and neuropathic pain. The process used to come to these conclusions wasn't just a diet that makes individuals feel better; there was science behind the food choices that affected what happened in the body at a molecular level.



You Are What You Eat

Controlling Inflammation through diet

Inflammation, the good and the bad

Inflammation is part of the body's immune system. In its simplest terms, when inflammation occurs, chemicals are released into the blood or tissues as part of the body's natural healing response. The “irritated” tissues then swell or become inflamed.

In a healthy body, inflammation is good because it helps the body heal. But too much of these chemicals (named “cytokines”) are destructive to normal cells. As a result, more inflammation occurs, which sets up a vicious cycle. Long-term or chronic inflammation is linked to some serious health issues – metabolic disorders such as diabetes,

weight gain and cardio-vascular disease.

Results from the study mentioned above also linked an elevated inflammatory response both with intensity of pain as well as emotional imbalance (e.g., depression). The researchers concluded: find a way to control inflammation, and an individual with SCI not only improves their health, but also, they actually will feel better as pain decreases and mood improves.

Controlling Inflammation

Two ways to control inflammation in the body is avoid foods known to be inflammatory, and eat more anti-inflammatory foods. Armed with

this knowledge David Ditor and David Allison worked with nutritionists to put together a suitable anti-inflammatory diet focused on:

- **Eliminating foods that cause inflammation:**
These are foods with high glucose levels, such as refined sugars and wheat products; processed foods; and foods that negatively influence cardiovascular health, such as hydrogenated oils/trans fats (e.g., shortening/lard found in baked goods).
- **Introducing foods and supplements with anti-inflammatory properties that actually reduce inflammation:**
Foods high in antioxidants, e.g.,

...continued from page 5

fruits and vegetables such as berries, broccoli, carrots and spinach; monounsaturated fats such as olive oil; omega-3 fatty acids found in certain fish (salmon), flaxseeds and walnuts; lean meats and low-fat dairy products; and certain spices (garlic, turmeric, ginger and chili peppers).

- **Anti-inflammatory supplements:** Omega-3 (now Ultra omega-3); chlorella (a high protein algae); antioxidants; curcumin (found in turmeric). Daily dose for each as prescribed by a nutritionist with expertise in this area.
- **Eliminating common food intolerances** that are known to raise the body's inflammation levels as the body "fights" the intolerance (e.g., lactose intolerance).

Life-long healthy food habits

A daily diet based on the above foods is based on a daily eating plan that includes healthy, fresh food choices, with plenty of fruits and vegetables and as little sugar and

“The diet was not rocket science, it’s just a healthier way of cooking and eating. Instead of following food rules, individuals just learned how to make good food a habit, and as a result, experience better healthy outcomes”

processed food as possible.

“The diet,” says David Ditor, “was not rocket science, it’s just a healthier way of cooking and eating. Instead of following food rules, individuals just learned how to make good food a habit, and as a result, experience better healthy outcomes.

“At the same time,” he adds, “we continue to also encourage those with SCI to engage in moderate exercise, an additional way to lower inflammation and remain healthy.”

Typical Food Choices for an Anti-inflammatory Diet

Breakfast

Lemon juice and water
Protein shake with fruit

Lunch

Chicken and salad

Dinner

Fish (3 times a week) or lean meat (mostly chicken) plus vegetables; fruit for dessert

Two Snack choices through the day (mid morning and mid afternoon):

Fruit, egg, hummus, or nuts

No coffee



Next Steps

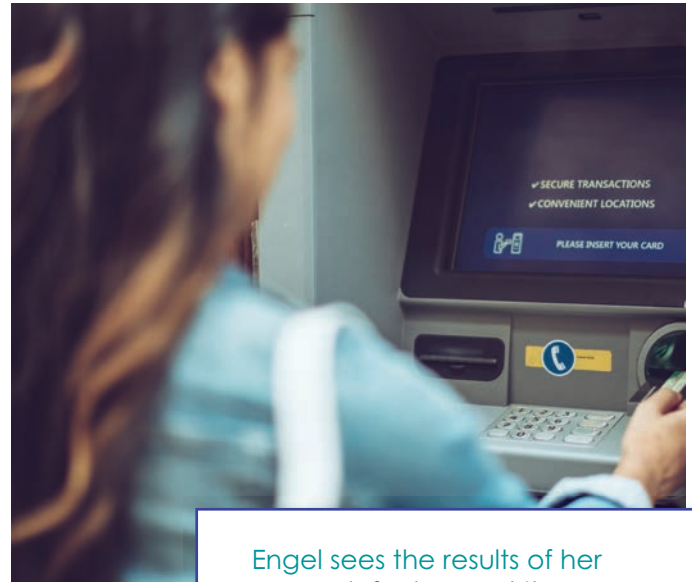
One logical next step would be to look at what foods are more effective than others at lowering inflammation. Ditor and Allison also would like to see diet guidelines for those with SCI, similar to the exercise guidelines recently released.

Understanding Consequences of Chronic Inflammation in Spinal Cord Injury is one of the ONF mentor/mentee funded studies where student mentees are given the opportunity to work along side senior investigators.

TBI and Financial Management

A Better Tool for Promoting Independence

Clinicians who work with individuals with traumatic brain injuries are often called upon to assess the ability of their client in specific areas of daily living, such as managing finances. These are often routine tasks such as bank deposits and withdrawals, paying bills on time and making spending decisions. Depending on the extent of financial management issues, family members or a public guardian may be given the legal right to manage the survivor's finances, or family members may informally take on the survivor's financial management responsibilities.



Engel sees the results of her research far beyond the institute where she conducts her research. In her work as an OT, and through interviewing families and survivors of brain injury about financial management, she sees how directly her work is affecting the lives of individuals with TBI and their families.

When Lisa Engel was working as an occupational therapist, she struggled with this aspect of her job because of the serious impact such a decision had on an individual's life.

"Money is tied to everything we do in our lives," she explains, "it affects where we go and what we do. Take that away from someone and you take away their independence, and their quality of life."

On the other hand, Engel also realized the risk that individuals and families face when someone no longer has the ability or judgment required to do financial management tasks such as paying bills, spending or investing money. "I had real anxiety about the decisions I was asked to make," she recalls.

Engel's interest in financial management after a TBI and finding ways to provide independence led her to research that would give clinicians a better way to make such an assessment as well as maximize independence for the TBI survivor.

Initiation, Planning, Organization, and Brain Injury

Individuals with a TBI are more likely to have difficulty with planning, organizing, sorting information, prioritizing and problem solving – the

very abilities typically associated with financial management. The concentration required to gather and sort information such as cash available, expenses to be paid and credit card due dates can be a challenge, particularly if family members don't know how to best support someone struggling with one of these tasks.

Maximizing Independence

Engle first conducted a systematic review that found that although there were some assessment instruments for financial management, none existed specifically for individuals with brain injury. She then directed her research toward a new assessment and treatment options that balance the extreme between losing total financial independence and putting an individual or a family at risk. Instead of taking away someone's entire financial responsibility, perhaps there is a way to provide support in specific areas.

"We've seen instances," says Engel, "where a family finds errors in someone's financial activities and they react by taking over. Instead, we hope to show how some survivors may be able to participate in some

tasks but need help in others."

Once an assessment tool is created, it will be validated through testing with people with brain injury and their families. Clinical guidelines then will be developed so that clinicians have what Engel needed before she started her research: a way to provide an evidence-informed financial management assessment of TBI survivors; and options for providing as much independence as possible.

This project is supported through a fellowship awarded to Lisa Engel, working under Dr. Deirdre Dawson at the Rehabilitation Sciences Institute, University of Toronto and the Rotman Research Centre, Baycrest. It is jointly funded by ONF and the Canadian Institutes of Health Research.



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