

NeuroMatters

Connecting YOU to the Research

IN THIS ISSUE

Back to School, Dealing with Concussions

New guidelines help teachers and parents

Back to school in the fall means back to the playground, recess and various formal and informal physical activities where children and youth run, jump, play – and fall. When a child or youth sustains a hit or jolt to the head, the result may be a concussion. For teachers and school administrators, it is important that they know the potential signs of head injuries, where to seek appropriate care, what to tell parents and caregivers, and how to support “return to play”.

“Teachers are responsible not only for each child’s learning in the classroom, but also their health and safety while under their care,” says one Ontario public school teacher. “They run around, bump into each other, trip over their shoe laces. Even with the best safety rules in

place, accidents happen. Knowing how to assess a bump on the head and what school procedures to follow is important. You then need to communicate clearly to the child’s caregivers about what happened.”

A teacher’s role is also critical

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Ontario Neurotrauma Foundation
Fondation ontarienne de neurotraumatologie

when a child recovering from a concussion returns to school. “Schools may need to make accommodations for children,” she continues. “By working with the family, an individualized plan can be put in place to support a child physically, academically and/or emotionally, and to help him or her stick with their recovery, as outlined by their doctor.”

Dr. Roger Zemek, network lead for the new Guidelines for Diagnosing and Managing Pediatric Concussion, agrees. “Pediatric concussion is not just the elite Bantam hockey players hit in a checking incident. It also can be a kid who falls on the stairs.”

“Teachers need direction for how to manage a child in their classroom post concussion, by working with the parents, doctor and the school to guide stepwise integration back to learning.”



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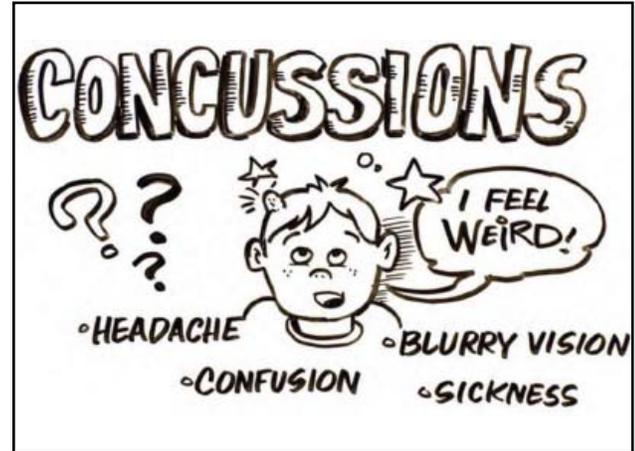
Released this June

The new Pediatric Guidelines released this June provide evidence-based recommendations that standardize the diagnosis and management of concussion in children ages 5 to 18 years old, from the initial assessment through to the period of recovery (which might last months.) Given that the highest incidence of concussion/mTBI is in the pediatric age group, the guidelines were designed for healthcare professionals as well as those in a wide range of care settings, e.g. teachers, school-based professionals, community sports organizations, caregivers and parents. Any of these individuals or groups may find themselves in a situation where they need to recognize a concussion and/or manage return to play as part of the recommended treatment for “cognitive” rest.

“**Pediatric concussion is not just the elite Bantam hockey players hit in a checking incident. It also can be a kid who falls on the stairs.**”

The Guidelines Provide:

- Specific guidance on what providers should tell parents and caregivers when a child or youth sustains a hit on the head (including draft letters to be sent home to parents/guardians and policy statement regarding pediatric concussions for school boards).
- Recommendations for what to expect and where to seek appropriate care following a suspected concussion. For example, a pocket tool for coaches or parents provides tips on how to recognize a concussion, advice on when to remove a child from play and when to seek emergent medical attention.
- Clear direction and instruction on what should be considered at various time points during recovery in order to improve how well the child or youth recovers.
- Information about concussions for school and sports communities.



Sharing what was Learned

Now that the guidelines have been released, the next step is implementation. “We’re in the process of working with various experts in order to best share everything we’ve learned,” says Dr. Zemek.

For example, representatives on the project team who liaise with school boards are now in the process of approaching administrators to have the guidelines implemented at the school board level. This is a necessary step before they can be formally shared with teachers and supervisors.

In the meantime, Dr. Zemek encourages teachers and any interested groups or individuals to check out the guidelines online, “There are form letters and sample discharge handouts for patients and families, various tools and checklists, all to be used and shared.”

The Pediatric Guidelines were initiated by ONF and developed by an expert panel including over 30 members across Canada and the United States. The project team included representation from the full spectrum of pediatric health disciplines. The document is provided freely for download at www.onf.org.





Understanding Clinical Practice Guidelines

The path to quality healthcare

Neuromatters often brings news about new “guidelines”, such as the recently released guidelines for pediatric concussion or the best practice guidelines for pressure ulcer management (pages 1,2 and 5,6). But what are “clinical practice guidelines” and why do health-care researchers and clinicians place so much importance on their development?

Making decisions about patient care is complex. In addition, the way in which healthcare is delivered varies widely from clinic to clinic and from clinician to clinician. Clinical practice guidelines, based on research evidence, are the best way to make sure that everyone, i.e. a nurse, physician, therapist, etc. applies the highest quality, and most consistent patient care and treatment.

It takes time and resources to produce guidelines, and calls upon a wide range of experts and stakeholders to advise, prioritize and evaluate. Various scientific step-by-step methods from recognized global healthcare organizations are used for analysis and review. The process for developing the new Pediatric Guidelines, for example, included the review of over 4,000 academic papers and took over 2 years to reach the stage where they are now ready to be put into practice.

Here's what typically takes place:

Defining “what” and “who”

Before work begins on guideline development, the organization or partnership leading the research define specific objectives for the guidelines. The group also clearly defines the needs of the “target audience” (*what health condition will the guidelines be applied to? and who will use the guidelines? (usually clinicians)*)

Involving stakeholders from the beginning

Two teams are set up to do the work, a systematic review team and guideline development group. Each includes a broad range of practitioners and stakeholders including scientific and clinical experts, organizations, agencies (e.g. government) and the general public (consumers with the health condition).

In order to make the guidelines be relevant and useful, the guideline development group seeks out the views and preferences of the users (clinicians) and/or the

The Canadian Nurses Association defines clinical practice guidelines as “systematically developed statements to assist practitioner and client decisions about appropriate care. They relate to specific clinical circumstances. They are set to influence practitioners. The goal of... guidelines should be to improve the quality of care.”
CNA 2002

consumers. Sometimes this takes place as a survey of user needs and expectations.

A rigorous development process

The systematic review team now begins a thorough examination of existing scientific research and practices on each topic that the guidelines will cover. They also explore whether previous guidelines have been created and if so, assess their quality. With the use of

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review processes that reduce biases or assumptions, the team is able to assess the level of evidence that each clinical recommendation is based on and determine overall strength.

Selected options for care are put forward and reviewed. Clinical knowledge and experience is very important in this step. All evidence used and all recommendations are rated on quality and strength as well as for specific outcomes. For example, care options are reviewed for health benefits, side effects and risks.

The development group now drafts the guidelines, working closely with the review team to make sure evidence is applied correctly. Various quality standards from global health research organizations such as the IOM (Institute of Medicine) are used in both developing and appraising the guidelines. AGREE II, for example, is a helpful tool for assessing the quality of the resulting recommendations based on the strength of the guideline development process.

Before publication

Before publication, the guidelines are once again assessed, this time by a third group of invited external reviewers.

At the same time, the development group focuses on making sure that once released, the guidelines have real value. The importance of including individuals on the team who know the health-care system and how care is delivered becomes very important at this phase. They identify cost implications and factors that might get in the way of the recommendations being implemented in a clinic or hospital.

Before concluding their work, the development group designs a procedure for monitoring and reviewing the guidelines as new evidence is available or treatment needs change. Most guidelines are



reviewed and updated every 3-5 years. The Guideline for Adult Concussion/mTBI and Persistent Symptoms, for example, is now in its 2nd edition.

What makes guidelines so effective?

The above process ensures that:

- Guidelines meet the actual needs of the patients and clinicians.
- Recommendations are specific, with no ambiguities, and options for management of a condition are clearly stated.
- Tools support the guidelines to make them easier to use (e.g. "pockets" guides, online reference tools, printed materials, workshops/ seminars.
- Everyone involved in the

guideline development process has an ownership in getting guidelines successfully into practice.

Why are guidelines so important?

Clinical practice guidelines are trusted resources. They are based on research evidence and clinical experience, and developed with the best judgment of experts, including consumers.

Well-designed guidelines are a very effective way of getting evidence from scientific research into practice and improving patient care. This is why guidelines are so important to a consumer. Their use means more consistent and higher quality care, regardless of where someone lives or the clinic or hospital they visit.



Changing Healthcare Practices

What Best Practice Development and Implementation in Pressure Ulcers Teaches Us

In 2011, ONF partnered with the Rick Hansen Institute and Alberta Paraplegic Foundation to form a Community of Practice (CoP) composed of six rehabilitation centres, two each in Ontario, Quebec and Alberta. The CoP became known as the Spinal Cord Injury Knowledge Mobilization Network (SCI KMN). The name reflected the manner in which the network collaborated across a wide range of disciplines and how it intended to communicate and disseminate what it learned.

The goal of the SCI-KMN is to improve outcomes for individuals with SCI in the areas of pressure ulcer, pain and bladder management. As of 2014, several key practices from the ONF-sponsored Canadian Best Practice Guidelines for the Prevention and Management of Pressure Ulcers in People with SCI have been fully implemented in the six centres. The project was successful in terms of changing healthcare practices in pressure ulcers, with an estimated 1,000 individuals with SCI impacted by the work. But its true value is what it is teaching researchers, clinicians, administrators and policy makers about the process of implementation and how a systematic, evidence-informed approach can be used to bring out sustained, institutional change in how healthcare is delivered.

Here is what has been achieved to date:

Implementation of key best practices

The treatment and management of pressure ulcers was selected as the first area of focus because it is identified as one of the most common health complications

affecting quality of life for individuals with SCI. Applying a state-of-the-art process, including extensive external consultation and stakeholder feedback for examining clinical practice guidelines (see pages 3,4), the CoP reviewed all available guidelines and then selected two guideline practices based on various criteria including having significant impact on patient outcomes:

- 1) Assessment of overall risk factors in individuals with SCI starting, ideally, during inpatient rehab and helping individuals know what issues they may face in the community post discharge.
- 2) Comprehensive and consistent patient education as part of an individualized treatment action plan.

Dalton Wolfe, Network Lead for the SCI KMN, at the Lawson Health Research Institute and Parkwood Hospital, St. Joseph's Health Care, points out the importance of both these standards:

"Each individual, depending on their circumstance, has different risk factors; one may have an issue with transfers, another related to positioning or any one of many factors," he says. "When a treatment plan is created, it and associated educational programming need to relate to these factors and need to be delivered to the patient in a clear systematic manner. Everyone (i.e., person with SCI and their health care team) need to be able to access the plan so they know what to do, given a particular situation."

Although it is too early to determine if the incidence of pressure ulcers has been reduced, the project provides researchers, clinicians and administrators with valuable new data so they can

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better track when pressure ulcers first occur and what additional practice improvements need to be made.

Going forward, the SCI KMN now is moving on to the implementation of best practices in pain management.

How to change and imbed new practices

The importance of the SCI KMN goes beyond the specific healthcare challenge of pressure ulcer management. The network clearly demonstrates that it is possible to improve clinical practice, even when existing practices are entrenched within institutions and healthcare settings. The system developed across the network to share information and mobilize the approach will contribute significantly to the field of implementation science, that is, how to bring about lasting change. Key to this success has been the adoption of a scientific framework developed by the National Implementation

Research Network for actively implementing new practices and programs.

One of the issues confronting healthcare is the time needed to get research and innovation into practice, and more importantly when improvements are made there are significant barriers to them being sustained. "An off-stated concern." Says Wolfe, "is that the transition from research to practice takes an average of 17 years. The SCI KMN has been able to implement in a sustainable way over two to three years!

"There will always be challenges to change," says Wolfe, "But this project is about development of a system so we have a repeatable and evidence-informed way to improve practice."

"Through this project," he says, "we've been able to build capacity to make change in a consistent and sustainable way. We can now take these processes for improvement and adapt them for improving care delivery in other areas of healthcare."

Upcoming Events



Toronto ABI Network Conference 2014

November 20th –21st, 2014
Allstream Centre, Exhibition Place,
Toronto, ON
www.abinetwork.ca

After and Beyond Neurotrauma: The Medical-Legal Conference

October 14th, 2014
Four Points by Sheraton Hotel and
Conference Centre,
Kingston, ON
www.onf.org

Concussion in Older Adults

First-of-its-kind research begins

Mention concussion and most people think of children, teens and young males taking a hit during a hockey game. But the second highest rate of traumatic brain injury in Canada occurs in senior adults (65 years and older). Until now, there has been very little research attention given to how older adults recover from a concussion, or mild traumatic brain injury (mTBI). It means that when an older person falls and hits their head, clinicians don't have the information they need to give that person, as well as their relatives or caregivers a reasonable expectation of how well they might recover.

A pilot study, **Prognosis for Mild Traumatic Brain Injury in the Elderly Population**, recently completed at emergency departments in Thunder Bay and Kingston, hopes to change this by being the first to advance this important area of research.



Finding out how senior adults recover from mTBI

The pilot surveyed 44 senior adults who visited an emergency ward at one of the 3 hospitals from 2012 to 2013. The individuals came specifically because of a head injury, in most instances sustained because of a trip and fall, or an object

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falling on their heads. Once the data was collected, the research team spent the early part of 2014 following up with each adult to find out about recovery.

"Most were fine after 72 hours," says Dr. Vicki Kristman, principal investigator for the project at Lakehead University in Thunder Bay. "It was those who continued to have symptoms who we were most interested in."

What the pilot tells us

"We looked at what factors may be associated with recovery," says Dr. Kristman. "The pilot wasn't expected to give us large enough numbers to make valid conclusions. But it has given us what we

need in order to put together a larger study."

From preliminary analysis, there do seem to be factors that affect recovery, for example, those with depression and those with high fatigue levels seemed to recover more slowly.

"We know now what size sample we need, what next steps to take, and the best method to gather the information to move ahead on a larger study."

Importance of advancing this research

Kristman points out that ONF was particularly interested in supporting the pilot because of the lack of research, worldwide, in the study

of outcomes after mTBI in older adults. "No research identifying those with the highest chance for good six-month recovery has been developed for the population aged 65 and over," she says.

As our Canadian population continues to age, the number of brain injuries sustained in this older age group will continue to grow, particularly for those older than 75. By increasing research knowledge on concussions in older adults, clinicians will be able to make more informed decisions about treatment, better advise on risk factors, and provide more realistic and helpful expectations to individuals and their relatives.

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non-partisan advocate.

One-on-one recruitment

Applying her skills in relationship building and communication, Brisbois explained the study details and clarified the process over the course of several visits to the potential volunteers. Part of her

role was to sensitively talk about what it means to be a "research-participant" and make sure everyone understood the process before giving consent. Often her work involved talking with family members and caregivers.

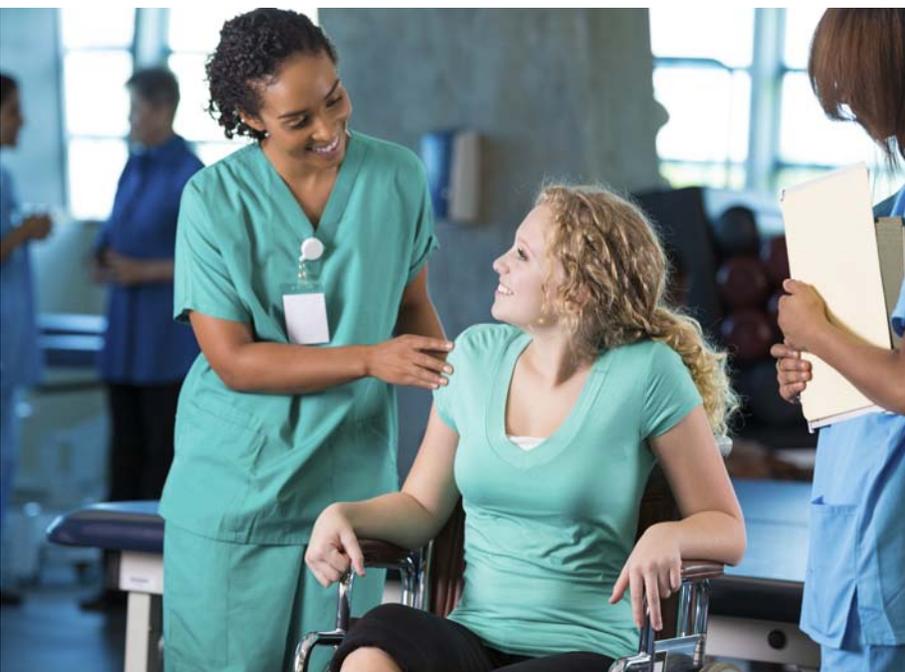
"Some patients had a very busy schedule of therapies or various

other reasons for not wanting to participate," explains Brisbois, "Others were very enthusiastic about the opportunity to take part. They saw it as a way of helping someone in the future."

Future steps

Led by two investigators, Dr. Cathy Craven and Professor Molly Verrier from the Neural Engineering and Therapeutics Team at Toronto Rehab, the pilot was successful in both improving patient experience and streamlining the recruitment process. "This has been a worthwhile initiative which has accelerated our research productivity and enabled Ontarians to participate in local, national and international studies," notes Dr. Craven. "The number of individuals opting to participate in a study, or consenting to discuss future research opportunities is striking."

Now that a model for centralized recruitment has been tested, it is hoped that a permanent process can be established with patients at rehab facilities such as Lyndhurst.

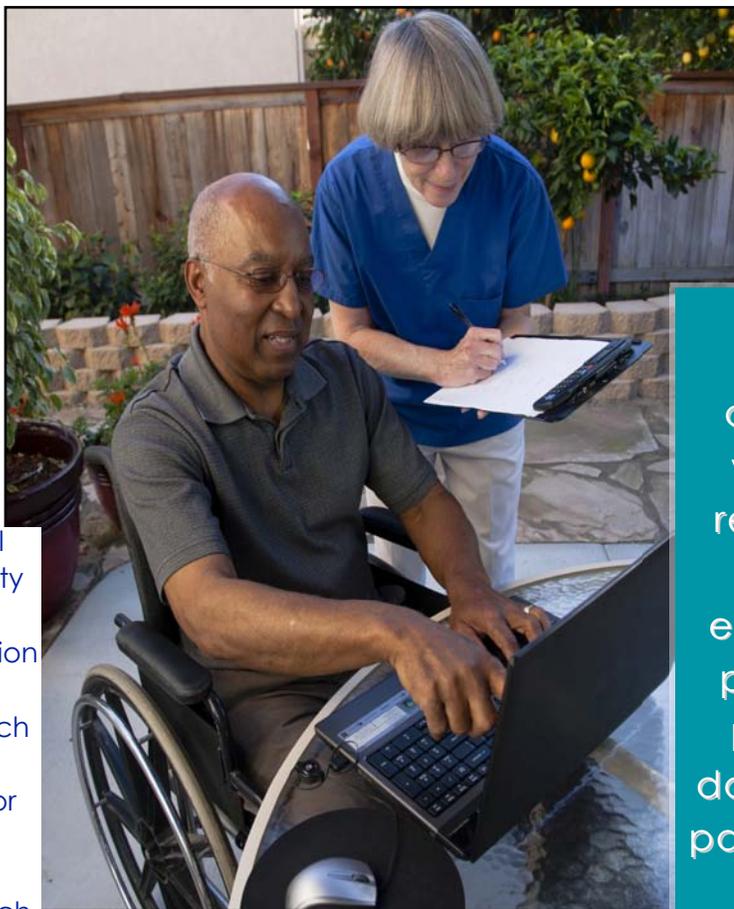


Being a Research Participant

Advancing SCI research with sensitivity and respect

The largest stand-alone spinal cord injury rehabilitation facility in Canada, University Health Network – Toronto Rehabilitation Institute (Lyndhurst Centre), admits about 260 persons each year. This creates both an opportunity and a problem for researchers and patients. A major rehab facility such as Lyndhurst provides the research community a means to further their important work because of the availability of individuals with spinal cord injury (SCI) who could be recruited for various research studies. It also means that the recruitment process – if not well coordinated – can burden patients recently admitted with a catastrophic injury.

Research scientists want to provide meaningful opportunities for individuals with SCI to voluntarily participate in research. However, the recruitment process can be long, complicated and costly, particularly in the specialized field of SCI. It is often difficult to find the right number of participants who fit the study requirements. In addition,



“It really is all about how can we reduce the research burden and make the experience more pleasant for the patient, and in doing so, increase participation in SCI research.”

the process used to recruit individuals must ensure that willing participants meet ethical and safety standards.

“In the past a person with an SCI could be approached by 7 or 8 researchers,” explains Louise Brisbois, coordinator for the past two years of a pilot project at Lyndhurst on Centralized Recruitment Strategies. “At any given time we have approximately 20 active research studies taking place here”.

Protecting patient experience

“The concept for the pilot was based on a simple idea,” says Brisbois, “It really is all about how can we reduce the research burden and make the experience

more pleasant for the patient, and in doing so, increase participation in SCI research.”

Brisbois' role was to be a liaison between the research community and SCI inpatients at Lyndhurst. For two years, 2011-2013, a pilot recruitment process was put in place with funding from ONF. Using patient consent and an electronic database, Brisbois tracked current projects and what criteria were required of participants. She then identified the most appropriate match between individuals and their study eligibility. Patients at Lyndhurst with SCI were then only approached once, and only by Brisbois, who acted as a

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