Navigating the INESSS-ONF Clinical Practice Guideline for the Rehabilitation of Adults with Moderate to Severe Traumatic Brain Injury in Canada

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Ontario Neurotrauma Foundation
Learning objectives

- Understand the development process for the INESSS-ONF Guideline for Rehabilitation after Moderate and Severe Traumatic Brain Injury
- Name some gaps in implementation of best practice in Ontario and have awareness of ongoing implementation activities
- Navigate the INESSS-ONF Guideline through clinical examples
Concussion / mTBI

Clinical Practice Guidelines

• Concussion / mTBI
• Moderate TBI
• Severe TBI

Standards of Care

Standards of Care

IMPROVE

• Quality of Care
• Patient Outcome
• Professional Capacity
• Efficient use of health dollars
• Access and coordination of services
An inter provincial partnership

INESSS-ONF Guideline Development Team:

- **Bonnie Swaine**, PhD, Center for interdisciplinary research in rehabilitation (CRIR) & Université de Montréal,
- **Corinne Kagan**, BA., BPS Cert. – ONF
- **Catherine Truchon**, Ph.D., MSc. Adm – INESS
- **Shawn Marshall**, MD, MSc (Epi), FRCPC, Ottawa Hospital Research Institute & University of Ottawa
- **Marie-Eve Lamontagne**, Ph.D. Université Laval, CIRRIS

Project coordinators

- **Ailene Kua**, M.Sc (ONT), **Anne-Sophie Allaire**, M.Sc (QC) & **Pascal Marier-Deschenes** (QC)

+++ Collaborators
Clinical Practice Guidelines

- Systematically developed statements that help clinicians and patients identify and deliver appropriate health care

Scientific evidence

Clinical expertise

Patients’ opinions and preferences

Systematic production process

Clinical practice guidelines
Guideline Development and Adaptation

1. Review and evaluation of existing CPGs
   May – Nov. 2013

2. Validation of the end-users’ needs and expectations

3. Synthesis of all existing documentation and evidence
   Mar. – Nov. 2014

4. Consensus process amongst experts
   Nov. 2014

5. Adaptation of the recommendations and production of the guidelines
   Nov. 2014 – May 2015

Final Product

INESSS-ONF Guideline

Implementation/Evaluation: INESSS-ONF Guideline
   May 2015 – May 2016
   Fall 2016

Presentations / Publications

GUIDELINE DEVELOPMENT PROCESS

Further input from panel experts

Refinement

Agreement

External Review

INESSS-ONF Guideline: Final Product
Validation of the end-users’ needs and expectations

Survey of end-users needs & expectations
– 53% were not aware of any CPGs for the rehabilitation of adults with moderate and severe TBI

Identification of relevant topics
– Comments and suggestions regarding new elements

Key implementation process elements
– Want training and think use of the CPG by the colleagues/team would facilitate implementation
Stakeholder consultation: Guideline topics

<table>
<thead>
<tr>
<th>Response</th>
<th>Chart</th>
<th>Percentage</th>
<th>Count</th>
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<tbody>
<tr>
<td>Access mechanisms</td>
<td></td>
<td>25%</td>
<td>78</td>
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<tr>
<td>Continuity-of-care mechanisms</td>
<td></td>
<td>59%</td>
<td>183</td>
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<tr>
<td>Coordination mechanisms</td>
<td></td>
<td>36%</td>
<td>111</td>
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<tr>
<td>Duration of interventions</td>
<td></td>
<td>66%</td>
<td>204</td>
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<tr>
<td>Length of stay</td>
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<td>36%</td>
<td>113</td>
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<tr>
<td>Intensity / frequency of interventions</td>
<td></td>
<td>79%</td>
<td>246</td>
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<tr>
<td>Rehabilitation models or reference frameworks</td>
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<td>74%</td>
<td>229</td>
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<tr>
<td>Program evaluation measures</td>
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<td>44%</td>
<td>137</td>
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<td><strong>Total Responses</strong></td>
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<td><strong>310</strong></td>
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<td>Response</td>
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<tr>
<td>Incidence and prevalence of TBI and its associated conditions</td>
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<td>General physical health</td>
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<td>TBI-related conditions (e.g.: heterotopic ossification)</td>
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<td>Epilepsy and other neurological disorders</td>
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<td>Endocrine disorders</td>
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<td>Vestibular and sensory impairments</td>
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<td>Diet and nutrition</td>
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<td>Motor impairments</td>
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<td>Cognitive function impairments</td>
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<td>Communication</td>
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<td>Behaviour disorders</td>
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<td>Orthotic devices and technical aids</td>
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<td>Positioning and mobility</td>
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<td>Pain management</td>
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<td>Fatigue and sleep disturbances</td>
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<td>Sexuality</td>
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<tr>
<td>Mental health (psychological and emotional conditions)</td>
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<td>Pharmacological treatments</td>
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<td>Substance abuse</td>
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<td>Alternative medicine (e.g.: acupuncture)</td>
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<td>TBI education</td>
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<td>Vegetative state and individuals with low potential for recovery</td>
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**Total Responses**: 303
Expert Panel Convened for CPG

Nov. 2014

PROJECT TEAM
• Anne-Sophie Allaire
• Mark Bayley
• David Caplan
• Mario De Bellefeuille
• Corinne Kagan
• Ailene Kua
• Shawn Marshall
• Bonnie Swaine
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• Stéphane Gagnier
• Shaun Gray
• Marie-Clothilde Grothé

MANAGERS
• Mitra Feyz
• Patsy McNamara
• Sylvie Valade
• John Zsofcsin *
• Debbie Furlotte *

DECISION-MAKERS and CONSUMER ASSOCIATION REPRESENTATIVES
• Gilles Bourgeois
• Jonathan Jean-Vézina
• Danie Lavoie
• Charissa Levy
• Jean-François Lupien
• Ruth Wilcock

* Advisory Committee Members
Revising Recommendations / Developing Novel Recommendations

- Level of evidence used by existing guidelines varies depending on the individual methodology.
- To achieve consistency among the recommendations, the level of evidence for each recommendation was assigned the INESSS-ONF grade.

<table>
<thead>
<tr>
<th>INESSS-ONF LEVEL OF EVIDENCE</th>
<th>Description</th>
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<tbody>
<tr>
<td>A</td>
<td>Recommendation supported by at least 1 meta-analysis, systematic review, or randomized controlled trial of appropriate size with relevant control group.</td>
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<tr>
<td>B</td>
<td>Recommendation supported by cohort studies that at minimum have a comparison group, well-designed single subject experimental designs, or small sample size randomized controlled trials.</td>
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<tr>
<td>C</td>
<td>Recommendation supported primarily by expert opinion based on their experience though uncontrolled case series without comparison groups that support the recommendations are also classified here.</td>
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266 RECOMMENDATIONS DIVIDED IN TWO SECTIONS

SECTION I
Components of the Optimal TBI Rehabilitation System
71 recommendations:
35 new & 36 existing

SECTION II
Assessment and Rehabilitation of Brain Injury Sequelae
195 recommendations:
91 new & 104 existing

Indicators & Outcome measures
SECTION 1: Components of the Optimal TBI Rehabilitation System

A. Key Components of TBI Rehabilitation
B. Management of Disorders of Consciousness
C. Subacute Rehabilitation
D. Promoting Reintegration and Participation
E. Caregivers and Families
F. Brain Injury Education and Awareness
G. Capacity and Consent

- target audience is health system leaders who are designing system
SECTION 2: Assessment and Rehabilitation of Brain Injury Sequelae

H. Comprehensive Assessment of the Person with TBI
I. Disorders of Consciousness
J. Cognitive Functions
K. Cognitive Communication
L. Dysphagia and Nutrition
M. Motor Function and Control
N. Sensory Impairment
O. Fatigue and Sleep Disorders
P. Pain and Headaches
Q. Psychosocial / Adaptation Issues
R. Neurobehaviour and Mental Health
S. Substance Use Disorders
T. Medical / Nursing Management

➢ specific strategies targeted at clinicians
Two types of key recommendations

➢ Fundamental Recommendations (N=11)
  ▪ elements that rehabilitation programs need to have in place in order to build the rest of the system properly
  ▪ primarily for program managers and their leaders as they reflect upon the service conditions for optimal rehabilitation provision.

➢ Priority Recommendations (N=104)
  ▪ clinical practices or processes deemed most important to implement and monitor during rehabilitation
  ▪ practices most likely to bring on positive outcomes for people with TBI.
Format of the Guideline

- Rationale
- System Implications
- Key Indicators
- Tools and Resources
- Summary Of Evidence
Development of Indicators

1. How will you know that people have followed CPG?
   • What are your Process Indicators? (Measurement of presence/absence/timing/quality of care process)

2. How will you know that the person with brain injury is better because of the implementation of CPG?
   • What are the Clinical Outcomes Measures? (Outcome measures typically measure impairments, activity level, roles in life or quality of life domains)
**Process Indicators (Examples)**

**Recommendation:** People with severe TBI who have not recovered independently in self care should be admitted to comprehensive inpatient rehabilitation as soon as they are medically stable and able to participate.

**Potential Indicators:**
- Proportion of people with severe TBI (i.e. GCS<9) referred to inpatient rehabilitation
- Average time from injury to onset of inpatient rehabilitation

**Recommendation:** All patients with TBI should be screened for depression during inpatient rehabilitation and at all transitions.

**Potential Indicators:**
- Proportion of TBI patients admitted to inpatient rehab with documented depression screening tool used
Outcome Measures

Measurement at Patient level of recovery

- Cognitive recovery as measured by the Wisconsin Card Sorting Test
- Physical recovery - 6 minute walk test
- Quality of Life measures
- Glasgow Outcome Scale
Pre-Implementation Survey

- Fundamental and priority recommendations too numerous to implement (N=109 in survey)

- Surveyed 44 programs (n= 26 in Quebec, n= 18 in Ontario) about
  - Level of implementation
  - Opinions about priorities
  - Opinion about feasibility of implementing recommendations (including potential obstacles)

- Goal: To identify a subset of recommendations not yet implemented in rehabilitation but of high priority and feasible to implement
Findings from the Pre-implementation Survey

• **Significant differences across sites were found:**
  - Motivation and capacity for engaging in implementation
  - Availability of resources, and regional priorities and funding

• **Common themes:**
  - Promote collaboration across Acute, Inpatient and Outpatient Rehabilitation and Community-based services
  - Improve **collaboration with mental health and addiction services**
  - Increase capacity to identify and manage **challenging behaviours**
  - Use **consistent discharge, transfer and follow-up protocols**

• **Develop a Community of Practice** to share best practices and tools, and establish a provincial **TBI Report Card**
Wanted to determine level of interest:

- Which recommendations do you wish to implement?
- What support would you like from ONF?
- Who (at your site, from other sites, LHIN) should be part of the implementation process?

- Willingness to be part of a shared network of providers?
- Support the creation of an TBI Report Card?
ONF facilitation role

- Assist with planning and enacting implementation projects
- Assist with developing capacity and resources (tools and strategies) for implementation
- Focus on sustainability (local, region, province)
- Hope for scalability across province
  - shared resources
  - community of practice
  - push for systematic improvements and policy change at the LHIN/province level
  - provincial strategy/report card
Who is working on implementation?

N= 12 locations

**Can be more than one facility** (acute, inpatient, outpatient, community) and more than one **sector** (MHA)
System Priorities

- Improve Coordination and Collaboration with mental health and addiction providers
- Improve Capacity to manage challenging behaviours
- Improve Discharge communication and follow up
- Maximizing access to full range of treatments
Local/Regional Priorities

- Compensation skills for memory impairments
- Cognitive communication assessment and treatment
- Sexuality
- Maximizing use of peers
Implementation Planning Tools

- Clear description of what implementing
- Identification of barriers, facilitators and what tools/resources needed
- Formation of Implementation and Support Teams
- Plan for evaluation and sustainability

- “Strategy over chance”
The way forward

- Catalyst funds: not fund and forget
- Accountability: how are we going to know that we have made a difference?
- Sustainability: let’s do it right so that it stays
- Collective competence: community of practice and prioritization through a “Report Card”
The website

CLINICAL PRACTICE GUIDELINE
FOR THE REHABILITATION OF ADULTS WITH MODERATE TO SEVERE TBI
Case 1

Ross is a 45 year old man who sustained a severe brain injury and had to have craniectomy and partial resection of the left temporal lobe due to severe elevated ICP.
Ross is just arrived on the floor from the ICU and is very agitated.

He is swinging at the nurses when they enter the room and yelling loudly.
With treatment with IM neuroleptics followed by oral neuroleptics Ross settles down but still very concerned.

- His blood work shows he has low sodium which is corrected.
- More alert and decreased need for sedative medications.
- Ross settles down but still has gradually developed increased yelling when the nurses walk in the room.
- Antecedent behaviour Consequence charting is completed and the yelling occurs only when a nurse walks in the room not others.
- Recognize the cause is pain.
- Reassurance reduces the frequency but it still happens.
Ross improves but the subacute rehab team feels they could improve the efficiency of the care they provide to people like him.

- What are some of the key practices?
- HINT  This is a system question
The director of the rehab services just came from managing the emergency and acute area and is asking why all the changes are needed in the service, he does not understand.
A new doctor comes on the service and asks why the patient needs more intense cognitive rehabilitation

“Where’s the evidence”
The director authorizes specialized behavioural training for the team and wonders how this is affecting team performance. What indicators should we use?
Lisa

- 30 year old woman married with no children
- Skiing accident sustaining a severe TBI - initial Glasgow Coma Scale = 8
- Coma for 48 hours and PTA for 7 days
- Has mild left hemiparesis
- Initially irritable/restless but improves and still little impulsive/lack of insight
- Admitted for rehab 3 weeks post injury
- in inpatient rehab, became independent in ADL and minimal supervision with community living skills
- receives outpt rehabilitation and improves with PT and OT
- husband notices some ongoing irritability and memory impairment
- very supportive employer is willing to take her back
- returns to work 8 months after injury as a lab technician
Lisa (two years later....)

- Gained 25 lbs- Lisa anxious about attending gym because she's aware of the appearance of the very mild hemiparesis
- Husband is reporting challenges in relationship including lack of awareness of impact on others, impulsivity and emotional lability
Lisa (two years later....

- Employer had expressed concerns about her memory, occasional outbursts and problem-solving skills
  - Laboratory faces cutbacks because of decreased government funding
  - Lisa laid off with other more junior workers
Lisa (two years later....)

- Lisa's mood is low because of lack of meaningful activities.
- Lisa would like to start a family however husband concerned that she may not be able to manage new baby.
Problems illustrated by Lisa's Case

- Irritability
- Memory
- Fatigability
- Cognitive communication
- Social cognition
- Vocational return
- Executive skills
Lisa's husband is provided with education about the signs of irritability and after working with the team to do an antecedent analysis recognizes that Lisa is irritable when she is tired, has slept poorly or if they spend longer than 1.5 hours in busy environment such as public places.
Early rehab - Problems with Fatigue

- Lisa is found to be hypothyroid and feels little better
- Lisa is taught about sleep hygiene
Optimization of learned activities into Community

- Lisa’s therapist take her to the gym and she gets into a routine that she follows
communication impairments resulting from underlying cognitive deficits due to neurological impairment
difficulties in communicative competence (listening, speaking, reading, writing, conversation, and social interaction) that result from underlying cognitive impairments (attention, memory, organization, information processing, problem solving and executive functions). (CASLPO)
Social cognition

Social cognition includes processes such as emotion recognition from facial affect and voice and Theory of Mind, the belief that others have thoughts separate from one’s own and that these thoughts influence others’ behaviors.

With cognitive communication training, Lisa is better able to recognize the social cues and when she loses track of conversation gets clarification from her boss or colleague.
Lisa’s Memory issues

- Commences use of her iPhone
- Let’s move into the 21st century!
- Taught some internal strategies for memory in her own environment
Lisa and her husband have learned to avoid the busy malls however find it somewhat limiting their lifestyle.
With education the employer recognizes Lisa's situations that are problematic and prompts her when she observes issues. Lisa receives training in certain metacognitive straining an executive problem-solving and adopts use of these on a daily that she uses regular basis.
- Avoids layoffs despite impairments
- Continues to require ongoing employment of techniques
- Now hoping to start a family.
Summary

- CPGs are important to evidence-based practice
- CPG has been adapted to improve TBI rehabilitation in Ontario and Québec
- Website provides a repository of recommendations, rationale tools, indicators, and evidence summaries
- Implementation of the CPG is starting in all the rehab centers
Questions

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judy@onf.org