Ontario Degenerative Cervical Myelopathy Virtual Summit 2020

Participant Report
December 14, 2020

For additional information on the Ontario **D**egenerative **C**ervical **M**yelopathy Summit, please contact:

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Ontario Degenerative Cervical Myelopathy (ODCM) Summit

The 2020 Ontario Degenerative Cervical Myelopathy (ODCM) Summit held a multi-stakeholder event to explore DCM in the Ontario context. The Summit brought experts, patients and a variety of stakeholder perspectives to participate in a discussion on topics such as:

- Increasing public, clinician and ministry of health awareness
- Deciding on a common nomenclature
- Improving access to timely diagnosis (imaging and referral)
- Improving communication between sectors (primary care – surgery - rehab-community)
- Improving access to acute care management
- Improving access to rehab
- Improving community living
- Management of secondary complications

Learnings from the Summit will support the development of an Ontario-based DCM strategy.

Appendix 01 contains a copy of the Meeting Agenda.

Appendix 02 outlines the suggested reading for the Summit

Participant Report

The Report captures information from the Summit as provided by the speakers and the participants. The purpose of the Report is two-fold.

- To provide all the participants access to the pre-reading and Summit Materials (e.g., PowerPoint Slides)
- To provide a resource to the operational teams that will use the Summit information to identify the next steps for planning and funding applications.

Event Supporters

Our thanks to our event supporters.

Ontario Neurotrauma Foundation

Ontario Neurotrauma Foundation
Fondation ontarienne de neurotraumatologie

Through research, knowledge mobilization and implementation initiatives we aim to prevent neurotrauma injuries and improve the lives of Ontarians with acquired brain injury and spinal cord injury

Mobility Clinic

Mobility Clinic
THE CENTRE FOR FAMILY MEDICINE

The goal of the Mobility Clinic is to help persons with mobility issues and their primary care providers with health care needs that may be difficult to manage, given existing physical and system barriers to care.

University of Toronto Spine Program

Surgery
UNIVERSITY OF TORONTO
Spine Program

The University of Toronto Spine Program is a unique collaborative program of clinical expertise, research, and education. The Program implements frameworks for innovation and excellence in the delivery of spine care and the translation of research.

The Krembil Research Insitute

Krembil
Relentless.

The Krembil Research Institute is the research arm of Toronto Western Hospital. Research within Krembil is directed at the development of diagnostics, treatments and management strategies in brain and spine disorders.

Participants

We want to thank everyone who took part in the event. **Appendix 03** is a list of the Summit Participants.

What is Degenerative Cervical Myelopathy

The following summarizes the key points about DCM (Badiwala, et al., 2020).

- Degenerative cervical myelopathy (DCM) refers to age-related osteoarthritic and congenital spinal column disorders that cause progressive narrowing of the spinal canal and compression of the cervical spinal cord, resulting in functional impairment. DCM is the most common cause of spinal cord impairment, and the resultant burden of disability on our society is expected to grow owing to the ageing global population.
- The pathophysiology of DCM involves static and dynamic factors that lead to chronic spinal cord compression and resultant ischemia, inflammation and apoptosis of neurons and oligodendrocytes.
- Diagnosis of DCM requires a careful history and physical examination to identify signs and symptoms of myelopathy and to rule out alternative diagnoses; clinical findings should be correlated with MRI findings.
- The natural history of DCM can include a period of stable neurological status in some patients; however, a substantial number of individuals experience progressive, stepwise decline in function.
- Current clinical practice guidelines recommend surgical decompression for patients with severe or moderate DCM and either surgery or a supervised trial of structured rehabilitation in patients with mild DCM.

Why is DCM Important to Address?

The following three points (Milligan, Ryan, Fehlings, & Bauman, 2019) highlight the importance of building a shared strategy to address DCM.

- The diagnosis of DCM is often missed or delayed
- The natural course of DCM presents as a stepwise decline, with symptoms ranging from muscle weakness to complete paralysis
- DCM is the most common cause of spinal cord dysfunction in adults.

Summit Results

Summit participants identified the following four priority areas of focus for DCM research from the top 10 DCM Priorities previously outlined by the AO Spine RECODE-DCM project (see appendix 2).

- Raising Awareness
- Diagnostic Criteria
- Assessment and Monitoring
- Rehabilitation

Table 1 lists the potential focus areas in year 1. The left-hand column outlines the topic, and the second column captures the desired result in one year.

Focus	Year 1 Focus
Raising Awareness	• Three presentations conducted in each of primary care, spine surgery, orthopedic surgery, and community
Diagnostic Criteria	• We will have identified gaps in our understanding of diagnostic tools and clinical signs • We will have a list of DCM red flags warranting further Assessment • For mild to moderate, what can we accomplish with just an x-ray?
Assessment and Monitoring	• Literature review • Initial clinical tool
Rehabilitation	• Ontario Consensus Guidelines for the Treatment and Management of DCM - divide into parts, only one part in Year 01

Appendix 04 – 07 contains additional information generated by the participants. The data will support ongoing planning and research activities in Ontario.

Next Steps

The information from the Summit will inform the development of the following.

- A formal public report to be shared with stakeholders interested in work on DCM
- Create a set of Working Groups to work on research towards identified priorities and/or help oversee or facilitate research projects towards DCM priorities.
- Establish a structure to support an ongoing dialogue about DCM in Ontario (Steering Committee, communication strategy)

Appendix 01 – Meeting Agenda

Ontario
Degenerative Cervical Myelopathy
Virtual Summit **2020**

Welcome to the Ontario Degenerative Cervical Myelopathy Virtual Summit 2020!

In this package, you will find the agenda for Day 1 as well as recommended reading materials. If you have any technical difficulties during the Summit, please contact lindsay.beuermann@family-medicine.ca

Day ONE Agenda – Monday, November 23rd, 11:00 am – 1:00 pm EST

Time	Topic	Presenter
11:00-11:10	Welcome and introduction to the day	Tara Jeji Jerry Mings
11:10-11:25	DCM background and overview of work done to date	Michael Fehlings
11:25-11:40	DCM and primary care	James Milligan
11:40-11:55	Lived experience perspective	Liang Zhang
11:55-12:10	Rehabilitation, prevention and non-operative perspective	Eldon Loh
12:10-12:15	Indigenous challenges	Melanie Jeffrey
12:15-12:25	Administrative data	Susan Jaglal
12:25-12:40	RECODE Project	Ben Davies
12:40-1:00	Facilitated discussion about future of DCM care in Ontario	Michael Fehlings James Milligan

Ontario
Degenerative Cervical Myelopathy
Virtual Summit 2020

Welcome to the Ontario Degenerative Cervical Myelopathy Virtual Summit 2020!

In this package, you will find the agenda for Day 2 as well as recommended reading materials. If you have any technical difficulties during the Summit, please contact lindsay.beuermann@family-medicine.ca

Day ONE Agenda – Monday, November 30rd, 11:00 am – 1:00 pm EST

Time	Topic	Presenter
11:00-11:10	Welcome and introduction to the day	Tara Jeji Jerry Mings
11:10-11:20	Review of the Ontario DCM opportunities	
11:22-11:45	Working Session – Identify the results we wish to achieve in Ontario at the end of one year.	All
11:45-11:55	Full Group Check	All
11:55-12:15	Working Session - Preparing for Group Presentation Share your result and the steps to achieve it in year 1	All
12:15-12:35	Presentations- Group Presentation	Groups
12:35-12:50	Next Steps for DCM	Michael Fehlings James Milligan
12:50-1:	Closing Remarks and Thanks	Tara Jeji

Appendix 02 – Recommended Reading

AO Spine Top 10 Research Priorities for DCM

Available at https://aospine.aofoundation.org/research/recode-dcm/research-priorities

1. **Raising awareness**
   What strategies can increase awareness and understanding of DMC amongst healthcare professionals and the public? Can these strategies help improve timely diagnosis and management of DCM?

2. **Natural history**
   What is the natural history of DCM? What is the relationship between DCM and asymptomatic spinal cord compression or canal stenosis? What factors influence the natural history of the disease?

3. **Diagnostic criteria**
   What are the diagnostic criteria of DCM? What is the role of imaging and when should imaging be used in the Assessment of DCM?

4. **Assessment and monitoring**
   What Assessment tools can be used to evaluate functional impairment, disability and quality of life in people with DCM? What instruments, tools or methods can be used or developed to monitor people with DCM for disease progression or improvement either before or after surgical treatment?

5. **Pathophysiology**
   What is the pathophysiology of DCM? What are the mechanisms of neurological injury and the molecular and anatomical consequences?

6. **Rehabilitation**
   What is the role of rehabilitation following surgery for DCM? Can structured postoperative rehabilitation improve outcome following surgery for DCM? What are the most effective strategies?

7. **Novel therapies**
   Can novel therapies, including stem-cell, gene, pharmacological and neuroprotective therapies, improve the health and wellbeing of people living with DCM and slow down disease progression?

8. **Socio-economic impact**
   What is the socio-economic impact of DCM? (The financial impact of living with DCM to the individual, their supporters, and society as a whole).

9. **Imaging techniques**
   What is the role of dynamic or novel imaging techniques and neurophysiology in the Assessment of DCM?

10. Individualizing surgery

Are there clinical and imaging factors that can help a surgeon select who should undergo surgical decompression in the setting of DCM? At what stage of the disease is surgery the preferred management strategy?

Presentation Slide Decks and additional information are online at the following URL.

Link: https://mobilityclinic.ca/ontario-degenerative-cervical-myelopathy-virtual-summit/

Appendix 03 – Summit Participants

Special thanks to the following Summit Participants

Day One

Name	Affiliation
Joy Lehmann	
Jay Varghese	Centre for Family Medicine Mobility Clinic
Mark Kotter	University of Cambridge, UK
Craig Bauman	Centre for Family Medicine Mobility Clinic
Melanie Jeffery	Centre for Indigenous Studies, University of Toronto
Julio Furlan	University Health Network
Liang Zhang	Person with Lived Experience
Jennifer Duley	Hamilton Health Sciences
Jefferson Wilson	University Health Network
Katrina DeZeeuw	The Ottawa Hospital
Ruchi Parikh	DCM Planning Committee
Patricia Nistor	DCM Planning Committee
Upender Mehan	Centre for Family Medicine Family Health Team
Joseph Lee	Centre for Family Medicine Mobility Clinic
Paul Miki	Person With Lived Experience
Eve Tsai	Ottawa Hospital Research Institute
Athina Hall	
Karen Smith	Queens University
Brian Chan	Toronto Rehabilitation Institute
James Milligan	Co-Chair DCM Planning Committee/Centre for Family Medicine Mobility Clinic
Anne-Marie Travers	
Harrison Mair	University of Toronto
Tim Worden	DCM Planning Committee
Swati Mehta	Lawson Health Research Institute
Micheal Fehlings	Co-Chair, DCM Planning Committee/University Health Network
Vidya Sreenivasan	The Ottawa Hospital
Christopher Witiw	University of Toronto
Lindsay Beuermann	DCM Planning Committee
Tara Jeji	Ontario Neurotrauma Foundation
Peter Anthanasopoulos	Spinal Cord Injury Ontario
Benjamin Davies	University of Cambridge, UK
Eldon Loh	Parkwood Hospital
Nadia Jaber	DCM Planning Committee

Day Two

Name	Affiliation
Julio Furlan	University Health Network
Eve Tsai	Ottawa Hospital Research Institute
Anne-Marie Travers	
Athina Hall	
Brian Chan	Toronto Rehabilitation Institute
Craig Bauman	Centre for Family Medicine Mobility Clinic
Eldon Loh	Parkwood Hospital
Joseph Lee	Centre for Family Medicine Mobility Clinic
Joy Lehmann	
Katrina DeZeeuw	The Ottawa Hospital
Liang Zhang	Peron With Lived Experience
Mark Kubert	ISAEC Low Back Pain Clinic - Grand River Hospital
Melanie Jeffrey	Centre for Indigenous Studies, University of Toronto
Nadia Jaber	DCM Planning Committee
Neil Duggal	London Health Sciences Centre
Patricia Nistor	DCM Planning Committee
Tara Jeji	Ontario Neurotrauma Foundation
Tim Worden	DCM Planning Committee
Vidya Sreenivasan	The Ottawa Hospital
Jerry Mings	DCM Planning Committee
Ruchi Parikh	DCM Planning Committee
Lindsay Beuermann	DCM Planning Committee
Michael Fehlings	Co-Chair, DCM Planning Committee/University Health Network
Jay Varghese	Centre for Family Medicine Mobility Clinic
Jefferson Wilson	St Micheals Hospital
Swati Mehta	Lawson Health Research Institute
Jennifer Duley	Hamilton Health Sciences
Karen Smith	Queen's University
James Milligan	Co-Chair DCM Planning Committee/Centre for Family Medicine Mobility Clinic

Appendix 04 - Raising Awareness

Brainstorming Space ***" What could we achieve in the next three to five years in Ontario for Raising awareness about DCM?"***		
Topic: Awareness		
• Consideration of target audience (clinicians + public- patients) • Level of awareness for primary care vs specialists • Neck pain vs DCM • What online resources available for raising awareness	• Joint efforts mobilized by the health professionals and the public • Identifying the issues and their impact • low-prevalence of DCM imposes the need for promoting it • * determine what target groups/individuals to be educated	1) Joint efforts mobilized by the health professionals and the public 2)Utilizing other related etiology's promotion jointly with DCM 3)Developing online resources on DCM for public and clinicians

Topic: Raising Awareness			
Year 01 Result	**Major Steps to Achieve Year 01 Results**	**Year 01 Outcome(s)**	**Year 02 – 05 Results**
1) Joint efforts mobilized by the health professionals and the public	• Conferences and small meetings and websites: • Use Ontario platforms like Ontario Annual Scientific Assembly • Integrate into huge world conferences like ISCOS • Myelopathy.org and other organizations	1) 3 presentations conducted in each of primary care, spine surgery, orthopaedic surgery, and community	2)Utilizing other related etiology's promotion jointly with DCM 3)Developing online resources on DCM for public and clinicians

Appendix 05 - Diagnostic Criteria

Brainstorming Space ***" What could get achieve in the next three to five years in Ontario about Diagnostic criteria?"***		
Topic: Awareness		
• Upright MRI used for neck conditions in the USA (2 in BC) • DMX (digital motion x-ray) • Rotational 3D scanner • CT myelography (for those ineligible for MRI). Can we order it? • We need to target GPs (awareness including diagnostic training for undergrads)	• For those without access to spinal centers (either issue with access or not comfortable). How can we help family clinics that will help diagnose without access to diagnostic tools? • Barriers to funding from the provincial and federal government • Barriers to getting to the centers, having somewhere to say, psychologically traumatic, knowing people	• Increase the focus on pain or red flags • Create a tool that identifies factors that can flag a patient and send them along a pathway to explore DCM • What can a GP do in a short period with high impact diagnostics? Least time consuming and most effective (x-ray)

Topic: Diagnostic Criteria			
Year 01 Result	**Major Steps to Achieve Year 01 Results**	**Year 01 Outcome(s)**	**Year 02 – 05 Results**
Scoping review of the diagnostic tools and identify holes in the data Imaging a second result?	Masters student (or undergraduate MDs) tasked with a scoping review of the literature A review of the review by GPs and neurosurgeons to offer their insights on mild, moderate and severe symptoms Mild and moderate DCM patients may never make it to a neurosurgeon. Inclusion of PTs, chiropractors (fluent in craniocervical disorders) and rehab practitioners. Anyone dealing with pain and a primary contact health care provider. Identify the lack of imaging infrastructure in Ontario	We will have identified gaps in our understanding of diagnostic tools and clinical signs We will have a list of DCM red flags warranting further Assessment For mild to moderate, what can we accomplish with just an x-ray?	Seek to fill those gaps (research) A cost-benefit analysis would be helpful in justifying the research. (Rehab, loss of income, etc.) Build in the infrastructure to remove barriers to imaging access

I am interested in working on Diagnostic Criteria

Athina Hall, Jay Varghese, Melanie Jeffrey (interesting to look at Southern vs Northern Ontario), Mark Rubert

Appendix 06 - Assessment and Monitoring

Brainstorming Space

" What could get achieve in the next three to five years in Ontario for Assessment and Monitoring for DCM?"

Topic: Assessment and Monitoring

Assessment

- Appropriate algorithm for a family doctor to use to screen for DCM – this is something that is really missing
- Who does the monitoring, and what's involved with that?
- What's the trigger for re-referral?
- Is this about providing tools for primary care? Or is this very general?
- Would like to see something that could be used on the front lines that can be administered rapidly – could prompt further investigation and referral
- Development of more sensitive outcome measures
- Look for alternatives to the MGOA
- Better identification of those who are appropriate for surgery

Monitoring

- How do you know when they're changing?
- What tests should you be doing?
- These critical gaps
- Who does the monitoring?
- Would the GP be comfortable doing the monitoring?
- Neurologist? Physiatrist? Surgeon?
- What constitutes appropriate follow up? What should we be looking at?
- Need an algorithm
- Objective test – grasp, 3D gait analysis
- Important to define a simple objective test that can be done quickly in the clinic
- Challenge for this population – different manifestations of DCM
- Better outcome measure
- Different phenotypes of DCM
- What are the criteria for surgery?

Topic: Assessment and Monitoring			
Year 01 Result	**Major Steps to Achieve Year 01 Results**	**Year 01 Outcome(s)**	**Year 02 – 05 Results**
Review Literature – Screening tool for GPs (symptoms and signs)	• Determine search terms • Synthesize data, what has already been done • What are the key elements that are needed for screening tools? • Could be a scientific or white paper • What do we know/what don't we know – knowledge gaps • Identification of other clinical tools that are out there (ex Down Questionnaire)	• Literature review • Initial clinical tool	• Refinement of tool • Potential to do Delphi for consensus building • Algorithm for GPs – good clinical practice for Assessment and monitoring • Convene expert panel for algorithm for GPs
Patient-Reported Outcome Measures	• How to monitor the patients	•	•

- Could be better education for residents on DCM

I am interested in working on Assessment and monitoring

Appendix 07 - Rehabilitation

Brainstorming Space ***"What could get achieve in the next three to five years in Ontario about Rehabilitation for DCM?"***		
Topic: Rehabilitation		
Currently: post-surgical physiotherapy – one of the challenges is the variability of symptoms. Treatment depends on residual symptoms.	Goals: • Specific protocol for different types of symptom clusters • An algorithm would be useful - even just generally • A protocol would be useful as hard to know the exact endpoint sin some cases – surgical versus other symptoms, whether OHIP covered or paid by the patient • Much overlap in general principals, under the umbrella of non-traumatic spinal cord injury, and quite a bit of overlap with traumatic spinal cord injury, though those with mild symptoms • Literature review even to guide these goals – tried in the context of DCM guidelines but not much, but did not mention paucity of literature and see how to apply the principles from traumatic spinal cord injury to DCM • Heterogeneous condition – need different algorithms – for example, the worst cases resemble traumatic injury that they are well served;	• Treatment of more mild cases seems to be more personalized as the more severe cases have principles closer to the traumatic population in terms of rehabilitation • Often challenging cases seem to be the mild cases for primary care as need to see what need to do with these cases as this is the population that struggles with accessing resources more than severe cases • Mild cases tend to be referred to practices that may have less experience with DCM than those with moderate to severe symptoms where more infrastructure is in place • Sending patients out for physiotherapy can at times be hit or miss, and with moderate cases, there is not always a clear path for rehabilitation – not that patients are rejected, rather the perception that physiatry is over-loaded – thus, a consensus on how these patients are referred would help – gathering demographics information would help to be able to properly advocate for what is needed

Topic: Rehabilitation			
Year 01 Result	**Major Steps to Achieve Year 01 Results**	**Year 01 Outcome(s)**	**Year 02 – 05 Results**
Want to focus on mild to moderate and identify the resources needed	• Clarify demographic to then expand on this – be able to put in place what these patients need - expand to include the pathways followed as the diversity of paths leading to rehabilitation, perhaps use current databases, but this is not exhaustive as these patients re only those referred to specialists • Patients with mild to moderate symptoms experience more difficulty getting rehabilitation referral, partially why we need more information • Often could be a more clinical consensus about the literature and have guidelines put together by a group of experts, and these become refined with time - the recommendations for mild and moderate cases both pre- and post- operatively, these guidelines should also address mental health concerns • Literature review identifying paucity of information already done, but a survey of expert opinion may be beneficial • Need to identify the best strategy for compiling these guidelines • Fee for service of the subsidized program would be better as a system is very overwhelmed – is have guidelines, easier to identify funding gaps and to be able to ask for private companies to fund this in their health care coverage - people with lived experience may be a way to start • Currently have some programs that can help guide future programs as well	• Ontario Consensus Guidelines for the Treatment and Management of DCM - divide into parts, only one part in Year 01	• Rest of guidelines if no finish by Year 01

I am interested in working on Rehabilitation

References

AO Spine. (2019, November). *The Top Ten Research Priorities for DCM*. Retrieved from AO Spine: https://aospine.aofoundation.org/research/recode-dcm/research-priorities

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