CPN

CHRONIC PAIN NETWORK

ANNUAL REPORT 2019/2020

Changing the way
pain is managed in Canada

MISSION

To innovate and improve the quality and delivery of pain prevention, assessment, management and research for all Canadians.

Officially launched in 2016, the Chronic Pain Network is a pan-Canadian collaboration of patients, researchers, healthcare professionals, educators, industry and government policy advisors to direct new research in chronic pain, train researchers and clinicians, and translate findings into knowledge and policy. The Network also provides direct funding to more than twenty research projects, covering population studies, behavioural studies, basic science and clinical trials.

Patients are engaged as partners to identify priorities to improve health outcomes, identify new treatments and deliver a more effective healthcare system to fellow Canadians. The ultimate goal of the Network is to reduce pain and improve function, participation and quality of life for those affected, while alleviating the economic burden of pain over one's lifespan.

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Dr. Norm Buckley
Scientific Director

A MESSAGE FROM THE SCIENTIFIC DIRECTOR

The 2019 documentary Pain Warriors tells the story of four individuals whose lives were disrupted by chronic pain. It takes a very real look at the impact of under-treated pain and the stigma faced by those living with it.

One of the greatest challenges for those impacted by pain is that the disease is invisible. Many afflicted have no choice but to make adjustments in their everyday lives in order to complete tasks that had previously been taken for granted, with very little sympathy or understanding from the rest of the population.

Since its inception, the Chronic Pain Network has sought to put pain on the radar - to give visibility and a voice to those who've been left behind and ignored. There is a growing recognition that those living with a disease are experts in their own right, with insights into priorities, treatments and policies, and who should be given equal opportunity to have a seat at the table. This is the embodiment of patient centered care and Patient Oriented Research.

In recent years, we've begun to see a shift in the way pain is perceived by the powers that be. Governments are beginning to take notice. In April 2019, the Federal Minister of Health announced the formation of the Canadian Pain Task Force, which included not only researchers from the Chronic Pain Network, but several of our patient perspective partners as well. On the International front, the World Health Organization, for the first time, included chronic pain in its 2019 International Classification of Chronic Diseases.

We are far from the end of our journey, but we now have a map to help guide us. We know where we are, and we've begun to put the resources in place to help get us to where we need to be. However, there are still large areas labelled "here be dragons."

QUICK FACTS

21 patient perspective partners, contributing 150 hours towards Network initiatives.

1,312 trainees reached through Network-funded training and capacity building activities.

More than 100 local site projects utilized Clinical Research Network sites, and 7 CRN multi-site projects.

121 pain-related publications from Network-affiliated researchers, clinicians and patient perspective partners.

47,700 impressions earned through our 2019 National Pain Awareness social media campaign on Twitter.

HIGHLIGHTS

Members of the Chronic Pain Network have been exceptionally busy in the last year. With four Network members providing invaluable insight to Health Canada regarding challenges and concerns facing those living with chronic pain as members of the Canadian Pain Task Force, and additional members providing support on its External Advisory Commitee, the Chronic Pain Network's coordinating centre has also provided valuable experience and the administrative support required to help launch the new Chronic Pain Centre of Excellence for Canadian Veterans.

The Centre of Excellence, announced by Veterans Affairs Minister Lawrence MacAulay in July 2019, seeks to improve well-being of Canadian Armed Forces Veterans, and their families, who are living with chronic pain by engaging a national network of interdisciplinary pain management centres using research and evidence-based strategies to improve care.

Within the Network, there continue to be exciting things taking place. The *Patient Engagement committee* was able to hold an in-person meeting in September 2019. They discussed the committee's achievements and the opportunities that have arisen as a result of Network activities, as well as aspirations for the future and further avenues for continued growth. A major accomplishment for the committee this year was the development of a manuscript on authorship and acknowledgment of patient partners in research.

Publications are just one of the methods utilized to further the Network's aim to guide future generations of pain researchers in Canada. The *Training & Mentoring committee* continues to grow this area by supporting five main educational opportunities: the Interfaculty Pain Curriculum, Pain in Child Health, the North American Pain School, the Pain Education Inter-Professional Resource and the Connaught Summer Institute. The Network also sponsors educational sessions for trainees in collaboration with the Canadian Pain Society. This year saw more than 1,300 trainees reached through Network-supported activities.

With the advent of COVID-19, the Network's *Indigenous Health Research Advisory committee* has deferred holding a knowledge sharing workshop aimed presenting an Indigenous perspective in health research. Focus would be an overview of Two-Eyed Seeing and a look at patient engagement practices with both the individual and communities. Speakers were to include Malcolm King, Alex McComber and Elder Margaret Lavallee. With the appearance of COVID-19, this workshop was put on hold. In the meantime, the committee will present a webinar about navigating knowledge about protocols and conducting Indigenous health research. The webinar is part of a joint initiative between the Network's Patient Engagement, Training & Mentoring and Knowledge Translation committees.

One of the main areas of focus for the Network's *Knowledge Translation committee* this year has been the creation of lay summaries for each project receiving Network funding. The committee has also supported the creation of lay summaries of articles found on the Knowledge Translation product CPNPainPLUS. To ensure that people with lived experience can continue to be integrated into pain research as true partners, it is critical that research is presented in accessible language for people of all ages and from all backgrounds.

With Network projects nearing completion, the *Patient Oriented Research committee* is beginning to wind down activities. Most projects have already undergone their final review, and the committee now seeks to take lessons learned over the course of the Network to create best practices to inform our plans for CPN 2.0.

The Network's *Adult Registry Working Group* has piloted the questionnaire that will be used as the main collection tool for the Canadian Adult Pain Patient Registry. Information from the patient questionnaire is integrated into a health condition report that can be given to clinicians prior to their appointment with a patient and at follow up visits. This will allow them to easily visualize the progression of pain-related conditions over time. The Pediatric Pain Patient Registry has completed its pilot of minimum dataset at SickKids, resulting in a final version of the paper questionnaire and patient summary form. The initial visit and the follow up visit questionnaire have been piloted and are now in the process of finishing the final protocol submission.

To date, seven multi-site projects have utilized the Network's *Clinical Research Network* (CRN). An additional 103 projects make use of local sites within the CRN. The CRN has also added one new site in Quebec, with two additional sites still in progress. Additional proposals for multi-site studies continue to be reviewed and new and innovative ways to foster collaboration discussed.

PILLARS OF SUSTAINABILITY

When members of the Chronic Pain Network's Steering committee met in the fall of 2019, their objectives were clear: consider the unique research infrastructure initiatives established during the first four years of the Network; review the pre-meeting consultations undertaken with Network stakeholders; reach consensus on the best value for pain research in Canada; and identify sustainability and matching partner opportunities. From this point. Attendees identified four main areas of particular interest and value for the next iteration of the Network: Biomarkers in Pain Research, the Canadian Pain Registry, the Clinical Research Network and Patient Engagement.

Mike Tomlinson, of Strachan-Tomlinson, facilitated the meeting, held September 25, 2019, in Toronto, Ontario.

Biomarkers in Pain Research

Chronic Pain Network researchers identified the fact that projects were underway that could lead to the identification important biomarkers to elucidate the chronic pain state. We saw cases where several projects that were collecting well-characterized clinical information measured biomarkers on a small scale, limited by local resources and availbility of assays. Large scale collaboration with existing biobanking facilities, which currently exist as several research centres in the country, would greatly extend the reach of biomarker research without the need to build new infrastructure. Our consensus meeting led us to believe that a biobank dedicated to chronic pain studies could be a means to streamline pain biomarker identification and improve their translational value.

Canadian Pain Registry

Historically, there has been no standardized way of measuring pain. The Chronic Pain Network created a Registry Working Group in order to put into place a national network of registries of chronic pain patients, as well as implement a common minimal dataset of quality indicators and outcome measures, in clinical settings across the healthcare continuum, that would serve clinical, administrative and research purposes. The Chronic Pain Network is in the process of finalizing both adult and pediatric minimal datasets and completing protocols. Having minimal datasets can help systematize observation of the evolution of pain attributed to a condition and decisions about treatment can be informed by patient and caregiver awareness of a long-term outcomes. Data collected from consenting patients would also be used to guide future research.

Clinical Research Network

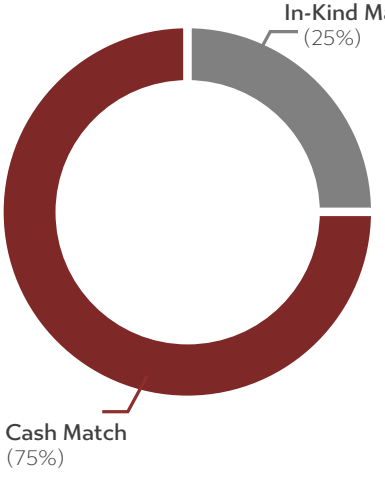
The vision of the Clinical Research Network is to bring together our busy multidisciplinary pain clinics from across the country and create a "research ready" network to support clinical trials, registry work and cohort studies, allowing for real-world pain research run directly through the Chronic Pain Network. The shared infrastructure of the Clinical Research Network also helps to facilitate cost-effective multicentre studies. In the last four years, the Clinical Research Network has grown, adding new sites in Quebec. Going forward, the Clinical Research Network has received expressions of interest from additional clinics to add new sites and find ways to better integrate patient engagement throughout projects utilizing sites, as well as create synergies between biomarker research and the Canadian Pain Registry.

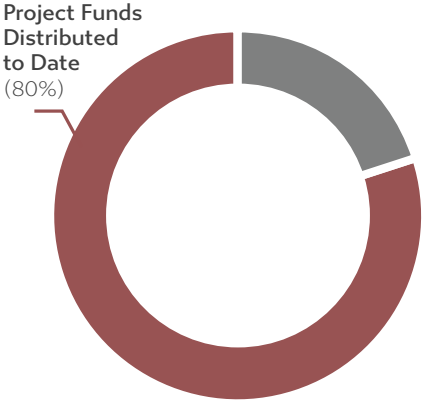
Patient Engagement

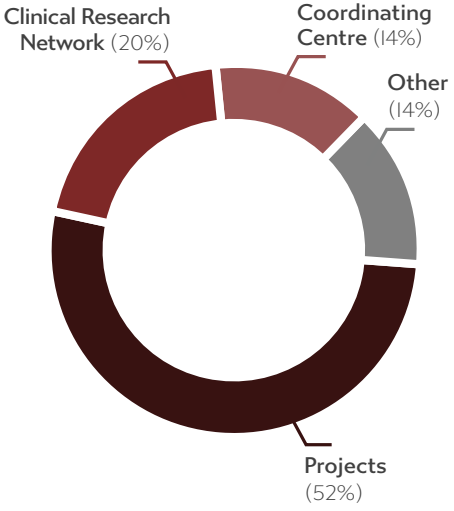
Patient Engagement is the foundation upon which the Chronic Pain Network is built. It has been incorporated into all facets of Network operations, including its governance structure, projects and training initiatives. Lived experience is recognized as an expertise in its own right, and, while the Network has made tremendous headway in this area in terms of representation, education and advocacy, it is clear that we are still only laying the groundwork for the changes yet to take place. The voices of people with lived experience need to be given greater influence on research, policy and health system redesign. With the formation of the Canadian Pain Task Force, and inclusion of individuals with lived experience on the Task Force itself, as well as in advisory capacities, we are in the infancy of a shift in how the scientific community and policy makers view and include those with lived experience. Patient engagement requires infrastructure to support recruitment and training of those living with pain in order to remain viable. Patients are still learning and evolving their understanding of research and how to contribute, just as researchers are learning how to better engage them. The Chronic Pain Network already has many resources in place to better facilitate this, but there are still core areas to expand and opportunities yet to be explored.

In subsequent Sustainability Planning meetings, the Network identified Indigenous Health Research activities as an additional area of focus to pursue. We are working to define what this will look like and how it will support the work of CPN 2.0.

NETWORK FINANCIALS







MATCH TO DATE

One of the requirements for the successful application of the Strategy for Patient Oriented Research (SPOR) Grant, such as the Chronic Pain Network, was securing a minimum of 1:1 match funding from non-federal government partners. Through both cash and in-kind matches, the CPN was able to identify more than $20 million over five years in designated funds from partnering institutions. The CPN has now received nearly 84% of pledged funds, with more than $5 million of the pledged cash and in-kind match received in Year Four.

PROJECT FUNDING

The majority of the Chronic Pain Network's budget each year directly supports research in Chronic Pain. This year, $1.5 million was awarded in Network funding was distributed to research projects across Canada.

To date, more than $5 million has been disbursed for research. Remaining Network funds will be distributed in the final year of the Network.

EXPENSES

Year Four of the Chronic Pain Network saw more than 70% of its budget spent directly on pain research through the funding of Network-affiliated research projects and the Clinical Research Network. Committee activities, such as in-person meetings (pre-COVID-19) and Patient Perspective Partner payments, made up 14% of expenses, with the Network's coordinating centre accounting for another 14% of spending.

“I truly believe that there is so much potential for patients to move the dial on research and become active contributors and perhaps, one day, even take the lead on research.”

- Jennifer Daly-Cyr
Patient Perspective Partner

“In the last five years, I’ve seen the quality of Patient Engagment go up, as well as the prevalence and the importance of it. It’s an increase that I hadn’t seen in the previous 20 years, and it’s because of the Chronic Pain Network and its champions.”

- Linda Wilhelm
Patient Perspective Partner

“The work that I’ve done at the CPN has led me to work with other projects, outside of the CPN. The project I’m involved with now is working to standardize pain education across Canada, and that is going to improve the treatment that Canadians are getting.”

- Lesley Singer
Patient Perspective Partner

Project Highlights

Research informed, mandatory course for all 1st year medical, nursing and dentistry students at Dalhousie University and development of this course into an online training program available for any organization/institute.

Continued development of the Kids Hurt App, including the addition of a bi-lingual Mi'kmaw language option and pilot testing with youth in one of the other SPOR project Indigenous sites (ACCESS Open Minds).

Project Involved:
14 Indigenous Elders
23 Indigenous youth
7 Indigenous trainees

ABORIGINAL CHILDREN'S HURT & HEALING INITIATIVE NATIONAL

Leader(s): Margot Latimer and John R. Sylliboy

Institution(s): IWK Health Centre, Centre for Pediatric Pain Research, Eskasoni Health Centre, Dalhousie University

Why was the study done?

A child's expression of their pain experience is complex and related to historical, social and cultural factors. Our research shows that the way Indigenous children/youth express their pain may not be consistent with the way health providers are trained to assess it. This can lead to under-treated pain that has a range of negative effects including impaired development, medical fears, anxiety, chronic pain, poor school outcomes and lack of trust in the healthcare system. Because of this long and short-term impact, it is critical that we work towards an improved understanding of the pain care experience for Indigenous children as well as an overall commitment to improving the health and wellbeing of Indigenous people of Canada.

How was the study done?

Since 2017 we have been reaching out to Indigenous communities/health centres across Wabanaki (Canada/parts of US) to expand our previous research. To date we have partnered with project leads from Hamilton, ON, Halifax, NS and Winnipeg, MB. Data collection/analysis is complete in ON and on-going at our other sites. Methods include gathering stories and art and reviewing pain-related health data. Through study involvement youth experience culturally teachings including Elder smudge teachings and Mi'kmaw artist teachings. Our hope is to collect and share knowledge in a respectful and mutually benefiting way for all involved. Knowledge gained highlights how Indigenous history needs to be considered centrally by care and service providers.

What were the study results?

Results from one site have been gathered, others are ongoing. Using the Medicine Wheel to guide analysis we found pain and management of it to be based in balancing mental, emotional, spiritual and physical health. Artwork and stories identified emotional, mental and spiritual pain while health data showed youth received mainly physical pain diagnoses (90%) and minimal mental health diagnoses (21%); a mismatch in what youth shared and what they seek care for. Conversation themes found predictors/indicators of imbalance and ways to re-establish this balance. Development and testing of the Kids Hurt App has also taken place as well as development of online training on Indigenous history, cultural teachings and culturally safe health strategies.

The ACHH 'Kids Hurt' app is also currently being updated to improve functionality, include 3D imagery and Mi'kmaw language option.

BIOBANK OF BIOLOGICAL SAMPLES FROM CHRONIC PAIN PATIENTS FROM CANADIAN REGISTRIES AND SCREENING FOR MOLECULAR MARKERS

Leader(s): Luda Diatchenko

Institution(s): McGill University

Why was the study done?

The main purposes of this study are to better understand the reasons why some patients that suffer with pain get better (achieve pain relief) with certain treatments while others do not; why pain becomes a long-term problem for some people; and how to prevent it from becoming a long-term problem. These discoveries could help us develop precision medicine, that is, a targeted medicine for specific subpopulations of patients.

Moreover the creation of the QLBP BIOBANK will enable future research on pain: the data collected from questionnaires as well as DNA, RNA, and/or protein stored in the QLBP BIOBANK once de-identified will be shared with other researchers that obtain approval by both the QLBP Steering Committee and the appropriate Ethics Review Board.

How was the study done?

Saliva samples collected from subjects enrolled in the Quebec Pain Registry. We sent these patients a study package, by mail, containing a saliva collection kit, along with a short questionnaire on their current pain status and the Informed Consent Form. DNA from 1,000 samples was extracted in-house with our own resources. Quality control and integrity analysis have been performed. We are now contacting participants with chronic low back pain enrolled in the Quebec Low Back Pain Core Study.

The prospective arm includes DNA, RNA and plasma samples purified from the blood and saliva of subjects enrolled from the Quebec Low Back Pain Core Study. We are focusing on acute low back pain participants (pain for less than three months), chronic low back pain participants (pain for more than three months) and healthy controls (no chronic pain conditions); participants must attend a visit during which a certified research nurse draws blood, collects saliva and assists them while they complete some questionnaires online. Participants with acute low back pain are asked to attend a second visit after three months.

The targeted enrolment is 400 subjects: 200 chronic low back pain participants, 100 acute low back pain participants and 100 healthy controls.

What were the study results?

The study is still ongoing and the aim was to complete the recruitment phase by June 2021. Delays have occurred due to COVID-19.

Project Highlights

Retrospective arm:
5,823 study packages containing questionnaires and saliva collection kit sent.
1,000 participants recruited
DNA from 1,000 saliva samples extracted

Prospective arm:
Monthly meeting with the Consortium including patient partners.

Patients enrolled:
93 chronic low back pain patients
13 acute low back pain patients
(of which 10 came for the 3 months follow up visit, 1 dropped out, 2 did not reach the three months yet)
17 healthy control participants

People working on the project (both arms):
1 Clinical Research Coordinator
1 Research Assistant
1 Research Nurse
2 undergrad students
1 exchange student

Project Highlights

Screeining of potential participants and trial enrolment began in 2017.

Once the final participant completes the trial, the database will be locked and analyses of data will begin.

Upon finalization of trial analysis and reporting, findings will be submitted for publication and knowledge translation activities will commence.

CADENCE: COMBINATION ANALGESIC DEVELOPMENT FOR ENHANCED CLINICAL EFFICACY

Leader(s): Ian Gilron, Luda Diatchenko, Nader Ghasemlou, Elizabeth Vandenkerkhof and Scott Duggan

Institution(s): Queen's University, McGill University, University of Manitoba

Why was the study done?

Chronic pain, including neuropathic pain (NP), affects one in three Canadians and costs more than $650 billion each year in North America. Current therapies have limited efficacy and dose-limiting adverse effects. Rational combination therapy with different drugs to treat fibromyalgia has shown potential for measurable improvements in pain relief, quality of life and healthcare utilization. Today, more than 50% of fibromyalgia patients concurrently receive two or more analgesics, but combination use is based on little evidence. Research is urgently needed to identify safer, more effective combinations. Our previous chronic pain trials showed superiority of combinations of sedating agents. However, additive benefit was limited because these agents have similar adverse effects, and doses must be reduced during combination therapy to ensure safety and tolerability.

How was the study done?

This study is a double-blind, double-dummy, randomized, controlled, 3 period crossover clinical trial comparing a combination of the anticonvulsant, pregabalin (PGB), with the non-sedating antioxidant, alpha-lipoic acid (ALA) to each monotherapy in chronic pain. Project outputs will advance knowledge about rational combination.
Following the finalization of trial registration, funding, ethics approval, administration and participant screening, the first trial participant was enrolled and began treatment.

What were the study results?

This study is ongoing, however, we hypothesize superiority of analgesic combinations that contain at least one non-sedating agent because of additive pain relief but non-additive AEs. Pregabalin (PGB), a sedating anticonvulsant, is proven effective for fibromyalgia and the antioxidant, alpha-lipoic acid (ALA) – currently the only non-sedating systemic agent proven effective for chronic neuropathic pain – also shows promise for the treatment of fibromyalgia.

CANADIAN SURVEILLANCE STUDY OF COMPLEX REGIONAL PAIN SYNDROME IN CHILDREN AND YOUTH

Leader(s): Krista Baerg, Susan Tupper and Allen Finley

Institution(s): University of Saskatchewan/Saskatchewan Health Authority and Dalhousie University

Why was the study done?

Complex regional pain syndrome (CRPS) is a devastating chronic pain condition that is underrecognized in children and youth. Few interventions for CRPS have been formally evaluated in the pediatric population and variability in the diagnosis and management of CRPS exists. Improved knowledge of the incidence and presentation of CRPS in Canada can help promote early detection and diagnosis.

How was the study done?

This study used the established methodology of the Canadian Paediatric Surveillance Program (CPSP). During the 2-year surveillance period, participating pediatricians and Canadian pediatric pain clinics reported any patient presenting between the ages of 2 and 18 years (up to the 18th birthday) with a new diagnosis of CRPS and completed a detailed case questionnaire. The complete protocol can be accessed at www.cpsp.cps.ca/surveillance

What were the study results?

A manuscript of findings is currently under preparation. Preliminary findings are presented in the *2019 CPSP Results*. For more information, visit: https://www.cpsp.cps.ca/uploads/publications/CPSPResults2019.pdf

Project Highlights

11 Canadian pediatric pain clinics collaborated during the 2-year surveillance period, completed in August 2019

The study tracks data from approximately 2800 Canadian pediatricians and pediatric subspecialists on CRPS incidence, clinical presentations, and times to diagnosis

Results will be used to promote early recognition and treatment to benefit patient recovery.

Project Highlights

77 participants recruited to an online mindfulness-based intervention for people living with chronic neuropathic pain.

Completed 18 interviews with people who live with chronic neuropathic pain and completed an 8-week online mindfulness-based pain management intervention, including techniques and skills learned and applied; barriers to practice; and research experiences.

4 papers published in 1 year.

CHRONIC PAIN IN THE EMERGENCY DEPARTMENT: UNDERSTANDING CONTRIBUTING FACTORS TO IMPROVE HEALTH CARE OUTCOMES, HEALTH CARE UTILIZATION AND PRESCRIPTION OPIOID ABUSE

Leader(s): Patricia Poulin and Catherine Smyth

Institution(s): The Ottawa Hospital Research Institute, St. Joseph's Care Group and Northern Ontario School of Medicine

Why was the study done?

A study at The Ottawa Hospital found that 10.4% of all Emergency Department visits were related to chronic pain, and of those visits, 36.5% were patients suffering from chronic pain. The purpose of this study is to determine the proportion of patients with chronic pain who are frequent users of the Emergency Department, who have had access to self-management, inter-disciplinary interventions or to a pain specialist; ascertain stakeholders' expectations of how chronic pain should be managed in the Emergency Department; and explore the different reasons for presentation, care provided, care expectations and access to self-management, interdisciplinary program or pain specialists.

How was the study done?

The initial phase of the project was completed through a series of chart reviews and administration of a comprehenvise patient questionaire to a sample from academic pain clinics across Canada. Interviews were also conducted with patients and primary care providers.

What were the study results?

Our team reviewed 988 consecutive patient admissions and found evidence of chronic pain documented in 13% of admissions and evidence of substance use problems documented in 12% of admissions. One in five patients with chronic pain in the Emergency Department also had documentation of problematic substance use. Those with chronic pain or substance use problem had substantially longer admissions than those without. There was very little evidence of any attention being given to substance use or chronic pain during these admissions. Our team continues to evaluate the effects of mindfulness-based interventions for people living with chronic neuropathic pain. We are about to complete data collection for a 3-year randomized controlled trial involving 77 participants with chronic neuropathic pain who have completed an online mindfulness-based intervention aimed at improving pain, quality of life, and mental health. The results of this study will allow us to determine if an 8-week mindfulness-based pain management course in addition to medical treatment optimization will have an improved pain and mental health measures as compared to a wait-list control group.

CIRCADIAN CONTROL OF CHRONIC PAIN

Leader(s): Nader Ghasemlou and Ian Gilron

Institution(s): Queen's University

Why was the study done?

Low back pain is the leading cause of disability worldwide and affects 80% of individuals throughout their lifetimes. In most cases, the pain is acute and individuals recover within weeks. However, a considerable number of individuals develop chronic low back pain where pain persists for more than three months, with inflammation playing a critical role in this response. Previous work suggests that pain fluctuates over the course of the day, where neuropathic pain is most intense at night while inflammatory pain reaches a peak in the morning. Understanding fluctuations in pain intensity is central to a thoughtful clinical pain assessment as these fluctuations may provide clues to the underlying causes and how to better manage pain. There are currently few studies examining how daily changes in the inflammatory response may influence patterns of chronic low back pain. Thus, the goals of our study are to: (1) describe the daily fluctuations in pain in people with chronic low back pain; and (2) identify biomarkers (in the blood) that could explain these fluctuations.

How was the study done?

We are recruiting adults 18 years of age or older who are living with chronic low back pain for at least 3 months, and who have internet access. Individuals are first asked to complete a baseline assessment of their pain before blood is collected in the morning and evening. Following blood sample collection, electronic diaries are completed every morning, afternoon, and evening for one week. These electronic diaries ask participants to rate their pain, mood, and fatigue on a scale of 0-10 to examine the daily fluctuation of each symptom.

What were the study results?

While our study is still ongoing, we have recruited more than 70 patients between the ages of 21-81, with roughly equal numbers of both men and women. Upon completion of our study, we hope to increase our understanding of daily fluctuations in chronic low back pain intensity by exploring how inflammatory factors can influence these pain fluctuations at the molecular level in the blood (biomarkers of pain). These findings may help influence future research and identify new therapeutic strategies to decrease or eliminate fluctuations in pain. As a result, patients may be able to function better throughout their daily activities.

Project Highlights

Ms. Lesley Singer, a patient-partner with chronic pain, worked in partnership throughout the development and implementation of this project. Together, we have streamlined data collection methods, identified roadblocks reducing participation, and improved our study design.

65 patients recruited with e-diaries completed and blood samples collected at two times of day

14 trainees working on circadian control of chronic pain, in both animal and human studies.

Project Highlights

We included 5 patient partners in our research team.

The research team, comprised of more than 30 individuals, including patients, researchers, web app developers and clinicians from more than 7 professions, has been developing and testing the JIA Option Map.

The JIA Option Map includes about 40 different ways to manage pain in juvenile arthritis, including treatments in the following categories: (1) splints, orthotics and other devices; (2) physical activities; (3) physical treatments; (4) educational approaches; (5) psychological and spiritual approaches; (6) pain medications; and (7) nutrition.

DEVELOPMENT OF A WEB APPLICATION TO HELP TEENS WITH JUVENILE ARTHRITIS AND THEIR CAREGIVERS MAKE INFORMED AND PERSONALIZED DECISIONS ABOUT PAIN MANAGEMENT OPTIONS

Leader(s): Karine Toupin-April

Institution(s): Children's Hospital of Eastern Ontario Research Institute, University of Ottawa

Why was the study done?

Juvenile Idiopathic Arthritis (JIA) is one of the most common causes of chronic musculoskeletal pain among young people, and can negatively impact all aspects of quality of life. Young people living with JIA can try many approaches to manage their pain, including medications and physical or psychological treatments. Choosing among these treatments can be difficult for families. Research also suggests that health care providers do not always provide young people with JIA and their families with the information they need on a wide range of treatment options relating to pain, nor discuss families' treatment preferences in depth.

How was the study done?

Our team developed the JIA Option Map, a web application that provides information on a wide range of treatments to manage JIA pain based on young people's and parents' preferences. We are now testing the JIA Option Map together with an online discussion with a health care provider, among 20 teenagers and young adults with JIA (aged 13 to 30 years), and 20 parents. We are evaluating whether this approach is acceptable, easy to use and useful over a three-month period.

What were the study results?

As a result of this research program, teenagers and young adults with arthritis, as well as parents will have access to reliable evidence-based information on a variety of treatments to manage pain, and support to make personalized decisions throughout the course of the disease. It may help young people become more engaged in their care, follow the chosen treatments, better manage their disease, and lead to better health outcomes. In the future, we will run a larger study to determine the impact of the tool on decision-making and health outcomes.

THE EFFECTS OF RHYTHMIC SENSORY STIMULATION ON EHLERS-DANLOS SYNDROME: A PILOT STUDY

Leader(s): Lee Bartel

Institution(s): Wasser Pain Management Centre, Mount Sinai Hospital, University of Toronto, Faculty of Music, Fred A Litwin and Family Centre in Genetic Medicine

Why was the study done?

Hypermobile Ehlers-Danlos Syndrome (hEDS) is a connective tissue disorder characterized by abnormally flexible joints, and is often accompanied by chronic pain. We planned to see if music and sound based low frequency vibrations can help reduce pain among hEDS patients.

How was the study done?

We conducted a study of 15 participants with hEDS and gave them sound vibration therapy. Participants took home a vibroacoustic device that plays music and produces vibration. They used this device 30 minutes a day 5 days per week over 4 weeks.

What were the study results?

Out of 14 patients that completed the study, 11 improved. We saw improvements in pain and improved mood. Many patients also noted that this had positive effects on their sleep and bowel movements. These results indicate promising preliminary results for sound based vibration therapy, a tool for managing pain related symptoms.

Project Highlights

After an unusual amount of delay our Mechanisms of Fibromyalgia project cleared REB but is still paused due to COVID-19 but we are gearing up to start in January 2021 if possible.

3 papers were presented to the International Association for Music & Medicine conference. This conference was held remotely as a video conference. Also, a paper was published: Vuong V, Mosabbir A, et al. The Effects of Rhythmic Sensory Stimulation on Hypermobile Ehlers-Danlos Syndrome: A Pilot Study. Pain Research and Management, 2020.

Project included contributions from patient perspective partner Kathleen Eubanks, who provided valuable input.

Project Highlights

4 trainees involved in the CRN funded studies

2 network-funded epidemiological investigations of psychiatric comorbidity and chronic pain were published in the high impact Canadian Journal of Psychiatry in 2019

Several papers resulting from this research have now been published, as well as posters presented at scientific conferences.

EPIDEMIOLOGICAL INVESTIGATIONS OF CHRONIC PAIN CONDITIONS AND PSYCHIATRIC DISORDERS

Leader(s): Renée El-Gabalawy

Institution(s): University of Manitoba

Why was the study done?

We conducted studies using population-based data to better understand the relationship between mental disorders and chronic pain conditions in terms of co-occurrence and how co-occurrence impacts people's health. Research has historically focused largely on depression and chronic pain conditions, and we aimed to extend this research with a specific focus on anxiety disorders, particularly generalized anxiety disorder, and post-traumatic stress disorder. We examined the impact of co-occurrence on suicide, substance misuse, and chronic pain severity/disability. By understanding the complex relationship between mental and physical health, we are in a better position to create targeted interventions.

How was the study done?

We used large population-based datasets that included tens of thousands Canadians and Americans. Using large epidemiological samples, we are able to examine trends in samples that are considered nationally representative (data that is representative of the population of interest). These surveys were previously collected, and we analyzed the data using sophisticated statistical approaches.

What were the study results?

We have published a large number of studies within this larger project. A few key findings are summarized here. Across studies, results indicated that anxiety disorders and post-traumatic stress disorder co-occur with chronic pain conditions at elevated rates. The co-occurrence of generalized anxiety disorder and chronic pain conditions can increase levels of disability, suicidal thoughts and behavior, and non-medical opioid use compared to the presence of conditions alone. Individuals with migraines and co-occurring generalized anxiety disorder may be at higher risk of maladaptive health outcomes. Social support and positive mental health may be protective for some of these outcomes.

iCANCOPE: RANDOMIZED CONTROLLED TRIAL OF A SMARTPHONE AND WEB-BASED APPLICATION TO MANAGE PAIN IN ADOLESCENTS AND YOUNG ADULTS (AYA) WITH CHRONIC PAIN

Leader(s): Jennifer Stinson and Chitra Lalloo

Institution(s): The Hospital for Sick Children (site lead), Centre for Global eHealth Innovation (University Health Network), IWK Health Centre, Stollery Children's Hospital, Alberta Children's Hospital, University of Saskatchewan, Nova Scotia Health Authority, University of Alberta, Women's College Hospital, Hamilton Health Sciences and Ottawa Health Research Institute

Why was the study done?

Chronic pain is common in young people aged 15-25 years. This pain can negatively impact all aspects of life. However, the developmental periods of adolescence and emerging adulthood also represent a critical window of opportunity to develop positive self-management behaviours and prevent future pain-related disability.

How was the study done?

iCanCope is a smartphone and web-based program designed to support young people with chronic pain. iCanCope was developed with extensive input from young people and healthcare providers. First, interviews and focus groups were completed to better understand the needs of this group. Second, a series of iCanCope design sessions were completed with patient partners to develop the final program. iCanCope features include: (i) symptom tracking and trends, (ii) goal-setting, (iii) coping skills toolbox, (iv) social community forum, and (v) chronic pain education.

What were the study results?

iCanCope is currently being rigorously evaluated through a randomized controlled trial supported by the CPN SPOR. This study will determine how the iCanCope program impacts the lives and self-management behaviours of young people aged 15-25 with chronic pain. Study recruitment is ongoing at 10 specialized chronic pain clinics across Canada. To date, 229 participants out of our target enrolment of 302 participants have been enrolled in our study. Preliminary analysis demonstrates that iCanCope can be deployed to participants with high fidelity (92% success) and this group demonstrates moderate-to-high program adherence over the 55-day study period. Post-study interviews are being conducted with a subset of participants to investigate program impact and satisfaction. Following completion of the trial, iCanCope will be made freely available to the public. iCanCope will increase the accessibility of pain self-management care for young people with chronic pain across Canada.

Project Highlights

229 adolescents and young adults enrolled in the iCanCope with Chronic Pain study. Over 6,200 daily pain check-ins have been completed by participants.

The iCanCope with Pain program is being adapted and tested in five countries, including Canada, the United States of America, Ireland, Australia and Norway.

To date, there have been 9 peer-reviewed publications involving the iCanCope with Pain project.

Project Highlights

Generated sensory neurons from iPS cells and characterized their phenotype.

In the process of generating patient-derived iPS cells and comparing excitability changes to control cells

Recent publication (Hildebrandt et al. 2019) describes the use of induced pluripotent stem cells (iPSC) to generate a variety of different cell types from volunteers of the Personal Genome Project Canada.

IMPROVING PERSONALIZED MEDICINE THROUGH DISCOVERY OF PAIN MECHANISMS USING PATIENT-DERIVED NEURONS

Leader(s): Steven A. Prescott and Michael W. Salter

Institution(s): The Hospital for Sick Children

Why was the study done?

Our sense of touch and pain begins with the activation of sensory neurons (nerves). Those neurons respond to stimulation with short pulses of electricity called spikes, which are relay information to the brain. How we perceive each stimulus depends on the number and patterns of spikes it evokes. If a neuron is injured, it may respond to a touch stimulus with too many spikes, causing touch to be mistakenly felt as pain.

How was the study done?

Our research seeks to understand the injury-induced changes that cause neurons to respond more vigorously than normal. Traditionally this is studied using neurons from rats or mice, but ideally we would study human neurons because each person's neurons may respond differently to injury, making them more or less susceptible to developing neuropathic (nerve) pain. But unlike a blood sample, neurons cannot be easily collected from a patient. The situation has only recently changed thanks to breakthroughs in stem cell technology that now allow neurons to be created from a specific type of stem cells (known as iPSCs) generated in the lab from easily-collected blood or skin cells.

What were the study results?

We have been working to produce human iPSC-derived neurons. Our recent publication (see link below) describes the generation of many different cell types from iPSCs generated from volunteers in the Personal Genome Project Canada. Based on their extensive genetic characterization, these iPSCs and the sensory neurons derived from them provide a valuable comparison for future testing of patient-specific neurons. We continue to study these human neurons to identify what changes cause them to over-react under pathological conditions.

This knowledge will help us understand neuropathic pain and its management.

Link: https://www.biorxiv.org/content/10.1101/666560v1.article-info

INDIVIDUAL PHENOTYPES OF CHRONIC PAIN: THE DYNAMIC PAIN CONNECTOME TOWARDS PAINOMETER DEVELOPMENT AND NEUROETHICS

Leader(s): Karen D. Davis and Cyril Schneider

Institution(s): University Health Network; Université Laval & CHU of Quebec

Why was the study done?

A one-size-fits-all approach to pain management does not work for all people with chronic pain because of differences in the brain that can cause individual differences in pain sensitivities and coping, and determine whether we respond to various treatments.
This study is being done to identify individual brain differences related to pain and how they may predict treatment response. An understanding of these linkages will help to develop a personalized and more effective approach to pain management. A second part of the study seeks to understand the opinions of people with pain regarding the use of new brain imaging technologies to diagnose and guide pain treatment. This neuroethics study examined issues of data privacy, objective vs self-report measures of pain, to establish a framework for neuroethics, legal and societal challenges related to brain imaging/function and possible of the self-report of pain.

How was the study done?

The study measured many aspects of pain sensitivity as well as brain activity in people who are healthy (as a control measure) and in people with different types of chronic pain. Data was also collected from people undergoing treatment for chronic pain to identify links between how well the treatment alleviated pain and the brain and pain sensitivity measures. For the neuroethics study, a survey is being used to determine the opinions of key stakeholders (people with pain, the general public, healthcare providers) in adopting a brain-based "painometer" test.

What were the study results?

Although the study is not yet complete, early findings indicate that there are several abnormalities in brain function and pain sensitivity measures that are commonly found in people with chronic pain. Some of these abnormalities are related to the type and severity of pain, some are related to whether a treatment will be effective, and some normalize after an effective pain treatment. Individual factors are also emerging including sex differences in brain circuitry.
The neuroethics study is also ongoing but, thus far, suggests that people with chronic pain are confident in the data privacy of brain imaging but do not feel that brain tests necessarily capture their individual experience of pain.

Project Highlights

Identified abnormal brain activity and connectivity in patients with neuropathic pain.

Characterized how abnormal brain activity associated with chronic pain can be impacted and reversed by effective treatment, as well as the variability across individuals in their ability to modulate pain.

Developed concepts regarding brain imaging representations of pain states vs pain traits.

Project Highlights

Worked with patient perspective partner Mary Brachaniec

Launched a social media KT campaign on pain in dementia/long-term care called #SeePainMoreClearly, where we created engaging content that we regularly shared regularly, as well as an informational website that has been visited by people from close to 30 countries (seepainmoreclearly.org).

The campaign has received close to 6,000,000 impressions on Twitter representing over 2,400,000 unique users from many countries. Our YouTube video has reached 51,000 views with the number of views increasing daily.

PAIN IN OLDER ADULTS

Leader(s): Thomas Hadjistavropoulos

Institution(s): University of Regina

Why was the study done?

Most long-term care homes in Canada do not have sufficient staff resources to adequately assess or treat pain among older adults in their care.
We do not know whether long-term care residents with poorly managed pain need more physician visits, hospital admissions or prescription medications than residents without pain problems.

How was the study done?

To answer this question, our research team evaluated the way that 24,870 Saskatchewan long-term care residents were cared for in our healthcare system between 2004 and 2015. The average age of these residents was 85 years, and one in three residents had significant pain problems.
We compared the way residents with pain problems accessed health services with the way residents without pain problems accessed health services.

What were the study results?

We found that long-term care residents with pain problems required more physician visits, hospital admissions and prescription medications than residents without pain problems. Our findings suggest that improving pain management for residents in long-term care could improve quality-of-life and reduce use of health services for these older adults. This can, in turn, can reduce overall health care costs.

PREDICTION OF CHRONIC PAIN AFTER UPPER EXTREMITY FRACTURE OR ARTHROPLASTY

Leader(s): Joy MacDermid and David Walton

Institution(s): University of Western Ontario and the Hand and Upper Limb Centre

Why was the study done?

The rates of musculoskeletal (MSK) pain from diseases like arthritis or injuries are quite different for men and women. While this varies for different conditions, overall, women have much higher rates of chronic MSK pain. We wanted to understand whether differences were related to how pain was measured, different risks, or differences in treatment outcomes that affect recovery following an injury or joint replacement surgery. We focused on men and women who broke their wrist or had an arm joint replacement as these are common sources of acute pain that sometimes becomes chronic pain.

How was the study done?

We did a series of studies to look at different potential reasons for pain outcomes.
MEASUREMENT studies were performed on different tools used to assess pain in men and women to explore whether biases might explain the higher pain scores typically recorded for women.
COHORT studies were used to determine what factors might explain sex or gender differences in outcome following a wrist fracture or joint replacement surgery. We measured biological and social factors at baseline, recovery at multiple timepoints, and used statistical models to identify factors that affected recovery.
QUALITATIVE studies (interviews with surgeons, therapists, patients) were used to determine how experience, beliefs, and decision-making affected pain outcomes.

What were the study results?

MEASUREMENT study findings indicate that many of the tools used to assess MSK pain outcomes did not provide appropriate scaling of pain, and a minority measured differently for men and women.
Our ongoing COHORT study will identify factors that we can use to predict who is at risk of chronic pain following a wrist fracture or arm joint replacement. We will use these factors to triage patients into alternative treatment pathways.
QUALITATIVE study findings indicate that clinicians are reluctant to discuss sex and gender, but latent presumptions do exist. Some patients feel that their sex or gender does affect how their pain was managed or experienced. We will use this information to provide more sex and gender sensitive treatment programs.

Project Highlights

Recruitment of participants is in progress in order to complete study sample.

Analysis of data and synthesis of manuscripts is currently underway for retrospective study.

Interviews for qualitative date were completed. Data collected with PT students on pain expectations and gender. Data collected with hand therapists on attitudes on Intimate Partner Violence (PhD Trainee).

Project Highlights

Manuscript identifying new model of spinal cord injury pain completed and submitted for publication.

Identified new therapeutic targets expressed specifically in people living with spinal cord injury pain, with the manuscript submitted for publication.

Worked in partnership with patient perspective partner Lesley Singer and members of the Kingston Spinal Cord Injury Support Group.

PROTEOMIC ANALYSIS OF CHRONIC PAIN TO IDENTIFY NEW THERAPEUTIC TARGETS AND BIOMARKERS

Leader(s): Nader Ghasemlou, Luda Diatchenko and Ian Gilron

Institution(s): Queen's University

Why was the study done?

The majority of people living with spinal cord injury (SCI) experience profound and debilitating pain over the course of their lives. Adequate pain management options do not exist, and people are often reliant on opioids and narcotics that carry risks. While the majority of SCI research uses animal models, finding promising therapeutic targets for people has been difficult. We therefore sought to use human biological data, like blood samples, to identify potential cellular and molecular signals underlying SCI pain in an effort to bypass this roadblock bringing fundamental research to the clinic. This strategy may also identify new, tailored treatments that could be effective and specific for the treatment of pain in various diseases.

How was the study done?

Using cutting-edge bioinformatics (computational) methods, our team has studied changes in gene expression among white blood cells collected from people living with SCI, with and without pain. This led to the

What were the study results?

We were able to identify several genes and networks of genes (interacting with each other in specific pathways) that are preferentially expressed in those living with SCI pain but not present in people living without pain after injury. Many of these targets control inflammation; we are now following up on these findings to identify whether they are also expressed in animal models and will work to identify their contribution to the pain response using a newly-developed SCI pain model in our lab. We hope that, with more specific treatment options available, we can reduce potential side effects from current therapies and offer more effective pain management.

RANDOMIZED CONTROL TRIALS OF NEUROMODULATION TO TREAT CHRONIC LOW BACK PAIN, COMPLEX REGIONAL PAIN SYNDROME, FIBROMYALGIA AND CANCER-RELATED PAIN

Leader(s): Cyril Schneider

Institution(s): Université Laval

Why was the study done?

The aim of this study was twofold : to better understand brain changes in each target pain condition and, based on this new knowledge, to better adapt neurostimulation in order to normalize brain function, reduce pain and improve the function on an individual basis. Neurostimulation includes the noninvasive nonpharmacological and painless stimulation of brain and of muscles.

How was the study done?

The experiments conducted were specific to each target pain condition and included case studies as well as experimental studies (randomized double blind controlled). Measures of brain excitability and adaptation together with clinical outcomes were collected at different time-intervals before and after treatment. Treatment was neurostimulation (usually over 10 days in a row, except weekends). The protocols were adapted on an individual basis owing to brain changes (e.g., hypoactivation as compared to healthy people was normalized by excitatory stimulation of brain, hyperactivation by inhibitory stimulation).

What were the study results?

Experiments are not completed in all pain conditions. Nevertheless, stimulation of muscles (repetitive peripheral magnetic stimulation) seems to have a pivotal influence on immediate decrease of pain and brain stimulation (repetitive transcranial magnetic stimulation) a long-term influence on pain management. To this end, brain stimulation protocols had to normalize the brain maladaptive changes related to chronic pain. And this could only be done on an individualized basis given that people with the exact same condition did not present with the same brain changes. Overall, muscle stimulation had to be combined with brain stimulation for the best and longest-lasting improvements, in the four chronic pain conditions targeted.

Project Highlights

Completed testing Non-Invasive Peripheral Stimulation and Non-Invasive Brain Stimulation – quasi-experimental study (one site lab but multi-site recruitment)

In the process of identifying subgroups of patients with specific CRPS, fibromyalgia and cancer-related pain and conducting Non-Invasive Peripheral Stimulation and Non-Invasive Brain Stimulation and physical/ occupational therapy protocols.

Beginning Knowledge Translation about the non-invasive neurostimulation / neuromodulation as an adjuvant to potentiate the after-effects of conventional therapy, in collaboration with all clinicians involved in pain & with assistance from the Knowledge Translation committee

Project Highlights

Performed evaluation of the conditioned pain modulation in a cohort of 360 healthy participants.

Achieved determination of reference data (efficacy of endogenous mechanisms of pain) in healthy participants.

Reproducibility of data acquisition using test-retest in 60 participants.

STRATEGIC APPROACHES TO PERSONALIZED DIAGNOSIS AND TREATMENT IN CHRONIC PAIN

Leader(s): Serge Marchand and Louis Gendron, with Phillippe Sarret and Nicolas Beaudet

Institution(s): Université de Sherbrooke and Centre de Recherche du CHUS

Why was the study done?

A considerable proportion of patients suffering with chronic pain are not efficiently relieved by their medication. Choosing the right medication for the right person remains a difficult challenge for clinicians, which could be resolved by the assessment of each patient's pain profile. The objective of this study was to develop a simple procedure to assess individual pain profiles which could be used in a clinical setting.

How was the study done?

We used a protocol developed in our laboratory (Toussignant-Laflamme and team, 2009) consisting of applying three consecutive harmless but painful stimulations (hot, cold, hot) to the forearm to measure endogenous mechanisms of pain modulation. Just before the experiment, we collected a series of psychological (e.g. level of anxiety, depressive symptoms) and physiological (e.g., blood molecules) measures with the objectives to link them together to estimate individual pain profiles. To date, 370 individuals (of different genders and age groups) took part in the project (targeted number of participants is 408). This study started in 2018 and we are confident to finish the recruitment by the end of 2020.

What were the study results?

This study is an opportunity to develop a new procedure to personalize pain medicine, that will help healthcare professionals provide the right and most efficient treatment for each patient. This study aims to provide a simple tool for clinicians, adapted to their daily practice, to measure endogenous mechanisms of pain control and offer an optimized medication care.

For more information: https://www.youtube.com/watch?v=ntywmLUYTsc&t=86s.

TARGETED PAIN THERAPIES FOR CANCER PATIENTS

Leader(s): Gurmit Singh and Jan Huizinga

Institution(s): McMaster University

Why was the study done?

Cancers originating in the breast, lung and prostate often metastasize (spread) to the bone, frequently resulting in bone pain that can be difficult to manage with pain medications. This study aimed to identify specific biomarkers (markers found by taking blood samples) that could be used to monitor the potential of developing cancer induced pain.

How was the study done?

We compared biomarkers in cancer patients who experienced a lot pain with biomarkers in a control group (cancer patients with no pain).
We also compared biomarkers in patients whose cancer had spread with biomarkers in a control group (patients whose cancer had not spread).
The blood samples were obtained from the Ontario Institute of Cancer Research bank of blood samples taken from cancer patients who had participated (or were participating) in other research studies. Consent was obtained from patients and Institutional Ethics approval was obtained.

What were the study results?

The study provided evidence that a set of biomarkers found in the blood of patients with breast, prostate or lung cancer were associated with pain. This knowledge could be helpful in developing new pain management approaches for patients with these types of cancer. These biomarkers will be analyzed further to see whether they are also associated with chronic pain.

Project Highlights

Completed data analysis and, from data, determined the effect of specific agents. Potential biomarkers have been identified.

Collaborated with Ottawa regional cancer centre to obtain clinical samples to conduct a Biomarker study associated with cancer pain.

The study was published in Journal of Pain Research.

Project Highlights

We have spent 30 hours working with our patient partner, Janice Sumpton, and continue to collaborate together on several new projects.

We have recruited 190 dyads from the main study site (ACH) into the study. All families have completed their baseline and follow-up assessments. We have recruited 30 dyads from additional sites (IWK and SickKids); of these, 25 have completed baseline and follow-up assessments.

We have published 7 peer-reviewed papers in high impact pain journals and presented this work in 26 presentations, with 3 staff members and 7 trainees (undergraduate, graduate, post-doctoral) working on the PATH Study.

THE ROLE OF PARENT MENTAL HEALTH IN PEDIATRIC CHRONIC PAIN

Leader(s): Melanie Noel

Institution(s): Alberta Children's Hospital (site lead), University of Calgary; Hospital for Sick Children and the IWK Health Centre

Why was the study done?

Chronic pain in children and adolescents is a rising epidemic, affecting approximately 1 in 5 Canadian youth, and costing society $19 billion USD/year. Many youth with chronic pain also have mental health issues, such as anxiety, depression, and PTSD. What is more, we've shown that 50% of their parents have chronic pain and many have mental health issues themselves, which affect their children's pain and functioning. This study aimed to answer the following questions: Why do chronic pain and mental health issues co-occur and how do they 'get under the skin' to influence the next generation? How can we better treat children and parents who have these co-occurring issues and prevent these problems from developing?

How was the study done?

This study was conducted at the Alberta Children's Hospital, SickKids, and the IWK Health Centre, where we assess mental health and chronic pain, as well as a variety of mechanisms that may account for this co-occurrence. These include cognitive (attention, memory biases), behavioral (parent responses to pain), physiological (sleep disturbances), and neurobiological (gene expression) factors. Over 200 youth (aged 10-18 years old) with idiopathic chronic pain have participated in this study. Parents and youth reported on their pain, mood, sleep and other factors at baseline and 3-months later. Specifically, they filled out a battery of questionnaires, then reported on their daily pain, mood and sleep for 7 consecutive days at each timepoint.

What were the study results?

Findings from this study show that many underlying mechanisms contribute to chronic pain in youth. We found evidence of an attentional bias in youth with chronic pain and showed that parent protectiveness and poorer parent mood predicted worse youth pain on a day-to-day basis. Higher PTSD symptoms, sleep disturbances, intolerance of uncertainty, and adverse childhood experiences in youth are related to worse pain. Diagnostic uncertainty is experienced by nearly a third of youth with chronic pain and their parents, and is linked to worse youth pain and health-related quality of life.

SOCIALLY MARGINALIZED POPULATIONS: ADAPTING PAINBC'S PROGRAMS TO MEET UNIQUE NEEDS

Leader(s): Kenneth D. Craig

Institution(s): PainBC; University of British Columbia; University of Victoria

Why was the study done?

Access to pain management is not equitably distributed, with people in socially marginalized populations less likely to receive care for persistent pain, to not endeavour to seek care themselves, and to suffer from social stigma when in pain. We have sought to investigate these challenges through literature reviews, assembling current knowledge, self-report of representatives of socially marginalized populations in the LGBTQ2S, refugees and immigrant newcomers, and Indigenous populations using focus groups, and examining how Pain BC's programs can be adapted for effectiveness with marginalized populations. The commitment is to building trust and improving care for people living with chronic pain who also experience social marginalization.

How was the study done?

We have undertaken literature reviews, focus groups with LGBTQ2S, refugee and newcomer, and Indigenous people, and revision of Pain BC instructional and publicity materials.

What were the study results?

The literature review (referenced in highlights) and the focus group qualitative data (referenced in highlights) were consistent with systematic inequities in delivery of care for chronic pain to socially marginalized populations. Trainer manuals and self-management materials are being adapted through use of images of diverse populations.

Project Highlights

Craig, K.D., Holmes, C., Hudspith, M., Moor, G., Moosa-Mitha, M., Varcoe, C., & Wallace, B. (2020). **Pain in persons who are marginalized by social conditions.** Pain, 161, 261-265.

Wallace, B., Varcoe, C., Holmes, C., Moosa-Mitha, M., Moor, G., Hudspith, Craig, K.D. (submitted for publication). **Towards health equity for people experiencing chronic pain and social marginalization.**

Photographs depicting people from diverse populations have been produced to enable people in marginalized populations to recognize themselves in images and instructional materials.
See: https://equiphealthcare.ca/projects/chronic-pain/project-summary/

Project Highlights

1 new patient partner providing support on the SYMBIOME project.

5 thesis-based graduate students supported through SPOR-funded research.

10 publications available, under review, or prepared for submission from the SYMBIOME work.

THE SYSTEMATIC MERGING OF BIOLOGY, MENTAL HEALTH AND ENVIRONMENT (SYMBIOME) LONGITUDINAL DATABANKING PROJECT

Leader(s): David Walton, Joy MacDermid, Jim Elliott, Walter Siqueira, Lynn Cooper, Brian Corneil, Eldon Loh, Gordon Good, Siobhan Schabrun and Jordan Miller

Institution(s): University of Western Ontario, McMaster University, McGill University, University of British Columbia, Queen's University, Northwestern University (Chicago), Western Sydney University (New South Wales), University of North Carolina at Chapel Hill, Canadian Pain Coalition and Gordon Good Law Offices

Why was the study done?

Chronic pain continues to be a burdensome issue for sufferers, health systems, and their communities. Many experts have endorsed more informed management in the acute pain period and identification of key prognostic/risk factors to prevent the development of chronic pain in the first place. The SYMBIOME project was conducted to collect rich biopsychosocial data on a longitudinal cohort of people recruited in the acute stage of musculoskeletal trauma, and to follow those for 12 months to identify trajectories and predictors of recovery / non-recovery (chronicity) after trauma.

How was the study done?

We recruited participants locally through the Urgent Care Centre of a major hospital. Data were collected as close to a non-catastrophic MSK injury as possible, including biological (blood, saliva, hair, and stool), psychological (distress, depression, threat appraisal, pain and disability) and social (education, gender roles, adult and early life stressors, socioeconomic status) data through self-report or in-person contact. Participants were then followed at 1, 2, 3, 6, and 12 months each time capturing additional data on recovery status using the Brief Pain Inventory as the primary outcome, and work status, healthcare usage, and emotional state as secondary outcomes.

What were the study results?

We recruited 120 acutely injured participants in the first phase of the SYMBIOME study. From those we have identified 3 recovery trajectories, of which ~45% continued to report moderate or greater persistent pain or interference problems at 12 months (Lee et al. 2020). We have further determined that recent life stressors are associated with acute pain but that the association is mediated by the effect of stress on sleep (Walton et al. 2020). Currently under review are manuscripts describing a new panel of blood markers that appear to distinguish high vs. low risk of chronicity, the effect of early life adversity on recovery from adulthood trauma, and further validation of the Traumatic Injuries Distress Scale for risk stratification.

PATIENT PERSPECTIVE PARTNERS - 2019/2020

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SUPPORTING INSTITUTIONS & ORGANIZATIONS

Alberta Children's Hospital Research Institute

Department of Anesthesiology & Pain Medicine, University of Alberta

The Arthritis Society

Association Québécoise de la Douleur Chronique

Bayer

Department of Anesthesiology, University of British Columbia

Canadian Anesthesiologists Society

Canadian Pain Society

Centre de recherche du CHUS

Centre de recherché du Centre hospitalier de l'Université de Montreal

Children's Hospital of Eastern Ontario

Children's Hospital Foundation of Saskatchewan

Department of Anesthesia, Dalhousie University

Eli Lilly Canada Inc.

Hamilton Health Sciences

Health Information Research Unit, McMaster University

Hospital for Sick Children (SickKids) Research Institute

Hotel Dieu Chronic Pain Clinic, Queen's University

The Improving the Lives of Children with Chronic Pain Charitable Foundation (ILC)

IWK Health Centre

Faculty of Medicine, Laval Université

Department of Anesthesia, University of Manitoba

McGill University

Alan Edwards Pain Management, McGill University

Michael G. DeGroote Institute for Pain Research and Care

Department of Anesthesiology, Université de Montreal

Wasser Pain Centre, Mount Sinai Hospital

Multiple Sclerosis Society of Canada

The Ottawa Hospital Research Institute

Pain BC

Pfizer

Purdue Pharma

Quebec Pain Research Network

Queen's University

University of Regina

College of Medicine, University of Saskatchewan

Saskatchewan Health Research Foundation

Faculty of Medicine and Health Sciences, Université de Sherbrooke

University of Toronto Centre for the Study of Pain

Faculty of Music, University of Toronto

Department of Physical Therapy, Western University

University Health Network Toronto

ADDITIONAL LINKS

Canadian Pain Task Force
https://www.canada.ca/en/health-canada/corporate/about-health-canada/public-engagement/external-advisory-bodies/canadian-pain-task-force.html

Pain Warriors Documentary
https://www.youtube.com/watch?v=0ynUOdG4C6A

VISION

To change the way pain is managed in Canada through improved assessment, prevention and provision of timely and optimal pain management.

The Chronic Pain Network has been made possible through funding by the Canadian Institutes of Health Research, the Strategy for Patient Oriented Research and partners across the country.

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