Pain Management in Children with SNI does not Always Improve Caregiver Wellbeing: Results of an RCT

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Background

Children with severe neurological impairment (SNI) represent a highly vulnerable population, often requiring round-the-clock care[1,2]. **Pain** is the most commonly reported symptom in this population, frequently occurring without an identifiable cause[2].

These children are often non-verbal, and have limited mobility3. → They have difficulty communicating: **'where it hurts'.**

We call this **Pain and Irritability of Unknown Origin (PIUO)**, which is highly distressing for the children, their caregivers, and clinicians[2,4].

Background

Caregivers of children with SNI undertake the majority of responsibility for their children's complex medical needs, such as:

- Administering medications
- Following complex feeding regimens
- Coordinating between specialists
- Symptom management
- Advocating for their child

All the while experiencing heightened anxiety, difficulty with sleep, and inadequate coping skills[4,5,6].

Research Question

Does treating or identifying PIUO in a child with SNI meaningfully change their caregivers' wellbeing?

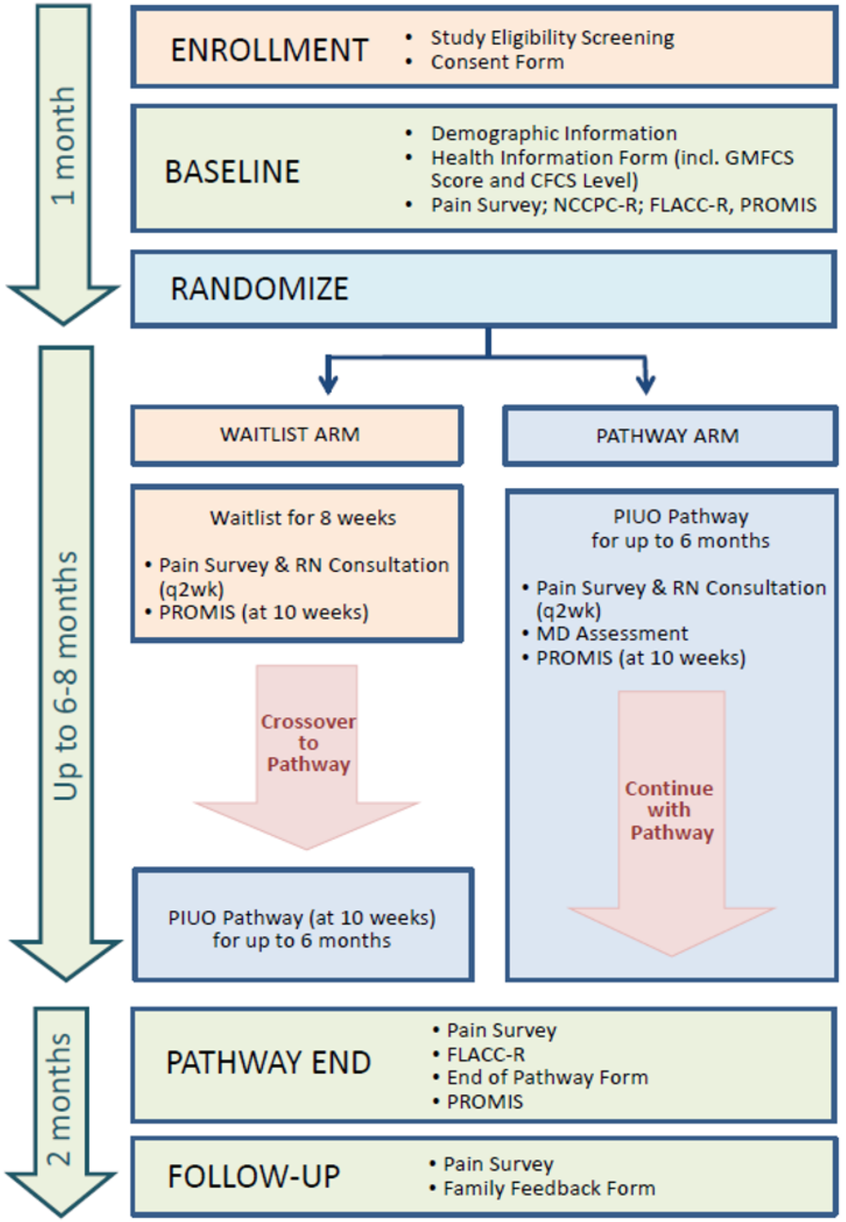


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Methods - Study Design

In a RCT at four tertiary care centres in Canada, we tested the "**Pain Pathway**", a clinical tool for systematically ruling out common causes of PIUO.

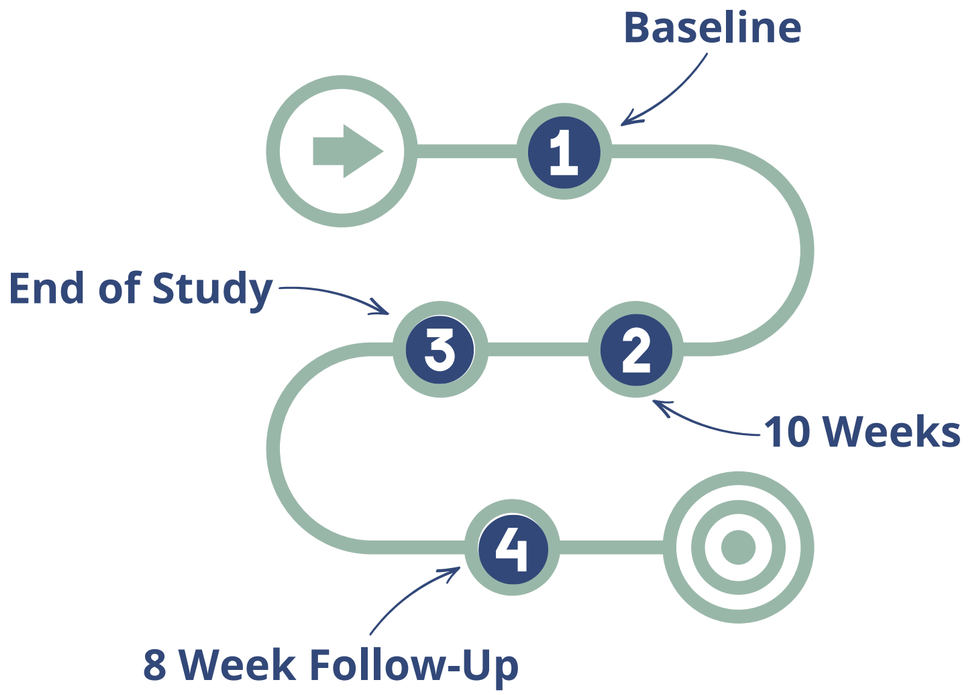
- Waitlist (control group) or intervention
- Crossover time at 10 weeks



Methods - Data & Analysis

Caregiver wellbeing was assessed using the PROMIS-57 measure at four time points. We also asked caregivers to rate their child's pain intensity (1 - 10) and frequency (0 - 7 days).

- Anxiety
- Depression
- Fatigue
- Pain
- Physical Functioning
- Sleep Disturbance
- Social Functioning



We fit a linear mixed model to the data while accounting for child pain scores to determine whether caregivers experienced a change in wellbeing based on their child's PIUO outcome.

Results

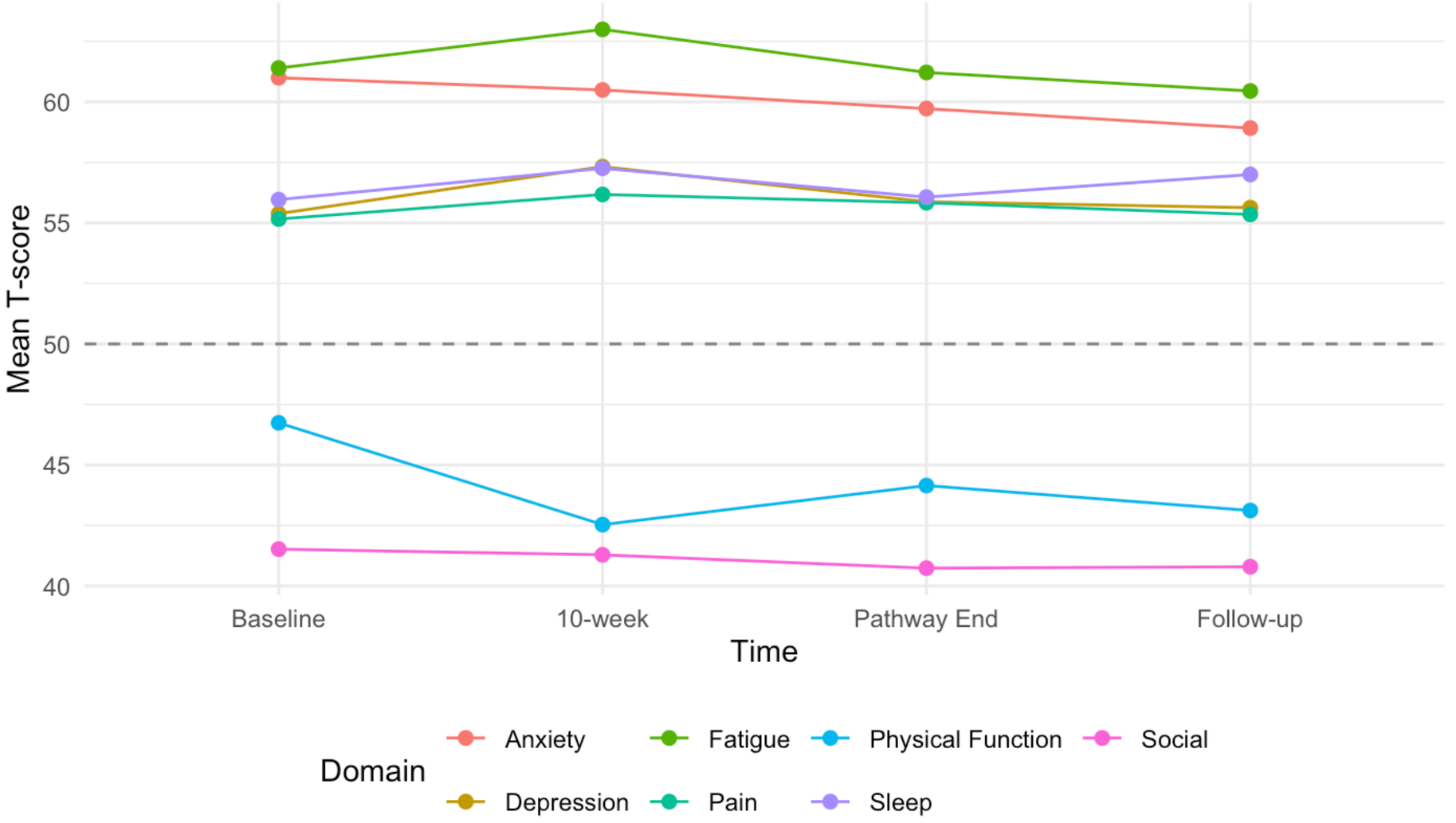
Of the 72 enrolled and randomized, 13 did not complete the intervention and 2 children died. 57 families completed the intervention.

The outcome of their child's pain is classified as:

1. PIUO Resolved (n = 14)
2. PIUO Cause Identified (n = 8)
3. PIUO Not Resolved/Identified (n = 35)

Results

For the most part, caregiver wellbeing remained stable.



Dashed line = population norm (μ = 50)

Results

Overall, caregivers scored higher on:

anxiety (60.1)

depression (56.1)

fatigue (61.6)

pain (55.6)

sleep disturbance (56.5)

and lower on:

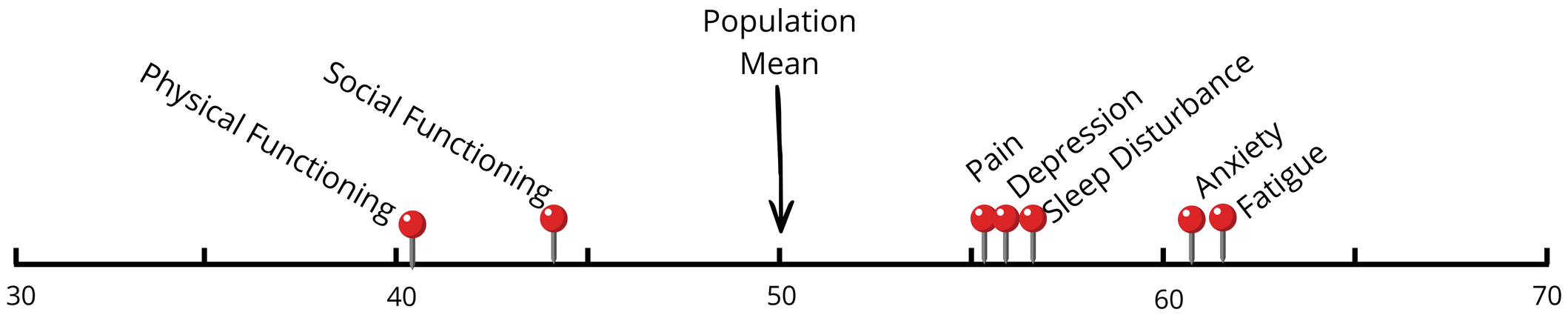
social functioning (41.1)

physical functioning (44.2)

compared to the population mean (μ = 50)

Results

Sample-wide scores across each domain demonstrated that caregivers of children with SNI experiencing PIUO are faring worse than the general population.



Results

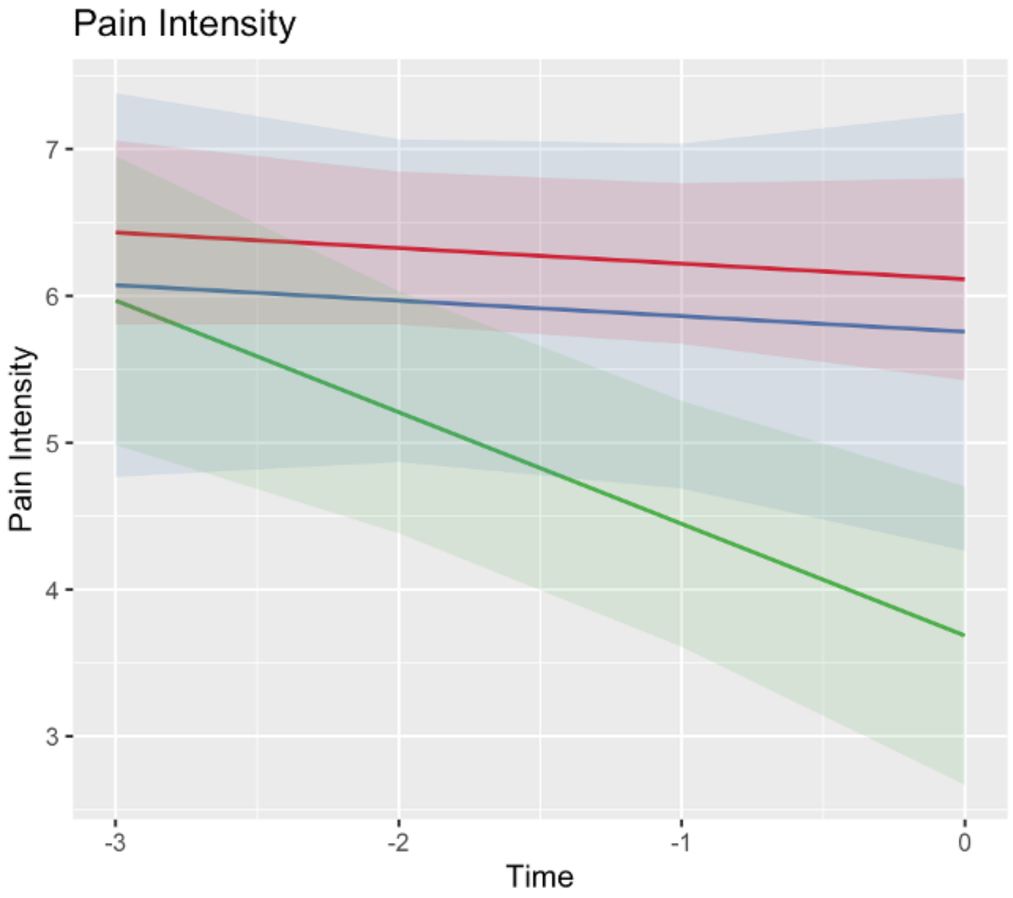
However, increases in a child's pain score was associated with greater caregiver fatigue and lower social functioning. Physical functioning declined over time for all caregivers.

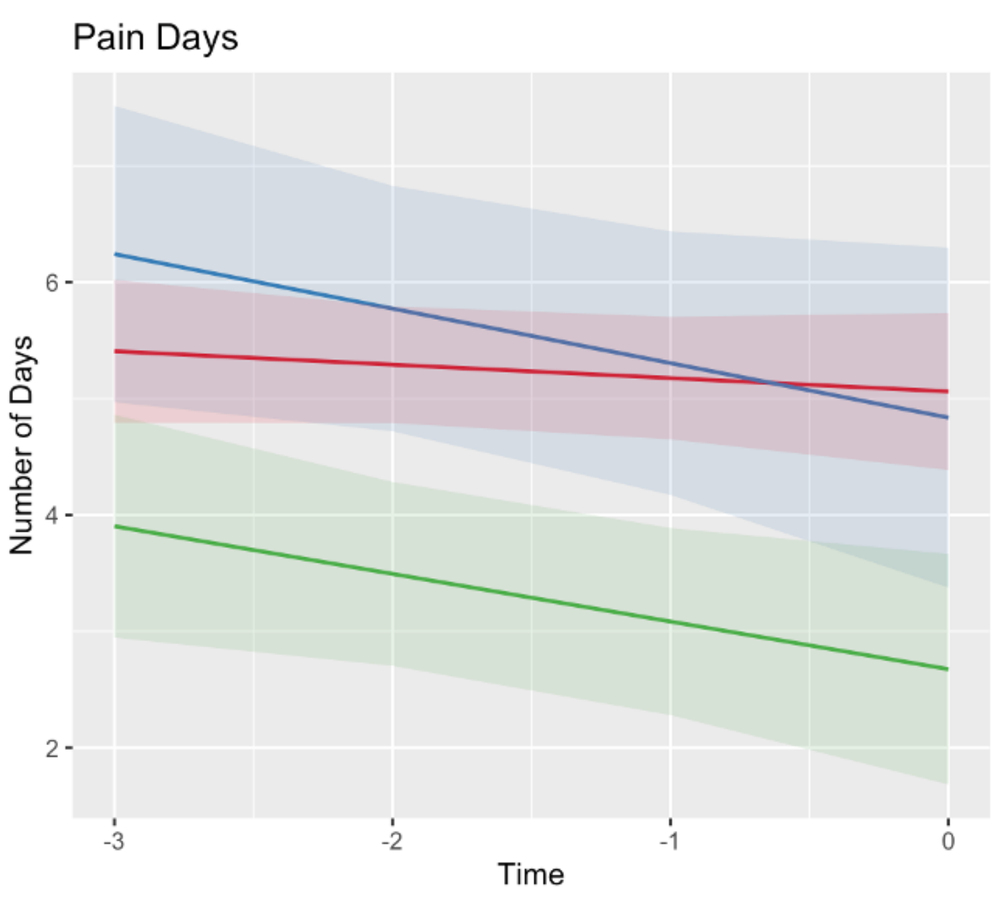
PROMIS Domain	PIUO Identified β (SE)	Time β (SE)	Child Pain Score β (SE)	PIUO Resolved β (SE)
Fatigue	2.18 (3.07)	.29 (.50)	**1.42 (.57)***	2.11 (2.53)
Pain	**7.74 (3.73)***	.36 (.53)	.75 (.62)	-.03 (3.06)
Physical Functioning	-4.67 (3.49)	**-1.32 (.54)***	-.96 (.62)	-1.39 (2.88)
Sleep Disturbance	**7.27 (2.55)****	.59 (.43)	.32 (.49)	-1.31 (2.10)
Social Functioning	-4.69 (3.02)	-.69 (.36)	**-.94 (.43)***	-.33 (2.47)

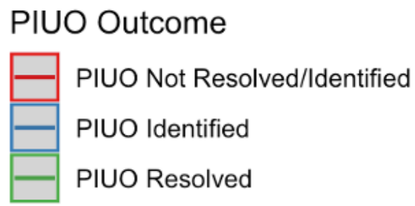
***Note.* *$p < .05$; **$p < 01$**

Results

Caregivers reported that their child's pain severity and frequency decreased from baseline to follow up on the study. This was particularly notable in children who had their **PIUO resolved**.







Discussion

1. Caregiver wellbeing was largely stable over time across all PROMIS domains, suggesting the Pain Pathway did not differentially impact caregivers.

2. Overall, pain intensity and frequency in children decreased over time. Pain scores were significantly associated with more fatigue and less social functioning in caregivers.

3. Although diagnostic clarity may offer some relief for families of children with PIUO, it is insufficient to meaningfully improve overall caregiver well-being.

Implications

These findings underscore a need for dedicated, home-based supports for children with SNI, and psychosocial supports for their caregivers to address broader family health and well-being.



Courtesy of Canuck Place Children’s Hospice, with family permission

References

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For more information, please email our study team at **pain.detectives@bcchr.ca,** or visit our website.