Ensuring equitable and inclusive virtual care for diverse youth with chronic pain and their families

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Ontario Chronic Pain Network – Pediatric Virtual Education Event
June 4, 2021
Mapping one family’s experience with pain

Increase in pain year over year
- no referrals
- no resources
- no care options
- Took 16 years for a diagnosis
  - Ehlers Danlos Syndrome

Began to use wheelchair to manage pain symptoms
- Loss of social connection
  - I later found an online social network existed for kids in hospital, but out-patients were not included.

Pain (migraines) after surgery
- Pain episodes not looked at as ‘connected’
  - We felt that they could have been treated together.

Pain (migraines) worsened
- Pain without a clear diagnosis
- “Check back in a month, if things are not better.”
- “Were going in circles”

Check back in a month, if things are not better.

Our family felt abandoned by the system

Transition to Adult Care

Co-authored a scientific paper

Taking the extra Grade 13 year

New symptoms cropped up
- “Grade 7 would be his last year at school.”

Joint pain started
- “We felt like there was a bigger issue going on.”

Completed Marine Biology course, Vancouver Aquarium

Sailing Certificate

Children’s Wish Foundation (Shark Tagging)

“One of the only things we actually got to do after so much pain.”

I don’t have an answer.
- “There’s no where close to home to get the care we needed.”

Required travel to access care

Took a long time to see a neurologist

I don’t have a neuro-ophthalmologist
- “That really hurts,” and the nurse said, “No it doesn’t.”

Perception of his pain not acknowledged or addressed
- “A factor that still effects him today.”

How it Began

Procedural Pain was not addressed

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New onset and worsening pain and mental health symptoms in youth during the COVID-19 pandemic.

Chronic pain in youth is already a health emergency.

Law et al., 2021; Killackey et al., 2021; Racine et al., 2020; Canadian Pain Task Force, 2020; 2021; Cui et al., 2020
Improving access, delivery, and coordination of care with a view to reduce disparities is a top patient-oriented priority for pediatric chronic pain.

Virtual care is a necessity.

Birnie et al., 2019; http://cmajopen.ca/content/7/4/E654.full
Phase 1: To identify recommendations for virtual care best practices for youth with pain and their families.

Phase 2: To identify virtual care solutions and create an evidence and gap map (EGM) to guide multisectoral stakeholders regarding virtual stepped care solutions for youth with pain and their families during the COVID-19 pandemic and beyond.

Phase 3: To ensure equity and inclusion in virtual care best practices to support vulnerable populations of youth with chronic pain (Black youth with sickle cell disease, Indigenous youth, youth with complex medical needs).
Patient Engagement is a Game Changer

- **Patient/Parent Partners**: 4 youth, 6 parents
- **Patient/Parent Advisors**: 7 youth, 4 parents
- **Patient/Parent Merit Reviewers**: 1 youth, 3 parents

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Virtual care solutions

✓ OUR GOAL
To identify recommendations for virtual care for youth <18 years old with pain and their families, like using apps, websites, or therapy over video call.

✓ OUR PROCESS
Our team of youth, parents, healthcare providers, and researchers conducted a rapid systematic review and found 16 relevant scientific articles published in the past 10 years.
Virtual care solutions

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What we know about Virtual Care for youth with chronic pain and their families:

Leveraging Virtual Care
- is acceptable, reasonable and effective
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- needs to include training, terms of use, and guidelines for health professionals, youth and families
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- should be transparent in communication (therapist vs. computer-generated messaging)
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**Best Platforms for Virtual Care**
- need to be user-friendly and acceptable to youth and families
- must be backed by science
- should involve youth, families, and health professionals in their development
- should be individualized or customizable
- must be comprehensive in terms of pain management (provide pharmacological, psychological, and physical strategies)
- need to use multimedia content (videos, text, images)
- must meet accessibility standards
- should be able to integrate social and peer support
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**Identified Gaps in Virtual Care**
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- need to consider potential harms and impact on the therapeutic relationship
- requires strategies to enhance engagement
- needs integration into clinical care pathways, face-to-face care, and electronic medical record
Evidence and Gap Map of Virtual Care Solutions for Youth with Pain and their Families

Peer-reviewed literature + App stores (iOS & Android) & websites + Call for Innovations

Birnie et al., in press PAIN

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Stepped Care Continuum

**Step 1:** Self-Guided (whole population; e.g., apps, websites)

**Step 2:** Peer-to-Peer (low needs; e.g., real-time peer support)

**Step 3:** Minimal Health Professional Involvement (moderate needs; e.g., real-time workshop, health professional-assisted e-supports)

**Step 4:** Ongoing Real-Time Health Professional Interaction (high needs; e.g., online individual or group therapy)

**Step 5:** Specialist Real-Time Health Professional(s) (complex needs; e.g., tertiary interdisciplinary care)

Evidence and Gap Map of **Virtual Care Solutions** for Youth with Pain and their Families

Birnie et al., *in press* PAIN

# Evidence and Gap Map of Virtual Care Solutions for Youth with Pain and their Families

## Level 1 - Self-guided

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## Level 2 - Peer-to-peer

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## Level 3 - Minimal Health Professional Involvement

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## Level 4 - Ongoing Real-time Health Professional Interaction

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## Level 5 - Specialist Real-time Health Professional(s)

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- **Critically Low Quality**
- **Low Quality**
- **Moderate Quality**
- **High Quality**

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Take Aways

Where is there evidence?

- Most virtual care solutions were widely applicable to youth with any chronic pain condition
- >100 self-guided apps and websites (level 1 stepped care)
- Apps report the most customizability
- Psychological strategies are numerous and highest quality evidence (mostly levels 1 and 3 stepped care)

Where are the gaps?

- Most self-guided apps and websites lack scientific evidence (critically low or low quality of evidence)
- Lacking at higher levels of stepped care (levels 4 and 5).
- Rarely integrated into an electronic medical record or communication with health professionals.
- Moderate number engage parents, with very little peer or sibling support
- Dearth addressing medication side effects and tracking, sleep, diet, substance use, school resources, information for teachers, and dealing with acute pain flares or crises (e.g., suicidality).
- <5% addressed web content accessibility

Birnie et al., in press PAIN
Equitable and Inclusive Virtual Care

- **Black youth with sickle cell disease**
  - 5 youth
  - 6 parents/caregivers

- **Indigenous youth with chronic pain**
  - 1 youth
  - 1 parent/caregiver

- **Youth with complex medical needs**
  - 4 youth
  - 5 parents/caregivers

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Equitable and Inclusive Virtual Care

Black youth with sickle cell disease

- Less travel & shorter wait times
- Increased accessibility to care – especially during pain crises
- Can facilitate increased engagement in therapies within home environment
- Important to have better access to psychological support or therapies

Youth with complex medical needs

- Less financial burden (e.g., no parking cost)
- Less travel & shorter wait times
- Increased accessibility to care
- More comfortable in home environment

Leveraging Virtual Care
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Equitable and Inclusive Virtual Care

Black youth with sickle cell disease

Lack of body language is hard – be sure to consider tone of voice (i.e., on the phone)

Indigenous youth with chronic pain

Consider scheduling. Challenging when appointments don’t occur on time.

Consider patient preference for a first meeting in-person if new healthcare provider.

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Youth with complex medical needs

Ideal to have consistent healthcare providers

Consider the environment for the youth and healthcare providers (i.e., no distractions, private space)

Consider adequate appointment length. Virtual visits are often shorter and youth can feel “rushed” out of the appointment
Equitable and Inclusive Virtual Care

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**Consider patient preference** – often prefer video over phone

**Coordinate care with multiple healthcare providers (or teams) at once**

**Strategies to minimize technical difficulties**

**Black youth with sickle cell disease**

**Youth with complex medical needs**

- Consider strategies to overcome technical challenges (e.g., poor internet access or challenge with a computer screen)

**Indigenous youth with chronic pain**

- A lack of hands-on teaching or demonstration for new care techniques
- Strategies to minimize technical difficulties (e.g., internet, computer screen, learning Zoom)
Equitable and Inclusive Virtual Care

Black youth with sickle cell disease

- Lack of physical exam/treatment
- Building relationships with healthcare providers matters, and this is harder to do virtually – especially new relationships
- Lack of standardization in what virtual care is offered
- Benefits some more than others. Want the option of continuing with face-to-face care
- Virtual care lacks the patient educational focus often included in face-to-face care

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Youth with complex medical needs

- Lack of physical exam/treatment
- More likely to feel uncertain about diagnosis or assessment virtually
- Certain aspects of care lost in the virtual environment (e.g., in clinic routines, connecting with nurses)
- Harder for some youth to engage
- Benefits some more than others. Very challenging for first visit.

Indigenous youth with chronic pain

- Lack of physical exam/treatment/tests
- Cultural barriers to virtual engagement (i.e., may not want to be on camera)
- Communication needs to be slower and showing listening
Responding to policymakers: Phase 1 & 2

Working Together to Better Understand, Prevent, and Manage Chronic Pain: What We Heard

A REPORT BY THE CANADIAN PAIN TASK FORCE, OCTOBER 2020

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Thank you!