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Pediatric Chronic Pain in the Midst of the COVID-19 Pandemic: Lived Experiences of Youth and Parents

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Abstract: During the coronavirus 2019 (COVID-19) pandemic youth with chronic pain have experienced additional barriers to accessing treatment and managing their pain. This study explored the experiences of youth with chronic pain and their parents during the COVID-19 pandemic. Individual semi-structured interviews were conducted with 20 youth with chronic pain (aged 13–20 years) and one of their parents, recruited from a tertiary level pediatric chronic pain program. Interviews occurred between the months of June to August 2020 and enabled participants to describe their experiences of the COVID-19 pandemic according to their own unique perspectives. Transcripts were analyzed using inductive reflexive thematic analysis. Four themes were generated and labelled: “temporality, mental health, and pain,” “coping with pain during a global pandemic,” “impact on care,” and “re-appraisal in the context of development and pandemic life.” Across these themes, youth and parents described their unique challenges of living with pain as they adapted to changing circumstances of the COVID-19 pandemic. Notably, youth experienced increased difficulties managing their mental health and pain, which were intricately connected and related to social isolation, temporality, and uncertainty exacerbated by the COVID-19 pandemic. Restrictions due to the COVID-19 pandemic impacted youth's access to care and their abilities to engage in coping strategies to manage their pain. The COVID-19 pandemic was also perceived to have interrupted youth's development and growing autonomy, prompting youth to re-appraise their current circumstances and imagined futures.

Perspective: This manuscript provides an in-depth understanding of the impact of the COVID-19 pandemic on youth with chronic pain and their parents. Youth and their parents perceived the COVID-19 pandemic to have impacted youth's mental health, pain, socio-emotional development, and access to care.

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The coronavirus 2019 (COVID-19) pandemic and its associated emergency measures have profoundly impacted the daily lives of youth worldwide. During the COVID-19 pandemic, youth with chronic pain have experienced additional barriers to accessing treatment and challenges in managing their pain due to outpatient chronic pain services being cancelled, reduced, and/or shifted to virtual care.^{9,13,14,43,47} Prior to the COVID-19 pandemic, youth with chronic pain already experienced high rates of internalizing mental health symptoms and disorders.^{10,36} Increased social isolation

due to COVID-19 restrictions, combined with reduced access to care, may place these youth at even greater risk of mental health difficulties and worsened pain.⁹ Indeed, high rates of symptom burden have been found among youth with chronic pain and their parents during the COVID-19 pandemic, including elevated insomnia, depressive, and anxiety symptoms.²⁷ However, we currently know little about the impact of the COVID-19 pandemic on the physical and mental health of youth with chronic pain.

Chronic pain has been shown to disrupt typical adolescent development, including youth's development of autonomy, identity, and peer relationships.^{25,26} Youth with chronic pain report that they feel different than their healthy peers in terms of their social development¹⁶ and that their pain is a barrier to achieving their goals.²⁹ Given that deterioration of youth mental health during the COVID-19 pandemic has been strongly associated with the stress of social isolation,¹¹ it is possible that youth with chronic pain have experienced further challenges managing their mental health and social relationships during this time. However, before the pandemic, pediatric chronic pain had also been shown to *accelerate* aspects of adolescent development in some ways, including youth's emotional maturity,²⁶ with many youth demonstrating resilience in the face of pain.^{12,21} Individual characteristics (eg, optimism, mindfulness) as well as family and social-environment resilience resources (eg, positive peer relationships, parent support) can serve protective roles for youth with chronic pain, and this may also be true during the COVID-19 pandemic.

Parenting a child with chronic pain is also associated with significant role stress, anxiety and depressive symptoms¹⁵ and impacts parents across social, relational, emotional and financial domains.^{38,39} Additionally, research suggests that up to 50% of parents of youth with chronic pain experience chronic pain themselves.³ Given that parent and family factors are known to influence youth's experience of chronic pain³⁹ and the COVID-19 pandemic has had a profound impact on parents, including increased prevalence of maternal depression and anxiety,⁴⁴ understanding parents' perspectives is critical.

The purpose of the current study was to conduct an in-depth qualitative analysis of the experiences of youth with chronic pain and their parents during the COVID-19 pandemic. The qualitative, narrative approach utilized in this study offers the opportunity to understand nuances of how the events of the COVID-19 pandemic have unfolded and were experienced by youth with chronic pain and their parents from their unique perspectives.

Methods

Study Design

This study adopted a narrative lens to study design.⁴⁵ This approach offers a provisional account of an individual's life at a specific moment in time and acknowledges

that life experiences are constantly in flux.^{1,20} Parent and youth narratives were elicited through a semi-structured interview anchored to the past (pre-pandemic), present (during the pandemic), and future (postpandemic), which allowed participants to describe their experiences of the COVID-19 pandemic as they unfolded over time according to their own unique perspectives.²⁸

Participants

Narratives were elicited through individual interviews with 20 youth with chronic pain (aged 13–20 years) and one of their parents. Youth and parents were recruited from the Complex Pain (n = 9) and Headache (n = 11) clinics of a tertiary level pediatric chronic pain program in Western Canada. Families were eligible to participate in the current study if they had previously participated in the Pain and Mental Health in Youth (PATH) study, a prospective study examining the pain and mental health of youth with chronic pain and their parents, between 2017 and 2020. Procedures for the broader PATH study have been reported elsewhere.^{2,32–35,41,48} Eligibility for initial enrollment in the PATH study included youth between 10 and 18 years of age who had been identified by a health care provider as having chronic pain (ie, pain \geq 3 months³⁰) without an underlying disease (eg, cancer). Exclusion criteria for both youth and parents included being unable to read/speak English, a diagnosis of a neurodevelopmental disorder (eg, intellectual disability, autism spectrum disorder), and/ or a serious mental health disorder (eg, schizophrenia, psychotic disorder). When the COVID-19 pandemic occurred, youth who had previously participated in the PATH study were purposively sampled to participate in the additional current qualitative study. Efforts were made to recruit a diverse sample of youth in terms of the types of pain experienced, youth age, and parent and youth sex. The current sample size was informed by characteristics of this study, including the study aims, the quality and richness of the data, and the researchers' skills in qualitative methods.⁴⁹ This sample size is also in line with previous qualitative research in youth with chronic pain.³³ See [Table 1](#) for sociodemographic characteristics of the sample.

Procedure

The institutional research ethics board (REB) approved the current study. Research staff contacted eligible families from the PATH study via telephone/email to provide more information about the study, invite participation, and obtain informed consent. Parents and youth who agreed to participate consented or assented using an online consent (or assent) form through Research Electronic Data Capture (REDCap), a secure online data collection tool.²² Parents and youth provided consent (or assent) to use quotations from their interviews for academic purposes. Once consent/assent was obtained, interviews were scheduled. Interviews were conducted with youth and their parents separately by trained graduate students in Clinical Psychology via telephone and

Table 1. Socio-Demographic and Pain Characteristics of the Sample

SAMPLE CHARACTERISTICS	N = 20
Youth age (M y, SD)	15.93 (2.36)
Youth sex (% female)	65.0
Parent sex (% female)	85.0
Youth Ethnicity (%)	
White	80
Other	10
Two or more ethnicities	5
Did not want to answer	5
Annual household income (%)	
\$60,000–\$89,999	30.0
> \$90,000	60.0
Did not want to answer	10.0
Pain locations (%)	
Multiple locations reported	45.0
Head	70.0
Muscles and joints	35.0
Other	20.0
Legs	20.0
Stomach	15.0
Chest	15.0
Youth pain intensity (M out of 10, SD)	4.95 (2.16)

audio-recorded for later verbatim transcription and analysis. Semi-structured interviews (Tables 2 and 3) were informed by previous literature and focused on exploring parents' and youth's experiences of the COVID-19 pandemic and impacts on their mental health, family, youth's pain, and parents' own pain (if applicable). Congruent with a semi-structured interview approach, interviewers used prompts to elicit further detail and clarity from participants regarding responses to interview questions (eg, What did that mean to you? Could you tell me more about that?). Interview duration ranged between 12 and 87 minutes (mean duration of youth interviews = 35 minutes; mean duration of parent interviews = 48 minutes). Parents and youth were each compensated \$20CAD in gift cards for their participation. Families were provided a list of mental health resources upon request.

Timeline and the Context of COVID-19

Interviews occurred between the months of June to August 2020 and were contextualized within the local and global socio-political context and timeline of COVID-19 policies/events. On March 16, 2020, where data collection took place, a provincial public health order prohibited all youth from attending school and youth did not return to school in person until the following school year after data collection. Over the following days, public health restrictions were implemented on public recreation, social gathering, and non-essential services. Isolation was required for individuals who tested positive for COVID-19, who were in close contact with someone who tested positive, and who travelled internationally. Restrictions were gradually reduced beginning May 2020, while physical distancing requirements remained in effect. A bylaw

Table 2. Interview Schedule for Youth With Chronic Pain

QUESTION NUMBER	QUESTION AND PROMPTS
1.	When did the COVID pandemic first start for you? What was life like for you when the pandemic first started? a. What was going on for you? b. What (if anything), did you find challenging or difficult? c. What (if anything), was going well?
2.	What was life like for you <i>before</i> the COVID pandemic began? a. What was going on for you? b. What (if anything), did you find challenging or difficult? c. What (if anything), was going well?
3.	Thinking about your life before the pandemic and when the pandemic first started, what changed for you? a. What have you been missing about your life before COVID-19? b. What are some of the good things/positives/silver linings that have come from this experience?
4.	Now can you walk me through from the start of the pandemic to where you are right now? a. What has changed? b. What has not changed?
5.	Where is your life going in the future? a. Where is it going in the next 3 to 6 months? b. Where is it going after the pandemic is over? c. How has COVID impacted/changed where you saw your life going before?
6.	What do you think you'll remember about this time?
7.	Tell me about your pain through all of this. What's changed? a. Was there a time since (you last took part in this study) that you didn't have pain? How long? b. Have there been new pains since COVID started?
8.	Tell me about your mental health (eg, sleep, anxiety, depression, etc) through all of this. What's changed? a. Was there a time since (you last took part in this study) that you didn't have issues with mental health? How long? b. Have there been new issues with your mental health since COVID started?
9.	Some people have said this time has triggered old memories from the past. Can you tell me about any memories from your life before COVID that have been coming up for you since the pandemic?
10.	We are interested in how families are talking to each other about the COVID pandemic. How are you and your parents talking about this together?

mandating masks went into effect in the major city where data collection took place on August 1, 2020.

Data Analysis

Data were analyzed using inductive reflexive thematic analysis⁶ and followed the 6-phase approach outlined

Table 3. Interview Schedule for Parents of Youth With Chronic Pain

QUESTION NUMBER	QUESTION AND PROMPTS
1.	When did the COVID pandemic first start for you? What was life like for you when the pandemic first started? a. What was going on for you? b. What (if anything), did you find challenging or difficult? c. What (if anything), was going well?
2.	What was life like for you <i>before</i> the COVID pandemic began? a. What was going on for you? b. What (if anything), did you find challenging or difficult? c. What (if anything), was going well?
3.	Thinking about your life before the pandemic and when the pandemic first started, what changed for you? a. What have you been missing about your life before COVID-19? b. What are some of the good things/positives/silver linings that have come from this experience?
4.	Now can you walk me through from the start of the pandemic to where you are right now? a. What has changed? b. What has not changed?
5.	Where is your life going in the future? a. Where is it going in the next 3-6 months? b. Where is it going after the pandemic is over? c. How has COVID impacted/changed where you saw your life going before?
6.	What do you think you'll remember about this time?
7.	Tell me about your child's pain through all of this. What's changed? a. Was there a time since (you last took part in this study) that your child didn't have pain? How long? b. Has your child had new pains since COVID started? c. What's this been like for you as a parent?
8.	Do you have pain? Tell me about your pain through all of this. What's changed?
9.	Tell me about your mental health (eg, sleep, anxiety, depression, etc.) through all of this. What's changed? a. Was there a time since (you last took part in this study) that you didn't have issues with mental health? How long? b. Have there been new issues with your mental health since COVID started? c. What's this been like for you as a parent?
10.	Some people have said this time has triggered old memories from the past. Can you tell me about any memories from your life before COVID that have been coming up for you since the pandemic?
11.	We are interested in how families are talking to each other about the COVID pandemic. How are you and your child talking about this together?

by Braun and Clarke.^{6,8} All interviews were transcribed verbatim and familiarization with the data was achieved through active reading and re-reading of the interview transcripts. All transcripts were read and discussed by the study team (AN, MN, TL, SS, KAB) on a weekly basis spanning a one-month period. Interview transcripts were analyzed using QSR International's

NVivo 12 software (2018), a computer-assisted qualitative data analysis package. Through a process of iterative review, familiarization, and discussion with team members, initial codes were inductively generated from the data and collated to identify potential themes. Initial analyses to generate codes and identify themes were conducted by the first author (AN). Potential themes were actively and iteratively reviewed and refined to construct final themes. Consultation and debriefing within the study team was frequently sought throughout the analysis to discuss developing themes and interpretations. All coauthors contributed to the analyses and interpretation of the data, providing credibility and trustworthiness with respect to the data and corresponding analytic interpretations.^{17,31} Finally, the data were analyzed within the final identified themes, and a final report was written. Quotations from a range of participating youth and their parents were included to ensure representation of a variety of perspectives within each theme. Braun and Clarke's 15-point checklist of criteria for good thematic analysis was followed as a method of ensuring quality regarding the approach to the data.⁷

Results

Four themes were generated from thematic analysis of the data. These themes depict the multifaceted impact of the COVID-19 pandemic on youth with chronic pain, specifically as it relates to youth's mental health, pain, socio-emotional development, and access to care. The themes were labelled 'temporality, mental health, and pain', 'coping with pain during a global pandemic, "impact on care," and "re-appraisal in the context of development and pandemic life." These themes are presented below with supporting verbatim quotes from youth and parents. Pseudonyms have been used to protect the confidentiality of participants.

Temporality, Mental Health, and Pain

Youth and their parents described close connections between youth's mental health and their experiences of pain. For youth, this was closely related to changes in their experiences of the passage of time, such that restrictions to activities of daily life had led to perceptions that time had slowed down. For some, as Emma describes below, experiencing time as slowed down amplified the connection between her stress and pain.

At the beginning, you know, there's a- I felt like a correlation between when my stress would increase and how much the pain was bothering me. Usually, I'm very good at just pushing it to the side and just moving on with my day, but all of the sudden I'm stuck at home and there's nothing to move on with. (Emma, age 20, female)

While many parents and youth noted little change in youth's physical pain during the COVID-19 pandemic, they noted increased worries, fatigue, irritability, and sadness. Parents were concerned that this would impact

their child's ability to continue to cope and ultimately lead to worsened pain. With engagement in many activities no longer possible, parents were concerned that this would impact the development and course of their child's pain and worried about how their child would cope with their pain and mental health into the future. As Liam's mother describes below, parents were concerned that there may be a finite amount of time that their child could manage their pain under these new circumstances.

I think probably the biggest thing that struck both my husband and I was that because [Liam]'s usual enjoyment, the things that he would really enjoy, he was no longer able to do, we were quite concerned about just how this would affect him and how long he would be able to keep going on and coping so well with the pain. (Liam's mother)

In addition to the overall stress of the impending COVID-19 crisis, implementation of emergency measures changed how time could be spent. New circumstances of daily living, such as increased time spent alone, reduced opportunities for meaningful accomplishments, and restrictions on enjoyed activities, fuelled difficulties with mood and anxiety. The loss of activities that had been anchoring experiences in youth's lives, providing meaning, joy, and identity, was deeply felt by youth and exacerbated mental health difficulties.

I've been dealing with anxiety for a while. I've had it since I was a kid, but I've learned how to tame it so it's not as bad. And then, now that I haven't been doing much, it's kind of harder to tame. 'Cause I'm used to being like, 'Oh I'll think about it later because I'm busy right now', so it'll kind of just disappear and then I won't worry about it. Then now, because... I don't really have anything else to do so I just kind of sit there worrying about things that I shouldn't. (Zoey, age 18, female)

Focused on comparing current responses to their situation with their previous wellbeing, some parents found it challenging to figure out whether their own emotions were adaptive responses to a highly stressful and uncertain situation or were indicative of worsening mental health. For example, one father described his struggle to ascertain whether his increased emotionality should be attributed to worsening depression or a normative response to the current stress of the pandemic.

Well I have- believe it or not, I've been, uh, fighting depression myself. [Noah] has also been fighting depression and is ongoing... So today I'm crying two to three times already now. I don't know if that's a sign of depression or just a sign of good emotions. (Noah's father)

For some youth, experiences of anxiety were related to a lack of initial knowledge about the potential impact of the COVID-19 pandemic on themselves and

their family, while for others, anxiety was related to a perceived disruption to their imagined future. In many ways, the current circumstances of the pandemic and state of global crisis had fundamentally altered youth's beliefs about the world upon which they had based their future. In essence, youth questioned life as they knew it and as it would be in the future, not only due to the pandemic, but also due to the resulting economic crisis, as well as broader environment and societal concerns. This is particularly impactful for youth with chronic pain who already experience considerable uncertainty regarding their pain, particularly with regard to how it may impact their future.

I've been, I guess, increasingly nervous about the future because there's just a lot more things that might not be new but at least now I'm aware of. But like, uh, economic, I guess, parts of it and, um, that the fires, you know, isn't something that will be going away probably, you know? At least until a little while, you know? Foreseeable future. (Noah, age 19, male)

Heightened uncertainty fuelled anxiety and pain, which were integrally connected. These perceived fluctuations in anxiety and wellbeing varied depending on restrictions and changes to daily life due to the pandemic and were experienced by youth as well as parents with their own chronic pain.

I would say that I'm definitely more anxious. Um, I've always suffered my whole life with anxiety and depression. Um, sometimes it's just more manageable than others, but I would say it's been a lot higher through this. Uh, I've had panic attacks, I've- and that's where also the pain from the stomach comes in 'cause I just don't know what's going on so I get a bunch of cramping and um, kind of how my body reacts to the anxiety. (Naomi's mother)

Youth and parents described difficulties managing their mental health within the context of the extreme uncertainty of the COVID-19 pandemic. The uncertainty of the time was intricately connected to youth's mental health, pain, and perceptions of a slower progression of time.

Coping With Pain During a Global Pandemic

Youth and parents described complex experiences of coping with pain in the midst of the COVID-19 pandemic. For many youth, restrictions due to COVID-19 impacted their ability to engage in the coping strategies for managing pain that they had previously built over time. COVID-19 restrictions were particularly problematic for youth who had integrated external activities into their daily coping practices. The removal of protective factors for youth with chronic pain, such as peer support and recreational activities, led to heightened attention to their pain.

I mean for me I was distracting myself so, I haven't been able to do that as well. I don't hang out with my friends- it [pain] was getting bad and I just wanted to take my mind off of it and I couldn't really do that. Just frustrating 'cause I kind of lost my support system... I think it's been harder for me to deal with like a spike or flare. (Amelia, age 18, female)

Interestingly, restricted opportunities for engaging with activities were perceived positively by some youth, resulting in reduced levels of pain and stress. Changes in daily life, including reduced expectations to physically move and socialize, were perceived to reduce pain.

If anything, actually my pain's been a fair bit better, because I haven't been aggravated by moving around to go to a bunch of different places and everything. (Jayden, age 16, male)

Youth also felt more able to avoid situational, pain-provoking factors as well as to adapt their environments to meet their needs of living with pain, resulting in reduced levels of pain.

My headaches have kind of taken a sideline through this because I don't have issues with lights and loud noises in my house generally 'cause I've just kind of made it comfortable for me, I guess. You know? If I'm not outside or under like really intense LED lights or having loud speakers or like large crowds or anything like that, it becomes less of a problem and much more manageable. (Noah, age 19, male)

For some youth who had often felt socially isolated prior to the pandemic, new restrictions on school and social activities were perceived to have removed pressure and resulted in reduced feelings of missing out and otherness. In some ways, youth felt validated that others now had insight into what it is like to stay home, an aspect of their lives living with chronic pain that often goes unnoticed or underappreciated. In some ways, restrictions due to the pandemic were perceived to 'level the playing field' between youth with chronic pain and their peers. However, youth felt that their experience of having chronic pain was invalidated when peers described being able to relate to the experience of isolation. Charlotte below uses the word "damaging" to express the deleterious impact of the nonchalant attitude of her peers.

Especially the comments that to you- like got to me originally were kind of the, "Oh, well, it's not that bad. Now I know how you feel all the time!" I'm like, "Yeah, you kind of know how I live by staying at home, but you don't understand what I'm going through" and kind of making that like short remark was a lot more damaging than they initially like thought. (Charlotte, age 18, female)

In an attempt to manage pain and the uncertainty of the pandemic, some youth and parents described shifting their focus to aspects of their physical and mental

health that were within their control. Through accepting broader uncontrollability and focusing on their own responses, including daily routines and perspectives, some youth found a sense of control within the uncertainty. For some, the COVID-19 pandemic was a time of introspection and a catalyst to developing skills to manage their pain and mental health.

Mostly, it [the pandemic] just kind of like- it helped me relax a little bit. I kind of became less worried about other people and more worried about my health, I kind of came to the conclusion, like I can't control everyone, but I can control me. (Charlotte, age 18, female)

Discussions regarding how parents and youth were managing their pain and mental health during this time were often linked to how they identified as an individual. Youth and parents discussed their response to the pandemic as directly related to their perceived sense of self and personality. For example, parents and youth often attributed their positive coping in the circumstances of social isolation with their identities as introverts. Jayden's mother below expresses that her children were "built for COVID", suggesting that a certain type of person would fare better than others under the circumstances imposed by the pandemic.

It hasn't been a negative, we kind of joke that our kids are so introverted that they kind of were built for COVID. Honestly, it didn't seem like that much of a difference. (Jayden's mother)

For others, the pandemic was much more difficult when restrictions were at odds with youth with more outgoing personalities.

It's been very, very hard for her, um, because she's so extroverted and she loves to spend time with her friends in person, and for the longest time she couldn't do that. (Jasmine's mother)

How youth managed their pain during this time was related to factors such as youth's personal identities and how pain had been managed prior to the pandemic. For some youth, the circumstances of this time made living with pain more manageable and adaptable, while for others, reduced activities and opportunities for socialization were major challenges to coping with pain. In either scenario, youth were forced to make changes to their daily pain management under uncertain conditions, which required introspection and shifts in perspective.

Impact on Care

The COVID-19 pandemic impacted youth's pain-related care in many ways, including reduced access to care. Many youth and parents experienced uncertainty regarding the absence of medical care and how they would manage their chronic pain. This is critical for

youth with chronic pain who depend on the support of physical and mental health services to engage regularly in education, recreational, and social activities.

Uncertainty is harder to deal with than some bad facts I think. It certainly is for me and [Charlotte]'s very much like that as well. . . the uncertainty of, you know, there's appointments that are cancelled but we don't know when they'll be rebooked so, certainly she was pretty agitated initially 'cause some of the treatments really help quite a bit with her condition and so, that part of it was tough. (Charlotte's mother)

In the absence of usual services and support, families turned to self-management the best that they could.

So, a lot of the normal things and routes that we would access for him were kind of taken away. We just kind of have to do it on our own. Like, I mean, and even when his knees pop out and they freeze and lock, um, we ice, rest, bring out the wheelchair or use his cryo machine, um, increase his incense, like we're – we just sort of manage it on our own. (Adam's mother)

In addition to reduced access to care, families had to consider increased health-related risks when hospital care was available. Families often found themselves carefully weighing the health risks associated with both seeking and not seeking in-person medical care for their child's pain, especially when their chronic pain was concurrent with other health conditions, thereby exacerbating their risk of contracting COVID-19.

There was one time where I think she was pretty close to wanting to go [to the hospital], but there was the fear of walking into a hospital. Nobody wanted to go to a hospital during any of this, so she just dealt with it. (Naomi's mother)

The COVID-19 pandemic created a shift in care for individuals with chronic health conditions, including greater emphasis on virtual care. This was perceived as positive in numerous ways for some youth and parents in terms of reduced commuting and appointment waiting time. However, for others, this move to virtual care was perceived as being unrealistic and unsatisfactory. Adam's mother below described that what was lacking for her and her son was not just reduced medical care, but the interpersonal connection and support they previously received from resources that had suddenly been cancelled or changed.

I think part of health care is not even the physio, or the OT, or seeing the nurse. It's that human connection and knowing that you have that person there to help you. . . especially during a pandemic, these children that have so much engagement and involvement with community resources, hospital resources, and then to have that sort of gone and just be expected for it to be delivered in an online or

telephone or telehealth way is super unrealistic. (Adam's mother)

Re-appraisal in the Context of Adolescent Development and Pandemic Life

A salient experience for youth as they reflected on their pain and the pandemic to date was that of re-appraisal. This related to individuals engaging in an active process of re-evaluating their current and future circumstances, in terms of opportunities as well as restrictions, compared with what they had imagined for their lives before the pandemic. Regarding restrictions, youth described a loss of external validation of achievements, such as graduation ceremonies, which had previously provided structure and meaning in their lives. For youth with chronic pain, who, prior to the COVID-19 pandemic, were already required to overcome disparities in their adolescent experience compared to their healthy peers, the loss of milestones, such as graduations, carried immense meaning for them. For example, for Naomi below, the meaning of thirteen years of school extended beyond academics and included a journey of overcoming additional obstacles associated with pain and disability. The COVID-19 pandemic had robbed youth not only of a milestone to celebrate their academic achievements, but of acknowledgment of their resilience in completing their education despite their pain and associated disability.

I don't like the idea of me having to do thirteen years of school for nothing. Just to get no graduation. (Naomi, age 17, female)

Youth and their parents described feelings of loss for the futures they had been planning prior to the pandemic. These losses related to re-appraisal of youth's imagined futures. Whilst some youth described the course of their imagined futures as fundamentally changed by the pandemic, others viewed the changes as more transient and more akin to their lives being put on hold, currently unable to live out their identity and autonomy.

I see COVID more as like a delay than a change. I feel like it won't change what'll happen. I feel like it just paused my life, stuck something, and I'm going to continue my life once it's over. (Aiden, age 13, male)

While many families expressed feeling closer as a family, there was also a tension between family connection and the impact of pandemic restrictions on youth's growing autonomy. While connecting with family was perceived as meaningful, the lack of peer connections was perceived to impact youth's natural development of independence and sense of self.

You know, before being in grade 10, she had plans. She wants to see what's around her, she wants to explore, she wants to develop, and people in her age are developing, you know? They're in their teenage years and they're – they are developing as a human

being. And when you don't have a human interaction, what kind of human are you becoming? (Victoria's mother)

Particularly for youth who were on the precipice of their next phase of life and at a critical period of development when the COVID-19 pandemic occurred, the current way of life and restricted opportunities was the antithesis of what a teenage life should be. This was particularly salient for youth with chronic pain who already experienced disruptions to their developmental trajectories, difficulties managing social relationships, and increased reliance on parents due to their pain, which was now compounded by the COVID-19 pandemic.

I like travelling, so if they keep the borders shut because people can't travel because of COVID, that's really gonna suck... When I grow up I kind of want to see the world and see like where I wanna live, what I wanna do, you know? (Victoria, age 15, female)

Whilst for many, re-appraisal was negative, resulting in experiences of perceived loss, areas of positivity and new learning were also often identified. Many youth and parents expressed moments of gratitude and silver linings of the current circumstances, including access to the care that was still available to them, albeit not in the previously experienced or ideal of ways.

I think a silver lining always to things like this is you just realize how fortunate you are, right? We do live in a country with acceptable healthcare for everybody, which I think has helped a lot. (Liam's mother)

For some, the pandemic prompted youth and parents to reflect on their personal identities. As such, reimagining the future and shifts in developmental trajectory were not perceived as wholly negative. Some parents and youth acknowledged value in this time, such that it provided opportunity for re-appraisal of their approach to life and what they desired for their futures.

For us, it is in some ways a bit of a character-building exercise in- you know, how do you handle the constant news about it, people's differing opinions about it, you know- the somewhat lack of social freedom, what are you grateful for, what do you want to do with your life? (Sophie's father)

A central element of re-evaluation was a sense of surprise at the ability of youth and parents to adapt so positively in the face of adversity. As Ian's father shows below, some youth and parents did not perceive it as possible to adapt to the ever-changing pandemic related circumstances, but they were indeed able to manage this, showing a greater awareness of their abilities. Alongside the many losses that the COVID-19 pandemic had brought, youth and parents acknowledged positive changes in their lives and realizations of their

own strength during this time. The sense of resilience these families expressed under the current circumstances could have perhaps been accelerated as a result of years of experience managing a life of challenges and uncertainty due to chronic pain.

It's strange that you adapt, and you think you can't, and you can, and I think it probably showed, I'm stronger than I thought I was... it [the pandemic] made us stronger as a family unit, but it's um, it's had its challenges that's for sure, but, um, and we're still in it. (Ian's father)

The COVID-19 pandemic was perceived to have effectively changed both where youth were in the present and where they were going in the future. How these changes were viewed by youth were closely linked to family support.

Discussion

There is an urgent need to understand the impact of the COVID-19 pandemic on vulnerable groups, including the lived experiences of individuals with pre-existing mental health and health conditions.²³ Since the onset of the COVID-19 pandemic, there have been calls to investigate the impacts of the pandemic on people living with chronic pain, in an effort to mitigate the potential consequences of this crisis.^{9,14} The current study explored how the COVID-19 pandemic has been experienced by youth with chronic pain and their parents. Through inductive reflexive thematic analysis of semi-structured interviews with parents and youth, 4 themes were generated: "temporality, mental health, and pain," "coping with pain during a global pandemic," "impact on care," and "re-appraisal in the context of development and pandemic life." Across these themes, youth and parents described their unique challenges of living with pain as they adapted to changing circumstances due to COVID-19 restrictions.

Youth and parents described increased worries, sadness, and social isolation during the COVID-19 pandemic and experienced this as being closely connected to their chronic pain. The difficulties of social isolation among young people during this time have been documented.³⁷ O'Sullivan et al qualitative explorations of high schoolers' experiences of the COVID-19 pandemic found that adolescents' difficulties related to their mental health stemmed from descriptions of loneliness and isolation from peers.³⁷ Another investigation of the impact of the COVID-19 pandemic on a nonpain sample of youth found that greater stress from social isolation was associated with deterioration in mental health, including anxiety and depression, while less stress from social isolation was associated with improved depression and anxiety.¹¹ Among a sample of youth with chronic pain and their parents, school closures and social isolation due to the COVID-19 pandemic were perceived to have both exacerbated and reduced youth's pain and distress.²⁷ In the current study, while some

youth struggled with the increased social isolation and removal of peer support, others perceived restrictions on social activities as having reduced stress such that it removed pressure and feelings of missing out that they had previously experienced as a consequence of their pain. Whilst this reduced pressure was perceived as positive by some youth, this may be maladaptive in the long term as it opposes current best practices for chronic pain management, which prioritizes functioning despite pain. Indeed, the current interviews were collected towards the beginning of the pandemic and youth themselves may have experienced this reduced pressure differently as the pandemic continued into the longer-term. Further, prior to the COVID-19 pandemic, youth with chronic pain already experienced high rates of internalizing mental health symptoms and disorders, including anxiety and depression,^{10,36} and commonly experienced social isolation from their peers.¹⁸ Among youth with chronic pain, lower levels of adolescent autonomy, which is developed through social opportunities, are associated with higher levels of functional impairment.⁴⁰ The increased social isolation of the COVID-19 pandemic may further widen the gap between youth with chronic pain and their healthy peers in terms of their social development.

For some youth, increased anxiety was specifically related to the COVID-19 pandemic; however, for many others, anxiety emanated from how the pandemic was perceived to have interrupted the futures youth had previously imagined. This is particularly salient for youth with chronic pain, as the pain itself is often associated with perceived losses regarding youth's expected futures,²⁴ which was now further compounded by perceived losses due to the COVID-19 pandemic. Some youth viewed current circumstances as having put their futures on hold, while others perceived that the onset of the COVID-19 pandemic had effectively changed their entire trajectory. Similarly, to how youth with chronic pain have previously described comparing their imagined futures to those of their peers,²⁴ youth now compared their imagined futures pre- and post-pandemic. While youth have broadly reported challenges related to missing important events (eg, graduation) during the COVID-19 pandemic,⁴⁶ for youth with chronic pain, these milestones carried meaning for their futures beyond education and employment, in terms of their ability to achieve their goals despite pain. As such, the cancellations of these events were experienced as deep losses, magnified by the physical and mental health challenges youth had needed to overcome to reach these milestones. Prior to the COVID-19 pandemic, chronic pain was known to disrupt typical adolescent development, including youth's development of autonomy, identity, and peer relationships.^{25,26} Restrictions resulting from public health efforts to reduce the spread of COVID-19 were further perceived to impact the developmental trajectories and identities of youth. The re-imagining of youth's futures at this time was also occurring in the context of extreme uncertainty, given constant changes and evolving knowledge related to COVID-19. Youth with chronic pain and their parents

often grapple with uncertainty regarding diagnosis and treatment for their pain.³³ Now, in the midst of the COVID-19 pandemic, youth and parents described further uncertainties regarding their daily activities, pain management, and access to care.

Many youth with chronic pain demonstrate resilience^{12,21} and even acceleration in their development, such as regarding their emotional maturity.²⁶ This was also true in terms of facing new challenges regarding the COVID-19 pandemic. In some ways, restrictions had reduced external distraction, thus opening space for introspection and re-appraising how they were currently managing and what they wanted for the future. Parents and youth expressed finding surprising strength during this time regarding their ability to manage their pain and mental health, even when faced with disruptions to their regular healthcare. Several families described aspects of this challenging time as "character building" and becoming "stronger as a family unit". Indeed, family and social-environmental resilience resources, such as these, can serve protective roles for youth with chronic pain.

During the COVID-19 pandemic, youth have experienced additional challenges coping with and managing their pain. This was a result of both changes to how time was spent, such as increased time alone, as well as increased barriers to healthcare, such as the cancellation of in-person medical services. Difficulties accessing evidence-based chronic pain care, which was already limited prior to COVID-19,⁴² were further exacerbated for youth at the very moment that, for many, their need for care increased. Youth and parents described fears of going to the hospital during the pandemic and, at times, having to choose between seeking pain-related care (eg, emergency department visits) and limiting risk of exposure to COVID-19. Throughout the pandemic, chronic pain services across Canada have had to transition to providing virtual care as virtual care practices are being evaluated.¹³ In the current study, the shift to virtual care, while perceived as positive for some (eg, due to reduced financial and time burdens), was experienced by others as insufficient. Improving access and delivery of evidence-based treatments for youth with chronic pain and their families has been identified as a patient-oriented research priority.⁴ Clearly, virtual care is needed to support youth with chronic pain and their families when in-person care is not possible. However, virtual care interventions must be designed to specifically meet the needs of the pediatric chronic pain population along the care continuum.⁵ While virtual care may remove barriers for some families and provide solutions in the short-term, as noted by families in this study, it is not sufficient to meet the needs of every family living with pain. In the current study, in addition to changes in pain care itself, the closure of other nonessential services, such as schools and recreational activities, also had a detrimental impact on youth in terms of their ability to cope with their pain on a daily basis.

There are some limitations to the current study. Firstly, COVID-19 cases and public health restrictions have differed internationally and across Canada. The

current findings should be considered in the context of the first wave of the COVID-19 pandemic in Western Canada. The interviews conducted in this study provided a snapshot of participants' experiences up to the time of the interview. Since these interviews were conducted, subsequent waves of the pandemic have occurred. Further research will be needed to understand the longer-term impacts of the COVID-19 pandemic on youth with chronic pain. Lastly, the majority of participants in this study were White, of high socioeconomic status, and female. The COVID-19 pandemic has disproportionately impacted racial and ethnic minorities and low-income individuals, and these impacts are likely to be long-lasting.¹⁹ Research suggests that youth pain trajectories

worsened during the COVID-19 pandemic among families who experienced secondary economic stress.²⁷ These health disparities are likely to further the impact of the COVID-19 pandemic on youth with chronic pain and their families and are not adequately represented in the current sample.

The personal accounts of youth and parents in the current study point to multifaceted impacts of the COVID-19 pandemic on youth with chronic pain. International investigations will be critically important to examine long-term impacts on youth with chronic pain during subsequent waves, and in the wake of, the COVID-19 pandemic and must include the lived experiences of youth and families.

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