Family attitudes and experiences with medicinal cannabis in pediatrics: An exploratory qualitative study

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Abstract

Background: In 2018, Canada became the second nation to fully legalize cannabis for recreational and medicinal use. This exploratory qualitative study investigated how and why families use medicinal cannabis for their children's health conditions in the context of full legalization and widespread acceptance.

Methods: Semi-structured interviews were conducted with 10 parents of pediatric patients attending BC Children's Hospital Oncology Clinic or Canuck Place Children's Hospice, who currently or previously used any type of cannabis for medicinal purposes. Participants were recruited through posters, email, or referral. Interviews included open-ended questions about the child's cannabis use. Interviews were recorded, transcribed, and thematic analysis was performed following an Interpretive Description framework.

Results: Patient age ranged from 22-months to 16-years. Primary reasons for cannabis use were epilepsy, cancer treatment, and chemotherapy management. Children were seen as being severely ill, and trying non-standard treatments was therefore warranted. Parents viewed cannabis as both a serious drug that doctors should prescribe, and a natural alternative health product, safe to pursue on one's own. Parents lacked information about medicinal cannabis from health care providers, and sought information and support from social media, dispensary employees, and other families. Parents were willing to obtain cannabis for their child despite reporting high costs, lack of resources and evidence, and uncertain safety or quality.

Interpretation: A sense of parental love and responsibility underlay parental decision making regarding cannabis for their children. Parents pursued medicinal cannabis regardless of obstacles, and needed reliable, unbiased sources of information to access on their own.

INTRODUCTION

Use of medicinal cannabis in pediatrics entered widespread public consciousness in 2013, when the CNN television network aired "WEED", a documentary highlighting therapeutic benefits of cannabis in children with severe epilepsies.[1] Over the past decade, medicinal cannabis for pediatric patients has continued to gain societal and scientific attention.[2–5] In 2018, Canada became the second nation to legalize cannabis for recreational and medicinal use. This exploratory qualitative study investigated how and why families use medicinal cannabis for children in the context of legalization and widespread acceptance.

Cannabis contains two main cannabinoids with proposed medicinal effects; cannabidiol (CBD), and delta-9-tetrahydrocannabinol (THC),[6] though other bio-active compounds may be present. We use the term medicinal cannabis for any combination of CBD and THC. CBD reduces seizure frequency and duration in children with treatment resistant epilepsies,[7] specifically patients with Dravet Syndrome.[8–10] THC is known to have anti-emetic, appetite stimulation, and analgesic effects useful for chemotherapy management.[11–15] Some oncology patients also seek cannabis for anti-tumor effects, despite lack of scientific evidence.[15]

Families in Canada can access cannabis products multiple ways. Products produced under pharmaceutical regulations (Controlled Drugs and Substances Act (S.C. 1996, c. 19)) assigned a Drug Information Number (DIN) are available via prescription as semi-synthetic drugs such as nabilone,[16] or highly purified plant-derived drugs such as nabixomols.[17] Non-pharmaceutical, standardized cannabis extracts can be accessed with medical authorization from over 150 producers, licensed under the Cannabis Act (S.C. 2018, c. 16). Lastly, caregivers may obtain

artisanal cannabis from recreational or grey/black market sources[18,19] without medical authorization. Products can be purchased from "dispensaries" where the provenance of the cannabis is unknown, acquired from others, or grown and processed at home.

There is a lack of robust evidence to guide cannabis practices across pediatric medical disciplines.[2,20,21] The Canadian Pediatric Society does not support pediatric medicinal cannabis use except for carefully considered, case-by-case bases, due to limited evidence and potential harms.[2] Additionally, few studies have explored family attitudes and experiences with pediatric medicinal cannabis [3,22,23]; most have focused on treatment types and parent-reported outcomes.[24–28] None have explored family experiences in Canada. Initiative to use cannabis products for children in absence of clear efficacy and safety data, along with increasing access in Canada, compels a better understanding of family perspectives. We aimed to explore attitudes and experiences of families using pediatric medicinal cannabis in Canada to set the stage for further studies.

METHODS

Upon ethics approval (H18-01112), participants were recruited through posters in clinics, email, or referral. Participants were parents/legal guardians of patients (<18 years old) attending BC Children's Hospital Oncology Clinic and/or Canuck Place Children's Hospice, who currently or previously used any form of cannabis for medicinal purposes. Palliative Care, where incidence of neurological disorders and epilepsy is high, and Oncology were chosen to represent areas of known pediatric cannabis use[4,11] while offering a variety of experiences. Participants were excluded if they did not speak English. Informed consent was obtained prior to participation.

In spring 2019, a qualitative semi-structured interview method was used to interview parents of 10 patients as individuals or with a spouse, without children present. An interview guide (Appendix A) developed by the study team outlined open-ended questions regarding the child's medicinal cannabis use, including current practices, decision making, perceived effects, safety, and legality. Interviews were conducted by trained interviewers (MG, DM) in person or by phone and lasted one hour.

Interviews were voice recorded, transcribed, de-identified, and added to Nvivo 12™ software for analysis.[29] Thematic analysis was performed following the Interpretive Description framework, developed by Thorne.[30] This framework is helpful when prior understanding of a phenomenon is limited, and is intended for use in healthcare to identify information for further investigation.[30] Team members coded interview content into categories that arose from the data, without pre-determined themes. Themes were then developed to exemplify priority areas that emerged. Data were analyzed separately by two team members (MG, CH), compared, and discrepancies discussed with a third member (HS).

RESULTS

Nine mothers and one mother/father pair completed interviews. Patient characteristics are described in Table 1. Product sources and types are described in Table 2. Products included edible oils with varied cannabinoid concentrations, nasal spray, and dried cannabis for smoking. Duration of use ranged from 2 weeks to 4 years. We identified 5 themes and 9 sub-themes (Table 3).

1. Child and family context

This theme included reasons for pediatric use, based on diagnosis and condition severity. It also encompassed parents' self-obtained knowledge and practical proficiency. This was important, as usual sources of information, such as nurses and pharmacists, could not provide guidance.

Children were perceived as being severely ill, so trying non-standard treatments was considered warranted [Sub-theme 1.1]. Management of epilepsy or chemotherapy side-effects were the primary reasons for use. Other desired outcomes included reduced pharmaceutical use, reduced anxiety, and anti-tumor activity. Children were taking multiple medications or treatments in addition to cannabis, such as "*doing chemo for her second relapse.*" Parents sought cannabis "*out of desperation,*" when traditional medications were not as effective as desired:

> "As a parent of a child with a terminal illness, we are more focused on the quality of life…Sometimes I felt like our daughter was going to die if we didn't do something about the seizure stuff."

Parents relied on themselves as experts on their child's cannabis treatment [1.2]. They conveyed precise details about dose and contents of products, despite often using unregulated products. Parents described fluctuating cannabis dose or frequency over time, and shared other practicalities:

> "We administer it via G-tube and we have…a really fatty substance that we can flush it with. Apparently the CBD oil needs fat in order to work best."

2. Decision process

Decision Process describes myriad complex factors that influenced parents' decisions surrounding cannabis. Most interview time was spent on this theme.

Parents received information about medicinal benefits, product types and practicalities through health care providers and informal sources: friends and family, media, online advocacy groups, and cannabis retail employees [2.1, 2.2, 2.3]. Despite reporting a mass of information online, parents described a significant lack of trusted medical information to guide decisions, especially if care providers were unsupportive [2.2, 2.3].

> "If your doctor is not open to talk about it, then your next line of research is the internet… Being able to decipher biased and unbiased opinions running through parent forums...is really hard."

Parents described difficulty deciding on cannabis sources. To obtain cannabis for children legally, doctors provided authorization to show licensed retailers. Families wanted more doctors to be open to suggesting and authorizing use [2.2]. However, parents indicated that local dispensaries offered easy access to cannabis; they could discuss their needs with staff and make purchases with few roadblocks [2.1]. Trust in cannabis product contents and consistency, along with prices and reputation were crucial when choosing dispensaries.

Parents experienced pressure both to use and not use cannabis [2.4]. A mother described that, after her pediatrician would not provide authorization, "[I] *felt pressure to not use it because I*

respect her opinion as a professional." However, lack of support did not deter parents from seeking cannabis; they turned to community sources or switched care providers. Most families reported social acceptance with pressure *to* use medicinal cannabis, and were advocates themselves.

> "Even though my daughter is only 5 years old, I want to empower her and know there is nothing wrong with [using medicinal cannabis]…I am really open about it."

Parents felt they were experimenting with cannabis [2.5]. They needed to learn through trial and error, and rely on their own observations because "*people's bodies are so different, not everything is going to work.*" They identified a lack of "*empiricism*" to guide decisions, and hoped for more research to inform dosing and safety.

3.0 Cannabis as an ambiguous medicine:

Cannabis was special in that parents viewed it simultaneously as a drug and as an alternative health product [3.0]. They wanted cannabis to be seen as equivalent to the regulated pharmaceuticals their children used, equating medicinal cannabis and standard oncology treatment: "[compared to cannabis] *there's way worse side effects when you do chemotherapy and radiation*." Others saw cannabis as distinct from standard medications, one parent preferring to "*get some seizure management with CBD than pharmaceuticals*". The ambiguity of cannabis was summarized by one parent who explained "*But it's not even a medication! It's like oil! It's like getting Omega 3,"* yet later described "*Just like any other drug, it can work for some…it should be one of the medications that [doctors] recommend.*"

4. Perceived effects

Parents described observed effects and concerns about use. Eight parents noted beneficial effects. Some saw dramatic changes; "*We were having 50-80 [seizures] a day, and on the cannabis we were… down to one a week.*" Others saw improvements but were unsure how much to attribute to cannabis. Parents also described the ability to reduce other medications as a significant benefit: "*We got him off quite a few, 20 medications. And we are on 3 with the cannabis.*" Two families saw no changes despite increasing dose or changing suppliers. Five families observed undesired effects such as fatigue, drowsiness, or slight intoxication.

Parents reported few concerns about long- or short-term side-effects of cannabis use. Side-effects of cannabis were considered insignificant compared to side-effects of pharmaceuticals; most parents were entirely unconcerned.

> "My son is already high on all this pharmaceutical shit he has been on, so for me, [cannabis] doesn't really make a difference."

5. Legal and financial landscape

Parents described navigating a complex legal environment and financial stress of obtaining cannabis. Families lacked a clear process to legally access medicinal cannabis, with uncertainty where to begin. Parents wanted resources to clarify Canadian laws. They did not have good understanding of cannabis regulations, and felt their child's cannabis use was in a legal "*grey area*" [5.1]. Those who obtained cannabis online from outside of Canada were concerned about risk of incarceration, and others "*worried about it not coming… it being intercepted at the post*

office." Inability to travel outside of Canada with their child's medication was another major concern because it restricted family life.

The amount of money that parents spent on medicinal cannabis varied based on product and dosing schedule [5.2]. Insurers did not cover cannabis products, so families had to pay out of pocket.

> "I am a single mom and it's a huge bill at the end of the month, but I do it because it's saving my kid's life… Maybe if it was regulated like a pharmaceutical, I would be able to get it covered and it would take a huge stress off of me."

Cost was a major challenge that limited dosing schedule. Parents reported that authorized products were taxed like recreational cannabis in Canada. Some found it *"cheaper"* to obtain products through illegal routes, though these were still *"very expensive"*.

INTERPRETATION

Our study describes family experiences as a first step to uncover family practices and attitudes around pediatric medicinal cannabis. To our knowledge, this is the first such investigation in Canada. The Canadian context adds a special perspective, as medicinal and recreational cannabis are legal nation-wide and there are a unique variety of legal and illegal avenues parents use to access cannabis for their children. We uncovered five overlapping areas of focus: child and family context, decision process, cannabis as an ambiguous medicine, perceived effects, and legal and financial landscape. Underlying these was a deep-rooted sense of parental love and

responsibility. Families were determined to improve their child's quality of life regardless of social or legal consequences, and felt responsibility to help their child, no matter what.

> "It was just a matter of having my daughter… not just do whatever I can to keep her alive but also to make sure she lives a life that is fulfilling and like she is a happy kid."

Parents identified significant challenges, including lack of reliable information and research, and costs of- and access to- licensed medicinal products. Physicians' personal beliefs were another hurdle that families had to navigate alone. These challenges contrasted to strong feelings of hope or praise for products and their effects. Willingness to overcome challenges demonstrated the importance of cannabis as a treatment option and directly reflected parents' sense of responsibility to help their children. Desire for care providers to offer cannabis, alongside willingness to use it without medical guidance, demonstrated the unique category of medicinal cannabis; parents felt it was a serious medication that doctors should prescribe, yet still a safe alternative to pursue on one's own.[3] Despite viewing cannabis as an alternative health product, parents wanted medical providers to offer cannabis treatments, and were disappointed in providers who refused.

Studies of health care provider perspectives have reported concerns about physical and mental side effects of medicinal cannabis,[31–33] but our participants reported few of these concerns. Condition severity may have influenced lack of concern, as nearly all children had life-long or terminal conditions. Yet, participants still spoke openly about concern with trade-offs when accessing legal or illegal sources. Illegal sources were described as cheaper and easier to access than legal products, but were less trustworthy, likely because they are not subject to the rigorous

quality, safety, and labelling standards of licensed products in Canada.[34] Others have identified similar parental concerns when accessing cannabis.[3,23,24] Again, underlying parental love and conflict emerged as families made difficult decisions about if and how they would access cannabis.

Our results suggest that some parents will pursue medicinal cannabis treatments for their children despite obstacles, and thus indicate the need for reliable, unbiased sources of information that parents can access. Resources should reflect the Canadian context of public access to varied product sources and qualities. The abundance of conflicting online information about pediatric medicinal cannabis[5] is a result of the lack of scientific evidence on efficacy and current practices. As such, our findings underscore the need for evidence to inform pediatric guidelines on safety, dosing, best products and practices for medicinal cannabis. Many others have reported similar needs for accurate efficacy, dosing, and safety information.[4,11,20,22,28,35] Robust pharmacological, clinical, and epidemiological research in these areas will directly address challenges identified by our participants, and should be a priority of medical and scientific communities.

Small sample size and local context may limit generalizability of our findings. However, this allowed us to provide detailed insight into unique experiences and needs within a Canadian community that may reflect other pediatric palliative circles. Selection bias may have been another limitation, as families who did not feel stigmatized might have been more likely to participate. We did not speak to children directly, and notably, no adolescents who used cannabis recreationally; this should be a separate project. We did not explore parental use of cannabis, and

this may be a factor in acceptance; it will be explored in future studies. Requiring families speak English may have limited participation of immigrant families.

This study is the first step in a larger research program of pediatric medicinal cannabis that includes a site-wide prevalence survey, longitudinal collection of observational data, pharmacokinetics research, and a Canada-wide registry and cannabis network.

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Table 1: Patient characteristics

Age	Sex	Condition	Primary Reason for Use
5 years	Female	Cancer	Cancer and chemotherapy side effects
8 years	Female	Cancer	Cancer and chemotherapy side effects
16 years	Male	Cancer	Cancer and chemotherapy side effects
9 years	Female	Cancer	Cancer and chemotherapy side effects
8 years	Male	Neurological/neurogenetic	Epilepsy
16 years	Male	Neurological/neurogenetic	Epilepsy
22 months	Male	Neurological/neurogenetic	Epilepsy
3 years	Female	Neurological/neurogenetic	Epilepsy
14 years	Female	Neurological/neurogenetic	Epilepsy
13 years	Male	Neurological/neurogenetic	Epilepsy

Table 2: Source and type of cannabis products

Source	Product Type[a]	Number of participants
Community dispensary/online	Non-standardized products (artisanal)	3
Medical authorization	Non-pharmaceutical, standardized extracts (licensed products)	5
Both community and medical authorization	Artisanal & non-pharmaceutical standardized extracts	2

[a]Categorization based on Pawliuk et al.[7]

Table 3: Themes and Sub-Themes from interviews

Theme	Sub-theme	Remarks
1.Child and family context	1.1 Child's condition and severity	Child's medical challenges and diagnoses, reasons for using cannabis *"Cannabis is the lesser of two evils."* *"There is no cure for what he has. So, it's a quality of life thing. We also hoped that it would help with his sleep, with his body movements, with his pains, with his dystonia"*
	1.2 Practicalities and parent expertise	Information on cannabis product type, contents, dose, and dosing schedule *"[The product] is 97% CBD and 3% THC"* Practical considerations and precise knowledge about administering or using cannabis and methods of administration *"He can't have edibles because he will throw them up [due to chemotherapy]"*
2. Decision Process	2.1 Suppliers and advocates	How parents learned about cannabis and their experiences with community and online dispensaries, support groups, and advocacy groups. *"All of the information I get from my friends, from Facebook sometimes."* *"[Dispensary staff taught us] how much to dose a person for their weight and their age and what they are dosing for."*
	2.2 Communication with health care providers	Interactions with their child's health care providers and process of accessing authorization *"I know the doctor doesn't like us to give it to our daughter".*
	2.3 Lack of reliable information	Resources that parents accessed for information on medicinal cannabis, and their desire for trusted information. *"If doctors could say, 'okay go to this link' and they have accurate or resourceful information for you to read about cannabis, that would be helpful for parents."*
	2.4 Peer and social pressure	Perceptions of personal or social pressures regarding cannabis for their child. *"I think socially things have made a lot of progress and people are accepting. It might be due to the legalization of [recreational] marijuana."*

	2.5 Need for research	Feelings of uncertainty and experimentation with their child due to lack of scientific evidence. *"I was trying to figure out a dosage and I was being told mixed messages… I think I am giving her enough right now, but I don't know".* *"It would be nice if they could actually do some sort of research where they can see that her body is changing by using [cannabis]."*
3. Cannabis as an ambiguous medicine		Perceptions of cannabis as both a regular medication and an alternative health product. *"Cannabis is just more natural"* *"Our son is very complex…He needs real drugs"*, referring to cannabis.
4. Perceived effects		Parent observations of desired effects, undesired effects, or no effects that cannabis had their child. *"He can function. He isn't a zombie and doped up [from seizure medication]…I am quite pleased with where we are at right now."* A better alternative to pharmaceuticals for their child. *"[Cannabis] is not opium…it is not going to put him into a coma and he is not going to die and all these things. Whereas I think he overdosed multiple times on Valium because we were trying to stop seizures".*
5. Legal and financial landscape	5.1 Regulations	Understanding of medicinal cannabis regulations in Canada and concerns about legal repercussions. *"Our only issue is when we cross the border [for international travel]…We cannot fly with him because he needs to take his medication with him and [cannabis] medication cannot be taken [across borders]."*
	5.2 Costs	Information on product pricing, financial challenges, insurance coverage, and taxation of medicinal cannabis. *"A 60ml bottle of the oil is $135…We go through 2 bottles a month"* *"It is costing us $318 a month…we would really like to double the dose but that that would be about $650."*

APPENDIX A: Interview Guide

1. How did your child decide to use Cannabis?
2. What are the reasons that your child is using cannabis?
3. How did you learn about cannabis use for your child?
4. Who is signing the medical form?
5. What have you learned from talking to other families in clinic who also use cannabis? (If you haven't, why haven't you talked to other families?)
6. What have you learned from talking to your primary physician, physician or nurse about using cannabis? (If you haven't, why haven't you talked to them?)
7. Can you talk about the pressures of using/not using marijuana for medical purposes?
8. Do you think that cannabis is a good treatment for your child and why?
9. Is your child currently using cannabis for medical purposes?
10. How long has/did your child use cannabis?
11. How did you choose the dosage?
12. How did you choose the supplier?
13. Who advised you about strain, usage, other details?
14. How much do/did you pay (per month)?
15. What are/were the effect that cannabis has had on your child? Are/were these the affects you hoped for?
16. Would you use cannabis for medical purposes in the future for your child or would you recommend the use of cannabis for medical purposes to other pediatric patients?
17. Are you using any non-traditional medicine/therapies for your child? What are they?
18. Why do/don't you use non-traditional type of therapies?
19. What are your main concerns about the medicines your child/teenager receives?
20. How did you consider issues around safety of cannabis? (drug safety, not criminal safety)
21. How did you manage concerns about legality of cannabis (i.e., getting caught)?
22. Can you talk about what you know about side effects of cannabis?
23. Has your child/teenager had any issues with cannabis treatments? (Side-effects, dosage issues).
24. What do you know about how medicinal cannabis is regulated in Canada?
25. How would your use of cannabis change if there was a Health Canada certified product for children, made by a drug company?
26. From your perspective, what do we need to do as health care providers to support the families in the decision making process of medical use of cannabis?