

Parent and Patient Perceptions of Medical Marijuana in the Childhood Cancer Context

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Key Words: medical marijuana, childhood cancer, parent, patient

Abbreviations:

AYA	Adolescent and young adult
FDA	Food and Drug Administration
IRB	Institutional Review Board
MM	Medical marijuana

Abstract

Background: Medical marijuana (MM) is legal in 34 U.S. jurisdictions. Yet, little is known about patient and parent perceptions of MM in pediatric cancer care. We examined attitudes, beliefs, and experiences regarding MM among parents of children with cancer and adolescent and young adult (AYA) patients, to help frame future research initiatives.

Procedure: In this qualitative study, we conducted semi-structured, one-on-one interviews with parents and AYAs at a comprehensive cancer center. Interviews were audio-recorded, transcribed, and coded using both descriptive and inductive coding approaches. We used content and framework analysis to identify key themes.

Results: Fifteen parents and 15 AYAs enrolled. Participants were generally receptive to MM use, concurrently weighing benefits and risks. Participants most often endorsed MM use for relief of nausea, anorexia, and pain. Simultaneously, participants identified concerns about MM, including potential physiologic and psychological effects on children and lack of research. However, concerns were frequently minimized, relative to chemotherapy or supportive care medications with perceived greater side effect profiles. Many participants expressed uncertainty regarding legal access, citing

complex processes to obtain MM. Few participants had discussed MM with their oncologist, instead seeking guidance from the internet, family, or peers. Importantly, we elicited several misconceptions regarding MM, including its utility as cancer-directed therapy.

Conclusion: Patients and families are receptive to using MM, motivated by potential for symptom relief and cancer-directed effects. Yet, lack of empiric evidence is a barrier, underscoring the need for robust clinical trial data to support MM recommendations and use.

Introduction

Legalization of medical marijuana (MM) across 34 U.S. jurisdictions has enabled broader access for children with serious illness. In the context of cancer care, patients and families are increasingly interested in legal MM. Yet, there remains a dearth of empiric evidence demonstrating safety and efficacy, pitted against evidence of potential harm in children.^{1,2} Marijuana also remains federally prohibited. Collectively, these factors hinder healthcare professionals from sanctioning MM.³

MM refers to use of the *Cannabis* plant to treat an illness or its symptoms. Two major chemical constituents of the plant include tetrahydrocannabinol and cannabidiol. Dronabinol, a synthetic tetrahydrocannabinol pharmaceutical approved by the Food and Drug Administration (FDA), is widely used to alleviate nausea and anorexia in children with cancer.^{4,5} Extensive experience with dronabinol has increased interest in other marijuana derivatives in the oncology space. However, until recently, plant-derived MM pharmaceuticals were not recommended. Rigorous clinical trials conducted in children with refractory seizure disorders have facilitated FDA approval of Epidiolex[®], a cannabidiol-based drug.⁶ The rapidly transforming legal and medical landscape yields greater inquiry into whether MM might have utility for children, adolescents, and young adults (AYAs) with cancer.

While prior research explored MM perspectives of oncology practitioners^{3,7,8} and adults with serious illness,^{9,10} the views of children with cancer or their families have not previously been elucidated. In this study, we sought to examine these critical perspectives through a qualitative investigation involving parents of children with cancer and AYA patients. We explored attitudes around MM use; receptivity to or experiences with MM use; awareness of legal regulations; and how patients and families derive information on MM.

Methods

Recruitment & Sampling

Between October 2016-February 2017, eligible participants were identified from inpatient and outpatient settings at Dana-Farber/Boston Children's Cancer and Blood Disorders Center in Boston, MA, a freestanding National Cancer Institute-designated comprehensive cancer center. We used referral and purposive sampling methods to allow for maximum variation in cancer diagnoses and demographics.¹¹ Upon confirmation of eligibility, we sought permission to approach from primary oncology teams.

Participants

Eligible parents had a child with cancer, ages 0-21 years, who was at least two weeks into receipt of cancer-directed therapy. Eligible AYAs with cancer were 13-21 years old and at least two weeks into receipt of cancer-directed therapy. All participants had spoken command of English and were on active treatment. We excluded from consideration any eligible individuals who were under the care of the study principal investigator (P.A.). In total, 22 parents and 23 AYAs were approached.

Sixteen parents and 16 AYAs agreed to participate, yielding 71% overall participation. Reasons for declining participation included research fatigue, physical illness, or near-completion of treatment. One enrolled parent and one AYA were removed from the study prior to participation due to patient illness severity.

Written informed consent, including a Certificate of Confidentiality, was obtained either directly from adult participants or from a parent/guardian of a minor participant, with assent of the minor. This study was approved by the Institutional Review Board (IRB) of the Dana-Farber/Harvard Cancer Center. Upon transfer of the principal investigator (P.A.) to Yale University, IRB approval and a data use agreement enabled continued analyses.

Study Procedures

We conducted in-person, semi-structured interviews one-on-one with participants, using an interview guide to help direct the conversation. (Table 1) Interview questions explored general attitudes regarding MM, experiences with or interest in its use, awareness of legal status, and sources of information. The interview guide was informed by our prior research and by known gaps in the pediatric literature.³ We also asked participants basic demographic questions. Interviews were conducted by trained members of our research team (A.R.W., P.A.). Interviews lasted 30-45 minutes and were audio-recorded and transcribed verbatim. Each study participant received a \$25 gift card as a token of appreciation. We conducted as many interviews as were necessary to achieve thematic saturation.

Analyses

Interview transcripts were coded and summarized by two trained investigators (P.A., A.R.). The analytic approach involved a multi-stage coding process and included both prefigured and

emergent codes.¹² The initial coding structure was primarily descriptive, with the interview guide serving as a framework for prefigured codes. A more inductive approach was subsequently utilized, with open coding to allow categories emerging from the data to form the broader thematic framework.¹³ The refined coding structure was then collaboratively and iteratively developed and applied to all transcripts. Each transcript was independently coded by the two investigators, followed by serial meetings to compare codes and address discrepancies. Greater than 99% agreement was achieved between coders.¹⁴ Informed by content and framework analysis approaches, comprehensive analysis focused on identifying key themes, drawing comparisons both within and across interviews.^{11,12,15,16} These methods were enhanced by use of NVivo v.11 (QSR International, Melbourne, Australia).

Data Availability

The data that support findings of this study are available from the corresponding author upon request.

Results

Fifteen parents of children with cancer and 15 AYAs with cancer were interviewed. Across all participants, 17 (57%) were women, 22 (73%) self-identified as White race, and 4 (13%) self-identified Hispanic/Latinx ethnicity. (Table 2)

Recurrent themes included receptivity to MM, weighing relative benefits and risks; uncertainty and challenges in legal access; and limited discussion with oncologists.

Weighing Relative Benefits and Risks

While generally open to MM, participants' interest in MM was tempered by concurrent recognition of both the potential benefits and risks. Almost all parents (n=14) expressed mixed attitudes toward MM. Parents described a willingness to pursue any therapy that might offer benefit:

"I've seen my child be so miserable with the side effects of treatments...I would do anything to just make her feel better." (Parent #1)

Many parents (n=9) expressed the importance of physician oversight, suggesting that physician guidance might influence consideration of MM for their child. Four parents stated that their child was using MM tinctures or oil, although one of these parents conflated dronabinol with MM, leaving three who endorsed MM use by their child. Parents whose children were not using MM expressed potential interest if recommended by a physician or if it would offer benefit. For some parents, their interest was mitigated by a desire for more research, their child feeling well currently, or negative experiences with dronabinol. Five parents acknowledged increased receptivity to MM following their child's cancer diagnosis. (Table 3)

Similarly, nearly all AYAs (n=13) expressed interest in MM while maintaining mixed attitudes. Only one AYA expressed an overtly negative attitude toward MM due to concerns around the effects of smoking. Some AYAs recognized a shift in their attitudes, citing greater openness following their diagnosis with cancer. AYAs frequently stated that MM should be utilized solely by individuals with a specific health need and that its use is a "personal decision." Many AYAs felt that MM could help with symptoms and that MM may be more favorable than existing medications. Five AYAs reported using MM, two of whom had used recreational marijuana previously. Like parents, several AYAs had difficulty distinguishing dronabinol from MM. AYAs who used MM discussed smoking or vaporization. Among AYAs who denied MM use, nine endorsed interest in MM if they grew more ill, had worsening symptoms, or if MM was likely to treat their cancer.

Parents and AYAs converged on several putative benefits to MM use, including symptom relief, relaxation, and anti-cancer properties. Regarding symptom relief, participants tended to focus on alleviation of anorexia, nausea, and pain. Five parents spoke to efficacy of MM, one of whom specifically described relief of nausea and pain for their child, yet conflated MM with dronabinol. Two parents whose children used MM felt it enhanced appetite and relieved nausea, with few adverse effects. Of the parents discussing the potential for MM to promote relaxation and relieve anxiety (n=6), one spoke specifically about their child's experience with anxiolysis. Others without direct experiences raised doubts, referring to what they had heard or perceived and questioning the veracity of claims of anxiolysis. Several parents described MM as a natural therapy, possibly less toxic than chemotherapy or opioids. One parent commented that MM might be a good alternative to conventional chemotherapy. Some parents (n=7), including parents of children using MM, expressed beliefs that MM could effectively treat cancer. Said one parent:

"We are giving [medical marijuana] for...how it targets tumors." (Parent #4)

Five of these parents acknowledged that the anti-cancer benefits may be somewhat unfounded. Only two parents refuted use of MM as cancer-directed therapy.

Similarly, AYAs reflected on possible relief of physical symptoms and anxiety. Eight AYAs, five of whom had used MM, felt MM was effective in relieving nausea, anorexia, and pain. Two compared MM to dronabinol, with one asserting that MM was more effective and the other equating the two agents in relieving nausea. One AYA felt MM paradoxically exacerbated nausea. Many characterized MM as a natural alternative, purportedly of better quality than recreational marijuana and seemingly less harmful than other medications. Four AYAs, two of whom used MM, also discussed MM as a potential cancer therapy. Most AYAs acknowledged that the curative potential of MM is not evidence-based. Rather, theoretical anti-cancer properties of MM were what AYAs had heard, perceived, or seen in documentaries.

Main concerns regarding MM for participants fit broadly into three domains, physiologic or psychological effects; social or economic impact; and drug-related concerns. Among parents, physiologic or psychological concerns included effects of marijuana on child development or the brain, risks of smoking, issues with focus or motivation, addiction, and the potential for getting high. Notably, most parents downplayed these concerns. Social or economic impact included concerns regarding stigma associated with marijuana use, diversion, recreational use, driving under the influence, or MM possibly serving as a gateway to other substance use. Drug concerns included lack of research or regulation.

Physiologic or psychological concerns raised by AYAs included the potential to become drowsy or altered from marijuana, addiction, or harm to the lungs from smoking. Many AYAs expressed uncertainty about how definitive these risks are. Social or economic risks included MM diversion to those without a medical need, stigma, use of MM as a possible gateway drug, and driving under the influence. A few AYAs also noted that MM may be costly if it is not covered by insurance. Drug concerns centered around limited knowledge of proper dosage or use and lack of research.

There was a consistent perception that that MM carries minimal risk. Six parents, three of whom had children using MM, denied any concerns. One parent felt that a plant-based therapy is innately healthy, and two perceived MM to be less toxic than chemotherapy. The remaining nine parents expressed notions of low risk in various ways. Most compared MM to illicit drugs, prescribed supportive care medications such as opioids, and alcohol, suggesting that MM is less harmful.

Likewise, almost all AYAs (n=14) perceived MM to carry low risk. Two AYAs had no concerns. AYAs expressed that MM may be safe in moderation, with fewer risks than alcohol, illicit drugs, or medications. Some reflected on personal experiences with recreational marijuana, where no harm occurred. Generally, they perceived MM to carry low likelihood of overdose.

Uncertainty and Challenges in Legal Access

At the time this study was conducted in Massachusetts, both medical and recreational marijuana had been legalized. Eleven parents, including three whose children used MM, described—with varying degrees of confidence—that MM is legal in-state. Parents qualified their answers with “believe it is” or “I’m not positive, but...” Two parents further commented on federal prohibition of marijuana. Eleven parents referenced a prescription they thought was required to legally access MM. Most parents were largely unaware of processes to obtain MM. Parents whose children received MM delineated various challenges in certification, including physician reluctance. One parent used diverted product from another child, stating that accessing MM is “quite a process.”

Eight AYAs, three of whom were using MM, confirmed that MM is legal in-state. The remainder were unsure of legality, in some cases even after using MM. Like parents, AYAs who had not used MM (n=10) expressed limited knowledge of access mechanisms. Those who had accessed MM described the process as “complicated.” Eleven AYAs referenced prescriptions.

Limited Discussion with Oncologists

Participants identified numerous sources of information through which they learned about MM formulations, potential benefits, risks, and means of access. The internet was the most common source, followed by family and friends, television news, healthcare professionals, movies or television, school curricula, or social media.

Six parents, including those whose children were using MM, discussed MM with their oncologist. In most cases, parents initiated the conversation. Responses from oncologists were mixed; one oncologist was overtly negative, one expressed limited knowledge, and two were hesitant. One oncologist told a parent it was “their choice” and should realize that MM has side effects. Another oncologist claimed to be a “quiet supporter.” Parents occasionally also initiated

discussions with other healthcare professionals, including pediatric palliative care practitioners, general pediatricians, and nurse practitioners.

Six AYAs had discussed MM with their oncologist, five of whom used MM. Three initiated the conversation, while one noted that their oncologist initiated the conversation. Responses from oncologists ranged from disagreement to surprise to cautious optimism. By AYA report, no oncologists were able to provide information regarding MM, emphasizing limited research. One AYA whose oncologist initiated the conversation about MM explained that MM was addressed in relation to dronabinol and nausea. Nevertheless, even this oncologist acknowledged that they “didn’t know much about” MM and referred the patient to the palliative care team. All five AYAs who used MM discussed with other healthcare professionals, most commonly nurses. Per report, no nurses outwardly rejected MM. One additional AYA discussed MM with a social worker.

Many parents (n=8) described conversations with friends or family. Some held specific conversations about their child’s potential use of MM, while others referred to more general conversations. One parent was concerned about stigma, prohibiting conversation. Discussion with other patients was uncommon.

Similarly, most AYAs (n=9) had engaged in discussions with family and peers, whose responses to MM varied widely, from skepticism to full support. When AYAs were asked about their parents’ response to MM, parents’ reactions appeared to be mixed, with only one describing an overtly negative attitude. AYAs often emphasized that their parents were not opposed to MM if it benefitted their child.

Discussion

In this qualitative study of parents and AYAs, we found that interest in MM is pervasive, particularly if MM were to offer some benefit for a child or AYA with cancer. Participants endorsed

relief of subjective nausea, anorexia, and pain. Many expressed concerns about effects of MM on the developing brain of a child, effects on lungs from smoking marijuana, lack of research, stigma, diversion, and out-of-pocket costs to obtain MM. However, participants tended to minimize concerns, weighing them relative to chemotherapy or supportive care medications with possibly greater side effect profiles. Importantly, participants held several misconceptions about MM, i.e. that MM might be prescribed or overseen by a physician, when in fact MM is not FDA-approved.^{5,17} Some perceived MM to have anti-neoplastic effects, which is not corroborated by human evidence.⁵ We further identified that few participants had discussed MM with their oncologist, some opting instead to initiate discussions with family, peers, or other healthcare professionals, including nurses. Many sought information about MM from internet sources, where accuracy of content is unclear.

Prior studies in adults with cancer confirm growing use of MM for symptom relief, in parallel with increased marijuana legalization.^{10,18} Moreover, acceptance of MM is widespread among oncology practitioners.^{3,8,19} Yet, with limited empiric evidence to support use of MM, healthcare professionals may not feel sufficiently informed to make specific recommendations.^{3,8,20,21} In our study, oncologists seldom initiated discussions about MM. When some patients or parents inquired, they encountered uncertainty or reluctance from the oncologist. This finding is consistent with a previous study from our group, revealing that pediatric oncologists infrequently recommend or facilitate access to MM.³ Even in adult hospice, physicians cite discomfort with recommending a substance that is not FDA-regulated.²⁰ Therefore, patients and families may rely on practitioners other than the primary oncologist to acquire MM, and its use may not be revealed in the course of cancer care.

Wisk et al. found in a recent survey that up to 28% of parents of AYAs with chronic conditions would consider MM if it were prescribed by a physician.²² Several participants in our study also expressed that they would be more accepting of MM if supervised by a physician,

acknowledging potential risks of MM use. Still, most believed that MM carries low likelihood of harm, referring to MM as natural and possibly even healthy. This echoes data suggesting a lower perception of marijuana risk among residents of states that have legalized MM, as well as a general U.S. trend of declining risk perception.^{23,24} We further surmise that state legalization of MM may lead patients and families to presume more rigorous empiric evidence or physician oversight than currently exists.

A prevailing belief among participants in this study was that MM might effectively treat cancer. While just one participant felt MM could supplant chemotherapy, a recurrent theme was the possible synergistic effect of MM with conventional therapy. Two systematic reviews on use of complementary therapies in pediatric oncology indicate substantial receptivity of patients and families to using herbal remedies like MM with curative intent.^{25,26} The supposition that MM has anti-cancer effects, sans human evidence to demonstrate this, has potential repercussions for practice.^{5,27} A national study of adults with cancer found that patients who sought complementary therapies were more likely to decline additional conventional cancer treatment and had a higher risk of mortality.²⁸ Although similar studies have not been conducted in children, families contending with childhood cancer may be particularly vulnerable to misinformation about the promise of understudied therapies.^{26,29} Future research should seek to establish whether MM or its components have anti-neoplastic benefit in humans and what its interactions might be when used concurrently with conventional treatment.

One limitation of this study is its focus on patients and parents at a single center. The attitudes expressed may not be wholly representative of individuals with cancer in other regions of the country. Second, this study was conducted in a state where both medical and recreational marijuana have been legalized, which may influence more permissive attitudes toward MM.²³ Third, as we relied on self-report and did not utilize other approaches, such as chart review, to obtain information, some participants may not have been forthright in disclosing MM use, perhaps inhibited by stigma or fear of reprisal. Finally, in conducting one-time interviews, we did not have the

ability to trend perspectives over time. As MM access expands, secular trends in attitudes should be explored.

Conclusion

This study amplifies the patient voice in current debates regarding MM use, with important implications for pediatric cancer care. Patients and families are receptive to using MM, without necessarily involving their oncologists. Motivations for MM include symptom relief and cancer-directed treatment. Risks of MM are characterized as relative, given the known toxicities of conventional treatment, reflecting a marked shift in what constitutes risk within a serious illness paradigm. Perhaps most importantly, this study calls for well-designed clinical trials that investigate MM use in pediatric cancer, as the many uncertainties surrounding MM lead both healthcare professionals and families to proceed with caution.

Conflicts of Interest Statement

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TABLE 1 Semi-structured interview guide

Attitudes, Beliefs, Experiences	
1	In general, what are your thoughts about the use of medical marijuana for children, adolescents, or young adults with cancer?
Probes	<p>What do you think are the benefits of using medical marijuana?</p> <p>What concerns do you have regarding medical marijuana?</p> <p>What do you think about the risk of harm in using medical marijuana?</p>
2	Are you/your child interested in using medical marijuana?
Probes	<p>What would you/your child use it for?</p> <p>What symptoms come to mind when you think about using medical marijuana?</p> <p>Do you/your child currently have any symptoms for which you would consider medical marijuana?</p> <p>Have you thought about using it to treat cancer?</p> <p>At what point in your/your child’s illness would you be willing to use it?</p>
3	Could you tell me about any experiences you have had with getting medical marijuana for yourself/your child?
Probes	<p>Have you/has your child ever used medical marijuana?</p> <p>What was the experience like?</p> <p>For what purpose did you use it?</p> <p>Have you/has your child used it during cancer treatment?</p> <p>If so, how did it impact symptoms or treatment?</p>
Legality and Access	
4	Could you tell me what you know about the legal situation around medical marijuana?
Probes	<p>Do you know if it’s legal to use medical marijuana in Massachusetts?</p> <p>What about across the country? Is it different in other states?</p>

Do you know how a patient can access medical marijuana in Massachusetts?	
Sources of Information about Medical Marijuana	
5	Could you tell me where you get your information about medical marijuana?
	Have people talked about medical marijuana in the clinic?
Probes	Have other patients or families talked with you about medical marijuana?
	Have you spoken with family or friends about medical marijuana?
6	Have you talked with your oncologist about medical marijuana?
Probes if Answer is Yes	Who initiated the conversation?
	What was that conversation like for you?
	What helped you talk about it?
Probes if Answer is No	Have you ever wanted to talk about it with your oncologist?
	What prevented you from talking about it?
	Have you talked with another healthcare professional about medical marijuana?

TABLE 2 Baseline characteristics of participants

	Overall (N=30)	Parents (n = 15)	Adolescent and Young Adults (n = 15)
	Median (Range)		
Age of Patient¹ (in years)	14.5 (2-21)	7 (2-21)	18 (14-20)
	n (%)		
Female	17 (57)	12 (80)	5 (33)
White race	22 (73)	12 (80)	10 (67)

Hispanic and/or Latin(x) ethnicity	4 (13)	3 (20)	1 (7)
First Language			
English	25 (83)	11 (73)	14 (93)
Spanish	3 (10)	3 (20)	-
Other	2 (7)	1 (7)	1 (7)
Highest Education Completed			
8 th grade or less	11 (37)	-	11 (73)
High school	7 (23)	3 (20)	4 (27)
College (Associate or bachelor's degree)	10 (33)	10 (67)	-
Master's degree or higher	2 (7)	2 (13)	-
Patient's¹ Cancer Diagnosis			
Hematologic malignancy	8 (27)	4 (27)	4 (27)
Solid tumor	14 (47)	6 (40)	8 (53)
Brain tumor	8 (27)	5 (33)	3 (20)
Proportion of Patients¹ Using Medical Marijuana	8 (27)	3 (20)	5 (33)

¹ For parent participants, "patient" refers to their child with a cancer diagnosis.

TABLE 3 Perspectives on medical marijuana, benefits, and risks

	Parents	Adolescent and Young Adult (AYA) Patients
<u>Attitudes Toward Medical Marijuana</u>		
Receptivity to medical	"...I think I'm interested in having research go forward to see the benefits of... cannabis as a drug	"I think it's...really important, it's gonna help people...whether they're...using for...treatment for their cancer, or...to

<p>marijuana</p>	<p>for... for a variety of...problems... I think probably it's...gonna be efficacious for pain medication...I know it affects appetite and sometimes anxiety...I'm not particularly certain how I feel about it with children...in the oncology setting." (Parent #1)</p>	<p>help with...symptoms from the chemo." (AYA #15)</p>
<p>Changes in attitudes in the context of a cancer diagnosis</p>	<p>"For us...we had to be desperate to...open our mind to it, which I feel bad about...I wish we would have done it sooner." (Parent #8)</p>	<p>"[W]hen I was in high school, I absolutely hated it...I thought it was like the worst thing... I never wanted to try it, never thought I would. And then, I learned about...how they classify it... with heroin... I thought you...tripped out and stuff like that? And then I tried it and it was... I can't believe this is all this is." (AYA #15)</p>
<p>Interest in medical marijuana</p>	<p>"...[W]ith something... that is grown and is natural and...could help...I would definitely be interested...." (Parent #2)</p> <p>"I mean, going forward it's just lots of scans and stuff like that, so I don't think that there's any reason for her to have it, going forward." (Parent #13)</p>	<p>"I'm a huge fan of it...one thing I was excited about when I got my tumor was, 'Sweet, I can now go get a medical card.'...that was the first thing I did when I got out of the hospital was, go get a medical license..." (AYA #12)</p> <p>"I mean, I'll have...a higher quality of a life...I won't have like to like be in the hospital all the time." (AYA #15)</p>
<p>Experiences with children using medical marijuana</p>	<p>"[W]e connected with that other parent and she... let us use some of her son's [supply], until we got... 'cause it's quite a process? And I felt safe and comfortable 'cause she's a really... good parent that educates herself, and... I felt like I trusted her to do that." (Parent #8)</p>	<p>"I knew the effects of recreational [marijuana], so...when I was experiencing nausea symptoms and sleep issues and...appetite problems...instead of asking for...new, more pills – which no one needs..." (AYA #14)</p>
<p><u>Perceived Benefits and Risks</u></p>		

<p>Potential benefits</p>	<p>“The pros, for our experience, have been...appetite increase by like astronomical amounts within 24 hours of starting it...” (Parent #8)</p>	<p>“[I]t can stop upset stomachs, it can help with pain...it could help with nausea...but I believe that there are...better medicines to treat that.” (AYA #10)</p>
<p>Perceived efficacy</p>	<p>“[My daughter] was post-transplant, so, she had zero appetite. She would not drink or eat...anything. And within 24 hours [of starting medical marijuana], she was asking for...ten different [food] items.” (Parent #8)</p>	<p>“[I]t’s great at just taking away whatever pain or especially nausea, which is what I fight with most.... I’ve lost 35 pounds, from the beginning of my treatment and it’s the only thing that lets me eat...” (AYA #12)</p>
<p>Medical marijuana as cancer-directed therapy</p>	<p>“I found... Phoenix Oil... stories about leukemia being controlled with that oil.” (Parent #4)</p> <p>“...[A] lot of people like don’t do conventional therapy, and they’ll just use [marijuana] as an alternative therapy to...fight cancer...” (Parent #7)</p>	<p>“...Some people...think it inhibits cancer cell growth.” (AYA #7)</p> <p>“[I]t’s not medically proven, but it’s anecdotally proven that... medical marijuana destroys tumors...it’s saved millions of peoples’ lives.... maybe not millions, but a lot of peoples’ lives.” (AYA #14)</p>
<p>Risks and concerns</p>	<p>“...I don’t know if there have been studies on the safety for children under the age of like six, for example...” (Parent #11)</p> <p>“I would just be concerned that it doesn’t get overused or prescribed when not even needed...” (Parent #15)</p>	<p>“[M]arijuana [i]s just like opioids, where...it’s not meant to be used for a long period of time...most people can get hooked on it...” (AYA #10)</p> <p>“The cons are... you know, it can be kind of pricey, ‘cause it’s not covered by insurance.” (AYA #12)</p>
<p>Minimizing risk relative to other medications</p>	<p>“I think for cancer patients, I’d be less concerned about things like addiction...and more concerned about... making sure that their symptoms are managed.” (Parent</p>	<p>“I don’t think it’s as bad as... many other drugs, like cocaine or heroin... does anyone really die from using it?” (AYA #1)</p>

	<p>#9)</p> <p>“...[T]here’s all these other legalized drugs that are so much worse than medical marijuana.” (Parent #11)</p>	<p>“I feel like it’s a lot safer than anything they try and prescribe, ‘cause I don’t want to get addicted to...you know, pain killers or other medications, when it’s not necessary.” (AYA #12)</p>
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Abbreviation: adolescents and young adults (AYA)

TABLE 4 Perspectives on legal access to medical marijuana and conversations with oncologists

	Parents	Adolescent and Young Adult (AYA) Patients
<u>Uncertainty and Challenges in Legal Access</u>		
Legality	<p>“Honestly, I absolutely have no clue as to...what is the legal situation... But I believe it’s now legal in Mass, right? (Parent #12)</p> <p>“You have to get a doctor that can prescribe it to you. And then you have to go to one of those dispensaries or something... there’s only a few in the state, and that you have to have a prescription for it. And that there are edibles there and there are... plants there, too. That’s all I know.” (Parent #10)</p>	<p>“...I’m pretty sure...it’s legal in certain states, medically only...I think it’s legal here in Massachusetts if you have a card...” (AYA #1)</p> <p>“I know it’s been legalized, here in the Commonwealth of Massachusetts. And, there are certain restrictions on...how you can buy it...certain places where you can buy it... I believe there’s already a system in place where you always need a new prescription when you run out.” (AYA #10)</p>
Perspectives on access	<p>“That they make you jump through hoops to get what you need for your child...it’s not accessible at all.” (Parent #7)</p>	<p>“[W]hen I was maybe 17 or 18, I tried to get a medical license through my pediatrician, and they kind of just laughed me, they were like, ‘You have to go to a less reputable...doctor,’ because they didn’t want to put themselves in that position of prescribing it.” (AYA #12)</p>

		<p>"I talked to my doctor...months ago...about getting a recommendation and he said, 'Yeah, sure. It's no problem for cancer patients, so.'...It was just that easy. It was fillin' out a little bit of paperwork and then I got my card and that's it." (AYA #14)</p>
<p>Oversight by medical professionals</p>	<p>"...[I]f it's under supervision of a physician...and where these kids have cancer and they're in a lot of pain, if they could maybe decrease some of the opioids that they take, you know... it'd be great." (Parent #10)</p> <p>"I assume that the research has been done that would show that it doesn't affect development. And I think if it's used safely, then... you know, that he's not becoming a pothead..." (Parent #11)</p>	<p>"For safety, I think that... patients should be having a follow up, maybe every week? And, also that...they should be given a supply up to the point where they have to go back for a follow up to get a new prescription every time." (AYA #10)</p>
<p><u>Limited Conversations with Oncologists</u></p>		
<p>Most common sources of information</p>	<p>"I would look there [internet], as well? But I would take whatever the oncologist said as to be factual." (Parent #13)</p>	<p>"Just tryin' to be...careful with...sources...just not going onto Google...not just like do a 2-second thing on it...I really...did a lot of research, I've read a lot about other people who have used it." (AYA #15)</p>
<p>Oncologists</p>	<p>"And, you know, and for whatever reason...it isn't being brought up...But I'd be curious to know her thoughts and...insight. You know, to have more insight so I am a little more educated about it." (Parent #2)</p>	<p>"I knew that they...weren't gonna write me [a recommendation], so I knew how to achieve what I wanted to get, without any kind of their approval...I know what works for me. If they were going to say, 'No,' I was still gonna get it." (AYA #12)</p>
<p>Friends, family, or other patients</p>	<p>"[A]ctually we have a mutual friend whose daughter...takes medical marijuana, due to epilepsy. So I called her and... she helped me navigate through." (Parent #7)</p>	<p>"I'm only hearing positive things and, you know, I'll be like, 'Dude you're having a hard time?' He's like- 'You need to smoke. You need to try it!' 'Cause, if it's not helping you then, you know, you don't</p>

	<p>“[S]he actually educated me, just as well as the wellness center when I went to her home, and her son is four, and she...showed me how she does the drops with him and she showed me the company, the name of the company and she... said that she knew the company owner, personally, and that they’re legitimate.” (Parent #8)</p> <p>“We have family, my in-laws, that believe it’s the cure-all for everything!” (Parent #9)</p>	<p>have to keep doin’ it. But, there’s no reason to suffer when you have this option.” (AYA #12)</p> <p>“Well, everyone, like, all my friends...and even...my mom was... really against it, and then once she saw...how much it was helping me...she...is completely fine with it, now.” (AYA #15)</p>
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Abbreviation: adolescents and young adults (AYA)