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Grassroots Medical Change: How Parents Seeking Medical Cannabis for Pediatric Seizures Impact Medical Paradigms, Expertise, And Community

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ABSTRACT: The study examines how families seeking medical cannabis for children with treatment-resistant epilepsy drive transformative change in medical paradigms and healthcare systems. Through interviews with nine parents, researchers identified how these families' experiences challenge conventional treatment approaches while demonstrating cannabis's efficacy in reducing seizures and improving quality of life. Our research reveals a consistent pattern: parents transition from desperate treatment-seekers to knowledgeable advocates as they navigate complex medical, legal, and regulatory barriers. Many families relocate as "medical refugees," sacrificing careers and support networks to access treatment. The findings highlight three dominant themes: the stark contrast between conventional treatments and cannabis efficacy, parents' evolution into system navigators and advocates, and the formation of supportive medical cannabis communities that facilitate knowledge sharing and collective action. These interconnected themes illustrate how grassroots patient advocacy can reshape medical practice and public policy when established systems prove inadequate.

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alternative medicine, medical cannabis, medical refugees, patient advocacy, pediatric epilepsy, seizures, treatment-resistant epilepsy

INTRODUCTION

Treatment-resistant epilepsy in pediatric populations presents a significant therapeutic challenge, affecting both clinical outcomes and quality of life for young patients and their families. Despite advances in conventional anticonvulsant therapies, a substantial proportion of children continue to experience inadequate seizure control, prompting the exploration of alternative treatment modalities. In recent years, medical cannabis, particularly cannabidiol (CBD)-enriched formulations, has emerged as a promising therapeutic option for this vulnerable population. Beyond seizure control, cannabis-based treatments have shown promising effects on broader aspects of patient well-being, including improvements in behavior, alertness, and sleep quality, with caregivers reporting enhanced energy levels, memory function, and social interactions. Parents of children with treatment-resistant epilepsy increasingly face the complex decision of pursuing cannabis-based treatments, often navigating this choice amid limited clinical guidance and varying legal and regulatory challenges, treatment accessibility, and social implications.

To investigate the lived experiences of families pursuing cannabis treatment for their children, we asked the following research questions:

1. How do families' comparative experiences with conventional treatments and medical cannabis challenge established medical paradigms for treating intractable pediatric seizures?
2. How does the necessity of navigating complex medical, legal, and regulatory systems transform parents from treatment-seekers into experts and advocates capable of driving systemic change?
3. What roles do emergent cannabis communities play in facilitating treatment access, knowledge sharing, and social support when families face geographic displacement and institutional barriers?

LITERATURE REVIEW

The therapeutic potential of medical cannabis, particularly cannabidiol (CBD)-enriched formulations, has emerged as a significant area of research in pediatric epilepsy treatment. This review examines the growing body of evidence supporting cannabis-based interventions for children with treatment-resistant epilepsy while also addressing the complex medical, social, and regulatory landscape surrounding these treatments. Current research indicates promising efficacy in seizure reduction alongside secondary

benefits in behavior, cognition, and quality of life. However, the field faces several challenges, including optimal dosing strategies, pharmacokinetic considerations, and accessibility barriers. Parents seeking these treatments often navigate a complicated terrain of medical skepticism, financial constraints, and legal uncertainties. While preliminary evidence suggests favorable outcomes, the need for more rigorous clinical trials remains paramount to establish definitive safety profiles and treatment protocols. This literature review synthesizes current findings on efficacy, examines practical implementation challenges, and explores the broader implications for healthcare policy and clinical practice.

Medical cannabis, particularly cannabidiol (CBD)-enriched formulations, shows promise in reducing seizure frequency for children with treatment-resistant epilepsy. Multiple studies report significant seizure reductions, ranging from 56% to 89% of patients experiencing improvements (Hausman-Kedem et al., 2018; Tzadok et al., 2016; Zafar et al., 2021). CBD doses varied across studies, typically ranging from 1-20 mg/kg/day (Tzadok et al., 2016). Some research suggests combining CBD with THC may be more effective than CBD alone (Erridge et al., 2022; Zafar et al., 2020).

Benefits beyond seizure control include improved behavior, alertness, and sleep (Porter & Jacobson, 2013; Tzadok et al., 2016). Caregivers reported enhancements in energy, memory, social interactions, and overall quality of life (Rosenberg et al., 2017; Sousa et al., 2023). Similar benefits were noted in children with complex motor disorders (Libzon et al., 2018). While generally well-tolerated, common side effects include drowsiness, fatigue, and gastrointestinal disturbances (Elliott et al., 2019; Tzadok et al., 2016). Despite promising results, researchers emphasize the need for more rigorous clinical trials to establish efficacy and safety definitively (Elliott et al., 2019; Huntsman et al., 2020).

Although cannabis-based treatments, particularly cannabidiol (CBD), have shown promise in reducing seizure frequency in children with treatment-resistant epilepsy (Elliott et al., 2019; Porter & Jacobson, 2013; Tzadok et al., 2016), challenges remain in determining appropriate dosing and understanding pediatric pharmacokinetics (Huntsman et al., 2020). While some studies report improved sleep, alertness, and mood (Neale, 2017; Tzadok et al., 2016), others highlight potential side effects such as drowsiness and gastrointestinal issues (Elliott et al., 2019; Porter & Jacobson, 2013). The efficacy of cannabis-based treatments may vary depending on the epilepsy etiology and concurrent anticonvulsant use (Neale, 2017). Legal and regulatory hurdles, as well as high costs, can impede access to these treatments (Chen et al., 2018). Despite growing interest and anecdotal evidence, more rigorous clinical trials are needed to establish long-term safety and efficacy (Chen et al., 2018; Elliott et al., 2018; Lorentzos & Webster, 2015).

When parents of children with drug-resistant epilepsy turn to medical cannabis as a last resort when conventional treatments fail, they face numerous social challenges, including resistance from neurologists, high costs, and legal uncertainties (Elliott et al., 2020; Sobo, 2017). Many parents encounter resistance from neurologists and struggle to obtain authorization, leading them to seek alternative sources (Elliott et al., 2020a; Elliott et al., 2020b). Due to limited guidance from healthcare providers, parents typically rely on diverse information sources, including social media and other families (Gibbard et al., 2021; Ryan et al., 2020). Parents often feel compelled to experiment with dosing due to a lack of professional guidance (Gibbard et al., 2021; Ryan et al., 2020). Financial barriers are significant, with some families spending up to $2000 monthly on uninsured treatments (Elliott et al., 2020a). The illegal status and stigma associated with cannabis create additional hurdles (Sobo, 2017; Sobo, 2021). Some have even pursued legal action to improve access (Dyer, 2020).

The reviewed research demonstrates both the promise and complexity of medical cannabis treatments for pediatric epilepsy. While significant seizure reductions and quality-of-life improvements have been documented across multiple studies, the path to widespread implementation remains challenging. The reported efficacy rates in seizure reduction, coupled with improvements in behavior, sleep, and social functioning, suggest that CBD-enriched formulations could represent a valuable therapeutic option for treatment-resistant cases.

THEORETICAL FRAMEWORK

This study is grounded in three complementary theoretical frameworks that together illuminate how parents navigate medical cannabis use for their children with seizure disorders: the theory of therapeutic decision-making under uncertainty (Scholz, 1983), lived experience as epistemic authority (Voronka, 2016), and the socio-ecological model of health behavior (Bronfenbrenner, 1977). Together, these frameworks support the analysis of how parents evaluate and navigate treatment uncertainties, the role of experiential knowledge in medical decision-making, the influence of multilevel contextual factors on treatment choices, and the interplay between formal medical knowledge and parental expertise. This theoretical foundation guided our analysis of parent interviews, informing both our analytical approach and interpretation of emergent themes.

The theory of therapeutic decision-making under uncertainty (Scholz, 1983) provides a lens for understanding how parents weigh potential benefits against risks when considering non-traditional treatments. This framework posits that the intersection of scientific knowledge, personal values, and perceived urgency of the medical condition shapes medical decisions in contexts of

limited clinical evidence. For parents of children with severe seizures, this decision-making process is particularly complex given cannabis's contested legal status and varying levels of medical legitimacy.

The lived experience as an epistemic authority framework (Voronka, 2016) foregrounds the unique knowledge that emerges from direct caregiving experience. This framework validates parents' experiential knowledge of their children's responses to treatment, positioning them as legitimate knowledge producers rather than passive recipients of medical expertise. Parents' detailed observations of seizure patterns, medication effects, and quality of life impacts constitute a form of expertise that complements clinical knowledge.

The socio-ecological model (Bronfenbrenner, 1977) contextualizes parents' decision-making within broader social, institutional, and policy environments. This framework illuminates how parents' therapeutic choices are shaped by multiple intersecting factors: healthcare systems' openness to alternative treatments, state cannabis laws, social stigma, support networks, and access to both traditional and alternative medicine. The model helps explain variation in parents' experiences across different regulatory and healthcare contexts.

This theoretical synthesis offers a robust foundation for exploring the complex intersection of parental agency, medical authority, and regulatory environments in the context of pediatric seizure treatment. By integrating these three frameworks, we recognize parents not merely as decision-makers operating under uncertainty but as knowledge creators whose lived expertise directly informs their navigation of multilayered systems. The study acknowledges the dynamic tension between established medical paradigms and emergent treatment approaches, particularly when conventional options have proven insufficient. This theoretical triangulation enables a nuanced analysis that honors the complexity of parents' experiences—balancing hope and risk, navigating legal and medical ambiguities, and advocating for their children's well-being within systems that may alternately support or constrain their therapeutic choices.

METHODOLOGY

This qualitative study employed semi-structured interviews with parents of children diagnosed with seizure disorders who have used cannabis-based treatments (N=9). Upon receiving approval from Empire State University's Institutional Review Board, participants (see Table 1) were selected using purposive sampling. The study targeted families who had relocated to Colorado to access medical marijuana, as restrictive drug policies in their home states had hindered their ability to obtain cannabis for treating catastrophic or life-limiting illnesses affecting their loved ones.

Recruitment was facilitated through the Realm of Caring, a nonprofit organization based in Colorado Springs, Colorado. Founded on August 7, 2013, Realm of Caring educates, guides, and empowers the public on the potential benefits of cannabinoid therapy for individuals with serious medical conditions such as cancer, multiple sclerosis, HIV/AIDS, epilepsy, Parkinson's, and Alzheimer's. They also provide access to concentrated cannabinoid extracts and monitor client progress through an IRB-approved observational research study conducted in collaboration with Johns Hopkins University.

Participants in our study engaged in interviews lasting approximately 45 minutes and were compensated with a $25 Amazon gift card. Prior to participation, written informed consent was obtained to ensure confidentiality. All interviews adhered to a semi-structured format and were audio-recorded for research purposes. Inclusion criteria required participants to be primary caregivers of children (aged 0-18) with documented seizure disorders who had administered cannabis-based treatments for at least six months. Interviews were conducted between July 2021 and September 2022, lasting 60-90 minutes each. The semi-structured interview protocol explored parents' experiences with traditional treatments, decision-making processes regarding cannabis use, administration methods, observed outcomes, and challenges encountered. All interviews were audio-recorded and transcribed verbatim, with identifying information removed to ensure confidentiality.

Table 1. ***Participants' Information***

Mother's Name	Child's Name	Diagnosis	Family Situation Summary	Treatment Experience
Nicole	Brandon	Infantile Spasms, diagnosed at 5 months	Lives in Colorado; worked in real estate but became stay-at-home mom	Brandon started cannabis in 2013; reduced seizures from 30-50/day to nearly zero; able to reduce other medications
Holly	Zane	Rare Catastrophic Epilepsy (1 of 40 in world)	Founded Realm of Caring; a pioneering advocate for cannabis treatment	Zane started 2012; went from 200 seizures/day to significant reduction; transitioned from hospice

Pamela	Jacob	Doose Syndrome (myoclonic astatic epilepsy), diagnosed age 1	Relocated from Ohio to Colorado in 2014; ended 30-year marriage	Achieved seizure freedom with THC-a; able to eliminate multiple pharmaceuticals
Diana	Madison	Epilepsy and Autism	Relocated from Pennsylvania with family, including 2 stepsons	Significant improvement with combined THC/CBD treatment; initial challenges with dosing
Grace	Lucas	Lennox-Gastaut Syndrome	Lives in Maryland; became a cannabis industry CPA	Achieved seizure control through CBD; helped pass state legislation
Natalie	Not specified	Multiple seizure types, diagnosed at 6 months	Early adopter of Charlotte's Web CBD	Significant reduction in seizures; improved cognition and development
Natasha	Molly	Lennox-Gastaut Syndrome, cerebral palsy	Relocated to Colorado from Nashville in 2014	Initially saw improvement with Charlotte's Web but later transitioned to pharmaceutical
Sofia	Leon	Spastic Quadriplegia, seizures	Relocated from North Carolina to Colorado in 2014	Successful with CBD treatment; reduced from 6 grand mal seizures daily to 1 every 10 days
Sarah	Ryan	Focal Cortical Dysplasia, diagnosed at age 4	Lives in Texas; epilepsy foundation board member	Started CBD 2014; seizure-free since April 2014; active advocate for legislation

Data Analysis

The analysis followed Saldaña's (2015) two-cycle coding approach. In the first cycle, initial coding employed descriptive and in vivo coding to capture researcher-identified themes and participants' verbatim language. This initial coding uncovered 708 unique codes. Second-cycle coding utilized pattern coding to identify emerging themes and theoretical constructs. This process revealed how the initial 708 codes could be organized into five major thematic categories: Treatment Journey and Efficacy, Access and Legal Challenges, Medical Professional Interactions, Family and Social Impact, and Advocacy and Education. Within each of these major constructs, 19 secondary themes emerged (see Table 2).

Table 2. ***Primary and Secondary Themes for Parent Interviews on Pediatric Medical Cannabis***

Primary Theme	Secondary Themes	Characteristic Interview Quotes
Treatment Journey & Efficacy	Surgical Treatments and Prescriptions	"... we started a regimen of ACTH (adrenocorticotropic hormone) shots to the legs every day... And at the beginning it seemed to help. After three weeks it started coming back... we [then] started medication for seizure control. He was doing anywhere from 30 to 50 spasms a day. He had brain surgery when he was a year and five months …the idea was to find the focal area and where they [seizures] were being formed and remove that." (Nicole)
	Side Effects	"Because of a lot of medications that she was taking, she was having…also a lot of behavioral issues…banging her head, self-harming herself kind of being violent and I was told, well, she is also on the [Autism] spectrum…So they started giving her some sort [of] an antidepressant…she was hallucinating, I could tell. This kid was just not sleeping, screaming all the time. It was really, really bad." (Natalie)
	Quality of Life	"When he was having seizures, we had no quality of life. I mean, my husband and I didn't. All we did was try to make our older two kids have as normal a life as possible. They were both very involved with sports and had a lot of friends and that was all we did. When he was on the ketogenic diet for 16 months, my husband and I did nothing but cook…every single moment we had we cooked on the ketogenic diet and did dishes

		and that was it. We never saw our friends. We barely did anything at all, never went to the movies, barely watched TV. We were also in the hospital all the time and it was just that was our life." (Grace)
Access & Legal Challenges	Burdens	"We had to move from Nashville... Not really much support. We found a realtor and looked at a few houses, but it was suburban areas and I am not a suburban person. That was tough, but those were the areas that were available and that were affordable because we had exhausted everything trying to get here... We don't have any family that's local. Everyone's afraid to fly. That's been hard." (Pamela)
	Reliable Access	"I'd heard about cannabis but not in the…medical way. Some of the moms…smoked cannabis and they would kind of 'feed' it to their kids. There was nobody talking about any tinctures. Someone told me.. there are some sodas that they have cannabis … and it really helps calm them down. I tried to contact [Realm of Caring] and I was told… there's this website you could try to email and contact them [Stanley Brothers]. They said, 'Okay, well we have a contact person there [in my state]. You can contact them.'" (Natalie)
	Advocates for Legislation	"In one of my other mom groups, one of the moms sent letters to her legislators to try to pass a bill and we looked into moving to Colorado as part of the green rush but my older two kids were very involved with their sports and their friends. My husband works for the federal government so moving out of Maryland just did not work with our family. It was a tough decision but we decided to stay and educate and try to get a bill passed here. I created an organization called Stop the Seizures. It was just a chance to try to pass a bill here." (Grace)
Medical Professional Interactions	Initial Reactions	"I kept him [the doctor] informed of everything. We had several, not arguments, but, little back and forth because obviously, there was a lack of research when we started. I told him, 'I have to do what I have to do for my son and his well-being'. No, he was not open at all. I remember one day it got pretty heated because I had taken him off all these medications and he said, I don't think this is a good idea. And I said, but he's doing really good. And he said to me, 'Brandon's gonna die.'" (Nicole)
	Finding Supportive Providers	"I walked into my doctor's office in December of 2013. We had a neurologist named Philip Pearl who is now with Harvard, but he was with the Children's Hospital in D.C. at the time and I had a stack of research about cannabis and epilepsy and was [as] nervous as you could possibly be. I was worried about child services to say the least, and his response was nothing's worked for your child. Go for it and let me know how you can get access to it because I have a lot of other patients who he thought would benefit." (Grace)
	Child Protective Services (CPS) Concerns	"There has been a situation where kids have been removed from the home, not just in Colorado, California, I'm thinking of a case in Arizona I'm thinking of a case where the Child Protective Services, you're talking to a neighbor and you say, 'I give my kid cannabis or something' and they call the Department of Human Services they have to investigate it." (Holly)
	Managing Dual Care Systems	"I thought doctors were going to be more open here because of the cannabis boom, but doctors were not, especially with neurologists; they were not. Even in Colorado…they were always pushing for medicine, saying that doesn't work. There haven't been enough studies." (Nicole)
	Medical Professionals as Advocates	"That same neurologist who said it would never work…She ended up being one of the doctors who testified in support of the [CBD] bill before it was signed. We were at a hearing, a committee hearing at the State Capitol and…three local doctors had come to

		support the bill and say that they would love to have this option of treatment available for patients who often have really medication-resistant epilepsy.'" (Sarah)
Family & Social Impact	Family Strain	"I left behind everything, my friends, my church. It was painful and we had known. And my husband at the time had just started with a new company and he said, 'Well I'm going to stay in Cleveland with my people and good luck. Have fun in Colorado and I'm staying here.' And I said, 'Okay, great. I'll go save our daughter's life and I'm going to go to Colorado.'" (Pamela)
	Community Support	"Well the Realm of Caring, meeting parents that moved like us, that really understood, a good sense of community here. Cannabis refugees, they call us, and we were supporting each other because we knew that we left everything behind." (Nicole)
	Social Stigma	"The worst part of it was kind of the stigma around it and most people who know what I've been going through with my son, I live in a relatively liberal area but sometimes there's just judgement." (Grace)
Advocacy & Education	Becoming Advocates	"I created an organization called Stop the Seizures, which wasn't even a not for profit.It was just a chance to try to pass a bill here. We got a bunch of parents together and we were very successful. I'm super proud. In the beginning, I told nobody that I was advocating, only on an as-needed basis." (Grace)
	Creating Support Networks	"So we were one of the, I would say we were one of the first five, the first ten families that came out into this network. We were one of the early ones so we just embraced each other as family and then as families would come in we would help with moving, we'd babysit, we'd connect them with doctors, get them cannabis, groceries. We just became a family out here. It's very unique." (Nicole)
	Educating Others	"I know everybody was super happy. I mean, and then a lot of parents, the same thing. They would ask me what did you do? When this thing works so well you can't just sit back and say I don't want to share. You want everybody to know that." (Nicole)
	Shared Lived Experiences	"We befriended each other. She had her son in a wheelchair as well. She's like, are you here for the medical marijuana thing? And I said, 'yes, I am.' She's like, 'yeah, so am I.' And sadly enough she… knew some religious leaders here in Colorado and they told her she can come and stay with her son. Well, that morning that she went to the doctor's appointment they had found out what she was here for which was the medical marijuana — and they said she could no longer stay at their house. I brought her home with me and she stayed with me a few times." (Nicole)
	Witnessing Growing Acceptance	"Oh, yeah. People have come around a long way…coming from a person that dealt with it from the beginning… I got death threats. I was told I was going to hell." (Nicole)

To ensure trustworthiness, we employed multiple validation strategies: Member checking with participants to verify interpretation accuracy, peer debriefing with qualified researchers, maintenance of an audit trail documenting analytical decisions, and regular research team meetings to discuss and refine emerging themes. Analysis continued until theoretical saturation was achieved, with no new themes emerging from the data. Disagreements in coding were resolved through discussion until a consensus was reached.

RESULTS

This study examines the experiences of nine parents who sought medical cannabis treatments for their children suffering from severe seizure disorders. Through in-depth interviews, we identified five major thematic areas that characterized their journeys: treatment journey and efficacy, access and legal challenges, medical professional interactions, family and social impact, and advocacy and education. These themes reflect the complex intersection of medical necessity, legal barriers, and personal sacrifice that shaped these families' experiences. Many relocated across state lines as "medical refugees," leaving behind jobs, extended family, and support networks in desperate pursuit of treatment options when conventional pharmaceuticals failed. Their narratives reveal a shared determination to improve their children's quality of life, often in the face of significant medical skepticism, legal risk, and financial hardship. Through their experiences, we see how parents became not only caregivers but also advocates, educators, and pioneers in an emerging treatment landscape. Their testimonies provide valuable insights into the lived realities of families navigating uncharted medical territory while balancing the practical, emotional, and social challenges of caring for children with severe epilepsy conditions.

Treatment Journey & Efficacy

The path to medical cannabis for these families was rarely their first treatment choice, but rather represented a last resort after exhausting conventional medical options. Parents consistently described a pattern of failed traditional treatments - including multiple anti-seizure medications, surgical interventions, and extensive neurological consultations - before turning to cannabis alternatives. These experiences highlight a critical gap in conventional treatment approaches for certain seizure disorders, where families find themselves navigating increasingly complex medication regimens with diminishing returns. Their collective journey illustrates not only the limitations of current medical paradigms for treating intractable seizures but also reveals the desperation that drove these parents to consider alternative treatments despite significant legal, financial, and social obstacles.

Surgical Treatments and Prescriptions. All the parents in the study share a common origin story: they initially tried traditional surgical treatments and prescription seizure medications and found limited success with these approaches. As Nicole said about her son, Brandon's, experience with surgical treatment,

> He had brain surgery when he was a year and… and five months… Unfortunately, with Brandon, it was all over the place...Side note: if I would have known about medical marijuana before, I would never had [sic] done that to my son.

The other parents discussed the journey they took to find neurologists and medications that could help their child's seizures. In Lucas's case, Grace found little relief with traditional approaches: "We had tried eight pharmaceuticals, seen about six different neurologists across the country…did all kinds of genetic testing and nothing stopped the seizures." Nicole also mentioned that they tried experimenting with different and combined medicine approaches to control Brandon's seizures: "We started medication for seizure control...adding another medication, another medication, another medication. He was up to four medications..." Echoing both Grace and Nicole's experiences, Sofia's son, Luca, was also prescribed multiple medications: "We went through so many medications and mixed medication and nothing ever worked." Sarah said that her son, Ryan, also got no relief with traditional anti-seizure medications: "He was being completely unresponsive to the…pharmaceutical medications that they were trying." Having endured a similar experience, Zane's mother, Holly, shared a bleak outlook on the potential effectiveness of future prescriptions on seizure control: "After you've failed three medications, statistically there's less than one percent chance that you're going to find a med that's going to work." In these interviews, it is clear that the families tried the traditional route to seizure treatment for their children and endured a lot of failed attempts and disappointments with the effectiveness of surgical, genetic, and prescription approaches.

Side Effects. Beyond the challenges of finding a medication that would reduce the seizures, several parents mentioned debilitating side effects while their children were on them. For Natalie, she witnessed some particularly frightening behaviors in her daughter while on prescription seizure medication, "She was hallucinating…not sleeping, screaming all the time…having … a lot of behavioral issues;…banging her head…just harming herself…being violent." Grace also mentioned Lucas's hallucinations and screaming while on medication: "She was hallucinating...this kid was just not sleeping, screaming all the time." Other parents mentioned cognition issues while on anti-seizure medications. Sarah explains how the medication's shared purpose and side effects impacted Ryan's cognition, "…the whole purpose [of anti-seizure medication] is to sort of numb the brain so that it doesn't seize. But in numbing the brain, (it) also makes it hard to learn…remember things… find words. It affects your speech."

Several parents contrasted these negative side effects with what they described as minimal to no side effects when using cannabis-based medicines. They specifically noted that their children were more alert, engaged, and functional on cannabis compared to traditional anti-seizure medications. All the parents in the study mentioned that CBD/cannabis often provided significant seizure reduction or elimination. However, the initial effectiveness of cannabis treatment sometimes varied - some saw immediate results, while others required patience and dosage adjustment. For example, Natalie told us "after six weeks my kid--the first thing I noticed is she was starting to sort of say words. Shocked. I didn't see any [seizures]." In Sarah's son's case, he has been

seizure-free since 2014. She said, "And then April, one day he just didn't have any drop seizures...And that was April 2014, and I'm knocking on wood because epilepsy parents are really superstitious."

Quality of Life. Many parents reported an improved quality of life for their child beyond just controlling the seizures (better sleep, cognition, and mood) and for the entire family. For Brandon, Nicole said she witnessed improved cognition/alertness ("he looks, you know, he engages with you"), better mobility/physical activity ("before he couldn't sit up straight...he could, like, get on his walker and walk around, give a lot of steps...now I had him on a tricycle, you know, paddling"), and improved appetite and digestion. Sofia mentioned "the doctor was very surprised that Leon has no pain." beyond seizure control, Natalie saw improvements in her daughter's language and sleep, "After six weeks…she was starting to sort of say words...she can put complete sentences together. She can say her needs...her appetite, her sleep. Now she sleeps really well." Grace cited Lucas's improved learning ability, better cognitive function, and reduced side effects compared to pharmaceuticals and positive digestive changes: "We saw cognition getting better...But the first thing that I saw the first day that I gave him the oil is that he went to the bathroom...We saw him sleeping much better." Beyond the improvements in the quality of life for the child, parents also mentioned how using cannabis improved their entire family's quality of life. During our interview with Sarah, she spoke about how Ryan's cannabis treatment helped her family. She said, "When he was having seizures, we had no quality of life."

The stark contrast between children's experiences on traditional seizure medications versus cannabis treatment represents a powerful testimony to the potential therapeutic value of this controversial plant medicine. While conventional treatments often provided limited seizure control at the cost of significant cognitive, behavioral, and physical side effects, cannabis treatments demonstrated a markedly different profile - offering not just seizure reduction but often unexpected improvements in cognition, communication, mobility, and overall quality of life. For many families, these comprehensive improvements transformed daily experiences from survival-focused to development-oriented, allowing children opportunities to engage, learn, and participate in ways previously impossible. Perhaps most significantly, these improvements extended beyond the children themselves to positively impact entire family systems, restoring capacities for normal family functioning that had been compromised by the all-consuming nature of managing uncontrolled seizures. These narratives provide compelling evidence for considering medical cannabis not merely as an alternative treatment of last resort but as a potentially valuable front-line option that might spare families years of ineffective treatments and lost developmental opportunities.

Access & Legal Challenges

The journey to obtain and maintain medical cannabis treatment for children with seizure disorders involved multiple interconnected challenges that extended far beyond medical decisions. Parents faced a constellation of obstacles that affected every aspect of their lives - emotional strain as they pioneered treatment approaches with minimal guidance, financial pressures from both relocation costs and ongoing treatment expenses, complex access barriers even in legal states, and the necessity of navigating legislative landscapes that often failed to meet their children's needs. These challenges converged to create a uniquely difficult path for families already managing the significant demands of caring for medically complex children, requiring extraordinary resilience and determination.

Burdens. The emotional toll on these mothers seeking medical cannabis treatment for their children was immense. They described feelings of desperation, isolation, and determination as they navigated uncharted medical territory. As Natalie explained, "I mean, obviously as a mom you're used to, you just want to get…your child better. So, I was like, oh, God, I gotta wait more." This impatience and urgency was a common sentiment among parents watching their children suffer while waiting for treatment access. Grace expressed frustration at the lack of organized cannabis treatment information: "I had to start at square one, which made no sense to me, you know, at all. I was like, 'this is…just infuriating that thousands, tens of thousands of people...nobody is writing down what they're doing.'" Parents had to pioneer their treatment approaches with minimal guidance, creating an additional emotional burden beyond the already challenging circumstances of caring for a chronically ill child.

Financial challenges presented significant obstacles for families seeking medical cannabis treatments. The costs extended far beyond just the medicine itself to include relocation expenses, legal consultations, specialized medical care, and often the loss of employment. Pamela described depending on family support after relocating: "When we first moved here, I was still married…so I didn't get alimony or child support… It was very little money, and so my dad helped me with that." Even after securing access to medical cannabis, the ongoing expense remained problematic, as Grace noted: "The price... I know a lot of people can't afford it because... usually those are pretty expensive and not everybody can afford it." The lack of insurance coverage for cannabis treatments meant families absorbed these costs entirely out-of-pocket, creating financial strain that compounded their other challenges.

Reliable Access. Families faced tremendous obstacles in obtaining consistent, reliable access to medical cannabis treatments. Many were forced to relocate to states where treatment was legal, while others engaged in complex, sometimes risky arrangements to secure medicine. As Pamela explained, "We had to move from Nashville, and we relocated in January of 2014 to Colorado. And, that's where we still live." Even when relocating, families encountered barriers, including waitlists and supply

challenges. Sofia described this journey after watching Dr. Sanjay Gupta's documentary on CNN, "We moved over here… jobless…we sold our home there... we were going to access it right away, but there was a standby list." The path to securing consistent treatment required extraordinary sacrifice, driving many families to become advocates for expanded legalization to ensure other families wouldn't face the same difficult choices they did.

Advocates for Legislation. Parents frequently became advocates for cannabis legislation in their home states after experiencing the challenges of relocation or restricted access. Although these advocacy efforts often led to legislative victories, sometimes they came with significant limitations. As Sarah from Texas explained, "Our bill passed...our governor signed our bill in June of 2015. But it was only for intractable epilepsy... in 2019, …our legislature here in Texas expanded the bill to include those with PTSD, Parkinson's…all sorts of neurological conditions." Grace mentioned that she initially considered relocating to Colorado but instead became an advocate for legislative change in her home state:

> We looked into moving to Colorado as part of the green rush …, but my older two kids were very involved with their sports and their friends. My husband works for the Federal Government, so moving out of Maryland just did not work with our family. It was a tough decision, but we decided to stay and educate and try to get a bill passed here. So, I created an organization called Stop the Seizures.

Parents often found themselves becoming experts on cannabis policy, educating legislators and the public about both research findings and the human impact of restrictive policies on families with medically complex children.

These intersecting challenges reveal how the pursuit of medical cannabis treatment required parents to develop skills far beyond caregiving - becoming researchers, financial strategists, advocates, and policy experts. What began as a desperate search for effective treatments often transformed these parents into powerful voices for systemic change. Their accumulated expertise, born from necessity and refined through experience, became an invaluable resource for other families and a catalyst for legislative reform. Despite facing emotional exhaustion, financial hardship, and complex access barriers, these parents demonstrated remarkable persistence in their determination to improve not only their own children's lives but also the landscape for families who would follow. Their stories illustrate how grassroots advocacy, driven by personal experience, can ultimately reshape medical, social, and legal approaches to treatment access for vulnerable populations.

Medical Professional Interactions

Parents seeking medical cannabis treatment for their children with severe seizure disorders inevitably had to navigate complex relationships with healthcare providers. These interactions ranged from confrontational to supportive, often evolving as treatment outcomes became apparent. The medical establishment's response to cannabis as medicine reflected broader societal tensions around its use, particularly for children. Parents found themselves caught between their desperate search for effective treatments and the established medical paradigms that often viewed cannabis with skepticism or outright rejection. How these relationships unfolded significantly impacted families' treatment journeys, access to care, and emotional well-being.

Initial Reactions. Parents frequently encountered resistance and skepticism from medical professionals when pursuing cannabis treatment for their children. The medical establishment's response ranged from cautious support to outright opposition. Sarah recounted a pivotal interaction: "The neurologist looked right at my husband, and she said, 'Are you going to get CBD?' And my husband is like, 'Is this a patient-doctor privilege conversation?' And she said, 'Of course.' And he said, 'Yeah, we are.' And she said, 'It will never work.'" Nicole faced similar opposition: "I remember one day it got pretty heated because, you know, I had taken him off all these medications and he said, 'you know, I don't think this is a good idea.' And I'm like, 'but he's doing really good [sic].' And he said, 'well, would you like to get my opinion?' And I said yes. And he said to me, 'Brandon's gonna die.' Just like that." This dismissive and sometimes confrontational stance reinforced parents' fears about discussing treatment options openly with healthcare providers.

Finding Supportive Providers. Some parents were fortunate to find medical professionals who supported their exploration of cannabis treatment. Grace shared:

> I walked into my doctor's office in December of 2013. We had a neurologist named Philip Pearl who is now with Harvard, but he was with the Children's Hospital in D.C. at the time, and I had a stack of research about cannabis and epilepsy and was [as] nervous as you could possibly be... and his response was 'nothing's worked for your child. Go for it, just let me know how you can get access to it because I have a lot of other patients who would benefit.'

Nicole described finding support in Arizona after relocating:

> They … had already passed their legislation. So they were much more open to hearing about what we were doing.... Like I was still having to bring our CBD with us, and I was having to give it to him, you know, just by myself. But much more accommodating and understanding … what we were trying to accomplish.

These positive interactions demonstrated a growing willingness among some medical professionals to consider alternative treatments when conventional approaches failed.

Child Protective Services (CPS) Concerns. Fear of child welfare involvement loomed large in parents' interactions with medical professionals. Natalie recounted: "We had to find…attorneys who … were willing to help these parents because they were at the hospital and they were saying…, 'my kid takes cannabis' and they were saying, 'No, no, no. What? What are you doing? No.'" Grace described the pervasive fear that affected even basic care decisions: "I was so worried to tell anybody, because…we had a real concern that…somebody might try to call child protective services on us... We never ended up going back to that doctor, ever." Diana shared a similar experience, noting how disclosure in medical settings could have serious consequences:

> …our friend that came out to Colorado did ask the dispensaries that they spoke to...based off of her weight and her age, you know, this is probably where we would start, but, … [it was] really … a …trial-and-error kind of thing... I never let the school know. The only person who knew was her aide.

The reality of possible CPS reports created an environment where parents carefully filtered information shared in various settings.

Managing Dual Care Systems. Parents developed sophisticated strategies for navigating dual care systems—maintaining relationships with traditional medical providers while simultaneously pursuing cannabis treatment. Grace described the delicate balance: "We were very concerned. Nobody knew anything about … the drug-to-drug interaction... we tracked his blood levels for a baseline before we added anything." Sofia shared how this dual-care approach evolved: "I know everybody was super happy. I mean, and then a lot of parents, the same thing. They would ask me 'What did you do?'" Many parents found themselves becoming educators for their medical teams, sharing research and experiences while still maintaining critical traditional medical services for their children.

Medical Professionals as Advocates. Over time, some medical professionals evolved from skeptics to advocates after witnessing the effectiveness of cannabis treatments. Nicole observed this transformation: "And it's the last time anything else was spoken about and I got any opposition from him [the doctor]. Last time. Never again. He never again mentioned it 'cuz …he saw how well he [Brandon] was doing…" Sarah witnessed a similar evolution: "And there she [the doctor] is looking to support [the] CBD bill when she had told me… the year prior that it would never work…" Sarah told this doctor, "'It's been almost a year of being seizure-free just on CBD.' And she [the doctor] said, 'Well, that's why I'm here.'" These transitions from opposition to support within the medical community played a crucial role in advancing broader acceptance of cannabis as a legitimate treatment option.

The evolution of medical professional attitudes toward cannabis treatment represents a microcosm of the broader societal shift in understanding and accepting cannabis as medicine. What began as isolated pockets of support gradually expanded as evidence of effectiveness accumulated through lived experiences. Parents often found themselves in the uncomfortable position of being more knowledgeable about cannabis treatments than their children's doctors, inverting traditional patient-physician power dynamics. Nevertheless, these pioneering families helped forge new pathways for collaboration between medical professionals and cannabis advocates. Their persistence not only improved their own children's care but also contributed to expanding treatment options for future patients, as former skeptics increasingly became advocates based on the undeniable evidence they witnessed firsthand. This transformation, while incomplete, demonstrates how patient advocacy can ultimately drive meaningful change in medical practice.

Family & Social Impact

The decision to pursue medical cannabis treatment for a child with seizures had profound effects that extended far beyond medical outcomes, reshaping family dynamics, social connections, and community relationships. Parents navigated complex social terrain while making life-altering decisions about relocation, employment, and family priorities. Their stories reveal both the painful fractures that sometimes occurred within family systems and the remarkable new support networks that formed among families with shared experiences. These parents became adept at navigating social situations where stigma remained prevalent, carefully managing information disclosure while advocating for their children's needs. The ripple effects of their treatment decisions touched every aspect of their social worlds, creating both challenges and unexpected opportunities for connection.

Family Strain. The pursuit of medical cannabis often created significant strain within family systems, sometimes leading to difficult personal decisions and relationship challenges. Diana described the painful custody battle that ensued when they decided to relocate:

> They [my family] fought us in court to get here so—we did get them here. And then they were here for the remainder of the school year; they basically decided they didn't want to be here anymore... I tried to call the police in Pennsylvania. I called the state police, and I said they were being kidnapped.

Pamela's cannabis journey contributed to the end of her marriage:

> My husband at the time had just started with a new company, and he said, 'Well, I'm going to stay in Cleveland with my people, so good luck. Have fun in Colorado, and I'm staying here.' And I said, 'Okay, great. I'll go save our daughter's life, and I'm going to go to Colorado.

These stories illustrate the profound decisions parents faced, sometimes having to choose between their child's medical needs and maintaining family unity.

Community Support. Despite the challenges, many parents found critical support systems within the medical cannabis community. Holly described how these connections sustained families through difficult times: "When we got here and stood out on our patio, where Pike's Peak is, I just felt, I just said, 'I'm home.'... We were all in the same…boat. And Courtney, of course, Courtney is who connected us with you. She was at the Realm of Caring... became friends … pretty instantly, like a week after I moved here with Madison." Sofia emphasized how these connections became like family: "The Realm of Caring has connected us all. You know, we were all in the same… boat... Pamela is one of our best friends here. She's like family to us. You know, we don't have family here, but they are our family." These support networks proved invaluable, offering practical advice, emotional understanding, and a sense of belonging that many families had lost when relocating away from established support systems.

Social Stigma. Parents continually navigated social stigma surrounding cannabis use, particularly for children. Nicole recounted how she had to carefully manage public perception:

> I know at the beginning everybody thought I was crazy. They thought you are an exhausted mom who just, you know, you just do anything, which is—some aspect is true... I had to lead with, 'It's non-psychoactive.' Because the minute I said cannabis, you know, everybody sort of went to, 'Oh, my God, why would you do that?'

Sarah described how stigma persisted even years later:

> I still always feel like there's stigma and judgment. And so I would say that that is still, you know, part of—like if there is a struggle, that it would be, you know, judgment about the choices that we made even back then. I'm not worried about CPS showing up at my door anymore. [Laughing.] But I feel like that's sort of always been there for us.

This ongoing stigma meant parents became adept at strategically sharing information about their children's treatment, often carefully selecting which social contexts were safe for disclosure.

These social dimensions of the medical cannabis journey reveal how treatment decisions were never made in isolation but within complex webs of relationships that could either hinder or facilitate access to care. The remarkable resilience these families demonstrated extended beyond medical advocacy to encompass building new social structures, educating communities, and finding strength in shared experiences. For many, the cannabis community became an unexpected source of belonging after leaving behind established networks—creating new "families of choice" built around mutual understanding and shared purpose rather than biological ties.

Advocacy & Education

The transition from desperate parent to powerful advocate emerged as a defining journey for many families using medical cannabis for their children's seizure disorders. What began as personal quests for treatment access frequently evolved into broader missions to change systems, educate communities, and support other families. These parents found themselves thrust into roles they never anticipated—becoming researchers, educators, organizers, and policy experts through necessity rather than choice. Their accumulated knowledge and lived experiences transformed into valuable resources that catalyzed broader social and legislative changes, creating pathways for future families and gradually shifting public perception about cannabis as medicine.

Becoming Advocates. Parents frequently described their unexpected evolution into cannabis advocates after witnessing the benefits in their own children. Grace's advocacy journey began when she created a grassroots organization after deciding against relocation:

> I got involved with the Epilepsy Foundation, Texas, specifically for that reason. And I actually like headed up a lot of sort of the grassroots efforts amongst the families... planned visits where we all would show up at our capitol on a certain day together, you know, with wheelchairs and kids in strollers.

For Sarah, advocacy became a moral imperative after experiencing her son's transformation:

> I love being a resource about CBD to families that are newly diagnosed and to share that, you know, it doesn't have to be a wait about—you don't have to try a bunch of really terrible medicines before you get to a place where you can have something that might work.

These parents recognized that their personal experiences could serve as powerful tools to drive systemic change, often prioritizing advocacy despite the additional demands it placed on their already challenging lives.

Creating Support Networks. The isolation many families initially experienced gave way to intentional community-building efforts that created vital support networks for incoming cannabis families. Sofia described how established families welcomed newcomers:

> Part of our blessing now is that when these new families come in, we know about them pretty much before they're coming, and then we become their welcome crew like they were ours before we got here. So, it's like this cycle of, like, 'Come on in. You're family now.'

Holly emphasized how essential these connections became: "Creating community around that because even if they don't get better, they have community. You can get through anything with community." These support networks served multiple functions—

providing emotional encouragement, practical information about dosing and administration, and logistical assistance with housing, medical care, and legal questions—creating a foundation that helped families navigate the complex landscape of cannabis treatment.

Educating Others. Parents frequently found themselves educating medical professionals, schools, family members, and the broader public about cannabis treatments, often developing significant expertise through necessity. Nicole explained this role reversal: "I think we knew more about CBD than she did. And she was willing to learn and help her other patient, but I'd have to take half a day off my work, pull Lucas out of school, and drive..." Grace described the careful educational approach needed with medical professionals: "We trained them how to have these conversations with their doctor. We knew that … the doctors are going to bring up these two things. They're going to say it's not FDA approved and … there's no research to support this." These educational efforts required parents to become well-versed in research literature, medication interactions, dosing protocols, and policy issues, transforming their personal experiences into credible knowledge that could influence professional practice and public perception.

Shared Lived Experiences. The power of personal testimony emerged as a crucial tool for advancing cannabis acceptance, with parents strategically sharing their children's success stories to counter skepticism and stigma. Sofia emphasized the importance of making these experiences visible:

> We were invited a couple of years ago to be part of a documentary, like a mini documentary, that was made by a friend of ours who also has a young son with epilepsy who got some funding to make this documentary about Texas families who are having success using CBD.

Similarly, Nicole recognized her responsibility to share their positive outcomes: "When this thing works so well, you can't just sit back and say, 'I don't want to share.' You want everybody to know that." These shared experiences served as powerful counterpoints to abstract policy debates or theoretical concerns, putting human faces on the potential benefits of cannabis treatments and creating compelling narratives that resonated with lawmakers, medical professionals, and community members.

Acceptance. Over time, parents observed gradual shifts in acceptance of medical cannabis, both within their immediate circles and in broader society. Sarah noted this evolution in the medical community when she talked about her experience with her son's doctor. Grace reflected on the changing social landscape: "I mean, over the years, so much work to get that changed. I don't know why we are still fighting this fight. But, obviously, we'll keep fighting. I mean, it's a struggle, but we should keep fighting that." While acknowledging that stigma and legal barriers persist, these parents witnessed meaningful progress in public understanding and institutional acceptance, validating their advocacy efforts and inspiring continued engagement in the movement for cannabis access.

The collective impact of these parents' advocacy and education efforts extends far beyond their individual families, helping to reshape the landscape of cannabis medicine for future generations. Their willingness to share vulnerable stories, educate from lived experience, build supportive communities, and persistently advocate for policy change has accelerated the normalization of cannabis as a legitimate treatment option. What began as isolated efforts to save their own children transformed into a powerful movement that has influenced legislation across multiple states, shifted medical practices, and challenged deeply entrenched cultural narratives about cannabis. Their experiences demonstrate how grassroots advocacy, driven by the authentic expertise of affected families, can ultimately create pathways for broader social and institutional change—gradually transforming the once-unthinkable into increasingly accepted medical practice.

The experiences of these nine families illuminate the complex interplay of medical, legal, social, and personal factors that shape the journey of seeking medical cannabis treatment for children with severe seizure disorders. Their stories reveal a consistent pattern: conventional treatments often provided limited seizure control with significant side effects, while cannabis-based treatments frequently offered not only improved seizure management but also unexpected gains in cognition, communication, and quality of life. However, accessing these treatments required families to navigate formidable obstacles—from relocating across state lines to managing intense financial pressures, confronting medical skepticism, and enduring social stigma. What emerges most powerfully from these narratives is the remarkable transformation of desperate parents into effective advocates and community builders. These families, driven by necessity and fortified by their children's improved outcomes, became researchers, educators, policy experts, and support providers for others following similar paths.

DISCUSSION

The experiences of families seeking medical cannabis for children with seizure disorders, while unique in their specific details, reveal consistent patterns that transcend individual circumstances. Through systematic analysis of the interview data, we identified three dominant cross-cutting themes that appeared repeatedly across families' narratives, regardless of their state of origin, specific diagnosis, or timing of cannabis treatment. These themes represent the core shared experiences that shaped families' journeys from initial treatment exploration to becoming part of a larger movement. What emerges is a picture of transformation - not just in children's health outcomes, but in parents' identities, social networks, and relationship to medical and legal systems. These

themes highlight how the pursuit of cannabis treatment represented far more than a medical decision, becoming instead a profound life reorientation with ripple effects across multiple domains.

Treatment Efficacy vs. Conventional Options

This theme emerges consistently across all interviews, revealing a stark contrast between traditional medical treatments and cannabis. Parents universally reported trying numerous conventional approaches first (multiple pharmaceuticals, surgeries, and extensive specialist consultations) with limited success and significant side effects. The dramatic improvements many children experienced with cannabis - not only in seizure reduction but in cognition, communication, pain management, and overall functioning - created a powerful narrative that challenged traditional medical paradigms. As Sarah noted about Ryan, "He's been seizure-free for years," while Nicole described how Brandon went from being unable to walk properly on multiple medications to riding a tricycle after starting cannabis treatment.

System Navigation and Advocacy Development

Nearly every family described a transformation from desperate parent to system navigator and advocate. This evolution occurred as families developed expertise in cannabis medicine, often exceeding their doctors' knowledge; learned to navigate dual medical systems; developed strategies for managing legal risks; and ultimately turned their experiences into advocacy. Grace's progression from researching treatment for her son to founding an organization called "Stop the Seizures" and organizing legislative visits exemplifies this pattern. Holly similarly transformed from a parent seeking treatment to founding Realm of Caring, which became a critical support organization for countless families. This pattern of personal necessity evolving into collective action appears consistently throughout the interviews.

Community Formation and Support Networks

Perhaps the most emotionally significant theme across interviews was the formation of new "families of choice" among cannabis refugees and advocates. Parents who often left behind their biological family, friends, and established support systems described finding a profound connection with other cannabis families. These networks provided not only emotional support but practical guidance, financial assistance, and a sense of belonging. Sofia captured this eloquently: "The Realm of Caring has connected us all... Pamela is one of our best friends here. She's like family to us. You know, we don't have family here, but they are our family." Holly similarly emphasized that "You can get through anything with community." These support networks functioned as information-sharing collectives, welcoming committees for new families, and ultimately as the foundation for broader advocacy movements.

These three overarching themes illustrate how the pursuit of medical cannabis became a transformative journey that extended far beyond a simple treatment decision. Parents' experiences reveal a cyclical pattern of reinforcement - the dramatic efficacy of cannabis treatment motivated families to develop navigational expertise and advocacy skills, which facilitated the formation of support communities, which in turn enhanced collective advocacy efforts and improved treatment access. This process ultimately contributed to shifting medical paradigms, legislative frameworks, and social perceptions around cannabis as medicine.
The intersection of these themes demonstrates how these families' experiences represent a form of grassroots medical and social revolution - challenging established treatment hierarchies, developing patient-led expertise networks, and creating alternative community structures when existing systems proved inadequate. Their journeys highlight how parental determination, when combined with collective action and demonstrated therapeutic success, can drive meaningful change in even deeply entrenched medical and regulatory systems. As medical cannabis continues to gain legitimacy and research attention, these pioneering families' experiences offer valuable insights for healthcare providers, policymakers, and communities seeking to better support children with treatment-resistant seizure disorders and their families.

CONCLUSION

This study provides compelling evidence of how families navigating medical cannabis treatment for children with treatment-resistant epilepsy become catalysts for paradigm shifts in both medical practice and public policy. The stark contrast between conventional treatment outcomes and cannabis efficacy created a powerful impetus for change, transforming desperate parents into knowledgeable advocates capable of challenging established medical hierarchies. These families' journeys reveal a remarkable pattern of evolution—from isolated treatment-seekers to interconnected communities that collectively advanced cannabis acceptance through shared expertise, strategic advocacy, and mutual support. Their experiences demonstrate how patient-driven movements can fundamentally reshape treatment approaches when existing medical paradigms prove insufficient, with parents' experiential knowledge ultimately influencing clinical practice, legislative reform, and social perceptions of cannabis as medicine.

Future research should expand on these findings through longitudinal studies examining how children's outcomes evolve over extended periods of cannabis treatment, including developmental trajectories, potential tolerance issues, and long-term side effects. Additionally, a comparative analysis of different regulatory models across states could identify optimal policy frameworks

that balance safety concerns with patient access. Research exploring healthcare providers' evolving perspectives on cannabis would illuminate how medical authority and parental expertise can be better integrated with treatment planning. Finally, as cannabis treatments gain broader acceptance, studies should investigate how these grassroots advocacy networks transform when their primary goal—treatment access—becomes less urgent and how the experiential knowledge developed by these pioneering families can be systematically incorporated into formal healthcare systems and medical education to benefit future patients and providers.

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