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Ethical Implications for Providers Regarding Cannabis Use in Children with Autism Spectrum Disorders

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Abstract

Children with autism spectrum disorder (ASD) are at risk for self-injurious behaviors that can be difficult to treat in the context of co-occurring low IQ and adaptive skills. Increased prevalence and decriminalization of cannabis in some states has led to more frequent questions for pediatricians about the use of cannabis for difficult-to-treat developmental and behavioral conditions. What do we know about the possible benefits and risks of cannabis use in children with ASD? How should the clinician respond to a parent who expresses interest in cannabis to manage behavior in a child with ASD? Ethical analysis including harm reduction, health concerns and information sharing will be discussed. We present commentary on the ethical implications of cannabis use in a child with autism spectrum disorder with severe self-harm behaviors.

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Given recent legalization of cannabis for medical and/or recreational use in many states, ethical implications about usage in children with autism spectrum disorders are discussed.

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Contributors' Statement Page

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In Oregon, medical cannabis has been legalized since November 1998 and recreational cannabis use since July 2015. Ubiquity has led to questions about safety and efficacy of use in pediatric patients, particularly those with difficult-to-treat developmental and behavioral conditions. What do we know about the possible benefits and risks of cannabis use in children with autism spectrum disorder (ASD)? How should the clinician respond to a parent who reports interest in cannabis to manage behavior? In this Ethics Rounds, we present a case of a child with ASD and severe self-harm behaviors whose parent is administering cannabis and we seek expert commentary on the ethical considerations.

The Case

A 4-year-old child was referred by his pediatrician to a multi-disciplinary autism clinic for diagnostic confirmation of ASD. He recently began to ambulate but he is nonverbal and engages in severe self-harm behaviors that include head banging. Child protection services had been involved because of observed bruising on the head. The home was judged to be safe, and he now wears a protective helmet to prevent injury. A trial of risperidone had been tried but discontinued secondary to significant side effects. He has participated in applied behavioral analysis (ABA) for 20 hours a week for the last year. A full team evaluation found him to be functioning at an age equivalency of 8 months and gave him diagnoses of ASD (level 3, requiring very substantial support) and global developmental delay. When asked about medications and supplements, his mother responded that she had been giving her son an “herbal supplement” provided to her by a friend whose son also has ASD. She added that it was very effective in reducing her son’s self-harm behaviors. He was calmer and more relaxed after receiving his “daily drop.” She had been able to remove his helmet and wash his hair for the first time in months. The mother’s friend recently told her that she made the supplement by distilling cannabis leaves that are known to have very low psychogenic properties. After receiving this information one week ago, the patient’s mother discontinued the supplement. Since that time, she has observed an alarming resurgence in her son’s self-harm behaviors. She asked the team for a recommendation about resuming the supplement.

Drs. Susanne W. Duvall, PhD, Olivia Lindly, PhD, MPH, Katharine Zuckerman MD, MPH, and Melissa Weddle, MD, MPH, comment:

Children with autism spectrum disorder (ASD) experience difficulties with inflexibility, patterns of restricted and repetitive interests and behaviors, and social communication deficits.[1] ASD is estimated to occur in approximately 1 in 68 individuals, with behavioral difficulties including self-harm behaviors being common (30–50%) and having significant impact on morbidity. These are more likely to occur in the context of limited communication skills, low IQ or low adaptive scores.[2–4]

Conventional behavioral treatment for ASD is difficult to access for many families[5,6] and most families receive less therapy than is recommended by expert guidelines.[7] Some children with severe presentations, as in this case, do not receive all recommended therapy hours or modalities.[8] Barriers to conventional treatment include paucity of providers, intensive nature of treatment, poor family knowledge about empirically supported

treatments, high cost and variable insurance coverage, among others.[9–11] Even when parents use recommended evidence-based therapies, such as early intensive behavioral interventions, outcomes are variable[7] and positive results are less likely for children with more severe presentations.[12,13] Psychoactive medications prescribed to treat behavioral symptoms associated with ASD (e.g., self-injurious behavior) or common ASD comorbidities (e.g., sleep disturbance) include antidepressants, stimulants, and antipsychotics.[14,15] These medications can have troublesome side effects such as tics or weight gain. They may be associated with severe adverse reactions such as neuroleptic malignant syndrome, leading to hesitancy to use by both parents and clinicians. Thus, many families seek out alternative or complementary treatments. Complementary health approaches (CHA), sometimes referred to as complementary and alternative medicine, encompass a diverse array of modalities such as herbal supplements, yoga, and special diets developed outside of or parallel to mainstream medicine; increasingly in recent years, this has included cannabis.[16]

Use of CHA is prevalent, especially in individuals with ASD. Recent studies suggest 17 percent[17] to 28 percent[18] of children with ASD use CHA.[19–21] When a parent asks about CHA, the clinician should use that opportunity to reassess the child's entire current service use profile, which is particularly important for families of children with ASD because the condition is associated with high rates of unmet service needs.[10] Clinicians could ask questions such as, "Tell me more about all of the services that your child is using for his/her autism?" and "Which treatments seem to be working or not working for you?" It is also important to assess the costs associated with CHA for ASD, as usually these costs are out-of-pocket.[11]

A family's decision to use CHA for a child with ASD is often multifactorial. Younger age,[22] greater medical complexity,[17,20,23] higher parent education level,[17,21,22] and greater conventional care use[21,22] may contribute to use of CHA for ASD. Parents may also have concerns about the safety of prescription medication.[23–25]

This case points to potential conflict between parent choice and child well-being. As clinicians, our duty is to promote the best interests of our patients. With any therapy, benefit should be weighed against harm. For cannabis, as with many CHA, there is insufficient evidence to delineate benefit and harm. In these situations, the clinician must consider the standard of care if it exists and review evidence of harm and benefit before offering recommendations.

The American Academy of Pediatrics (AAP) Clinical Practice Guideline on CHA suggests that pediatric clinicians should monitor (versus discourage) the use of CHA of questionable effectiveness and discourage the use of treatment with clear health risks (e.g., chelation, hyperbaric oxygen therapy).[26,27] The AAP opposes medical cannabis for children but recognizes that cannabis may be an option for "children with life-limiting or severely debilitating conditions and for whom current therapies are inadequate."[28] What is the evidence behind this stance and how does it apply to our patient?

This parent gave her child a type of cannabis with low psychogenic properties, most likely cannabidiol (CBD). Of the more than 80 cannabinoid chemicals found in the cannabis plant,

delta-9-tetrahydrocannabinol (THC) and CBD have been most studied. THC is responsible for euphoria or intoxication through its activation of the CB1 receptors found on neurons and glial cells in various parts of the brain. THC also interacts with the CB2 receptors, found mainly in the immune system.[29,30] CBD has low affinity for the endocannabinoid receptors and does not have psychoactive properties. CBD alters neuronal excitability by other means and may have antioxidant and anti-inflammatory properties.[31]

Evidence supports therapeutic effect of CBD for treatment of adults with spasticity,[32] central pain,[33] and social anxiety.[34] Anecdotal reports suggest efficacy of CBD in treatment of drug-resistant epilepsy[35–37] and one trial of CBD to treat children and young adults with Dravet syndrome showed a decrease in convulsive seizures.[38]

We know less about potential benefits of CBD use in children with ASD. Online advocacy groups such as Mothers Advocating Medical Marijuana Use for Autism (MAMMA),[39] the Autism Support Network,[40] and Pediatric Cannabis Therapy[41] share personal stories of marked behavioral improvement in children who are treated with cannabis. To date, there are no published studies of cannabinoid use in children with ASD.

What do we know about safety and side effects of cannabis exposure in children? Most of the studies that address adverse effects consider chronic recreational cannabis use, presumably THC-dominant strains. Regular cannabis use in adolescents is associated with short-term decreases in working memory, IQ, executive function, sustained attention, and motor coordination, with long-term effects of altered brain development, addiction, poor educational outcome, diminished life achievement, and increased risk of chronic psychosis disorders.[44,45] It is unclear how, or even if, these findings apply to the child in our case. A review of CBD use specifically[46] concludes that CBD is well tolerated in humans, though none of the cited studies included children or adolescents. The previously cited study of CBD treatment of refractory seizures in children and young adults with Dravet syndrome found adverse effects that included somnolence, loss of appetite, and diarrhea.[38]

Cannabis availability is increasing in the United States, with medical marijuana now legal in 29 states and District of Columbia, and recreational marijuana legal in 8 states and District of Columbia.[47] In Oregon, where this patient lives, recreational use for minors (age < 21 years) is currently illegal; however, Oregon has no lower age limit for medical cannabis use. Certain criteria must be met to prescribe marijuana, including presence of a “debilitating medical condition,” a designated caregiver to provide supervision, and an attending physician statement that verifies the diagnosis and certifies that the use of cannabis may mitigate the symptoms.[48] In those states where recreational cannabis is illegal, the clinician should counsel about the legal risks of administering it to a child.

In the United States, clinicians have limited ability to interfere with parental decision-making; we respect the authority of parents to decide for their children unless a decision poses an unacceptably high or immediate risk.[49] When evidence is insufficient to point to clear benefit or harm, the clinician should engage in a shared decision-making approach. Because evidence points to negative THC effects on developing brains, it is prudent to advise caution in giving THC-containing preparations to children. Evidence is insufficient to

support efficacy or adverse effects of CBD. The clinician should communicate to parents about what is known and unknown about effects of cannabis, both THC and CBD, on children.

Given that this child has tried conventional ASD therapies, including intensive ABA, without significant improvement and his CBD use has been associated with reduced self-harm, it would be ethically inappropriate for the clinician to advise against its use. There is no evidence that the potential harm of CBD outweighs benefit for this patient. If this family has indeed pursued all conventional therapies, cannabis may be an option for this child who has a severely debilitating condition for whom current therapies have been inadequate, as delineated in the AAP policy statement.[28] It is important to note that the clinician must discuss with parents possible risks of this treatment and review alternate interventions. We do not know what other ingredients may be in the preparation, and their potential risks. In accordance with the AAP Clinical Practice Guideline on CHA, continued monitoring is recommended.[27] The family should be provided with the poison center number in event of adverse effect, accidental ingestion or overdose. Finally, when a child takes a cannabis product outside of state-sanctioned medical cannabis provisions, the family should be counseled about potential legal implications.

Reporting this case to child protective services is not warranted, and would seriously jeopardize the parent-clinician relationship as well as increase the likelihood that the parent will withhold important health information in the future.

Dr. Michael E. Msall, MD comments:

Families who have a child with complex disabilities need comprehensive networks of support.[50] As their doctor, it is crucial to understand a family's supports, the quality and comprehensiveness of these supports, the gaps in meeting the child's and family's needs, and the impact of these gaps on family life.[51]

Until very recently, children who were nonverbal with challenging behaviors were presumed to be severely intellectually disabled. If, in addition, they had been late walkers like this child, they would often be diagnosed with cerebral palsy. Many medical professionals, including neurologists, psychiatrists, and pediatricians, too often assumed that no habilitative or behavioral management strategies would be helpful. As recently as the 1980s, many individuals with such intellectual disabilities and challenging behaviors were sent to residential facilities where the quality of medical care, supervision, and behavior supports were limited.[52] As a result, children were often out of control with challenging behaviors, and physical and chemical constraints were liberally applied. It was not unusual for these individuals to receive high doses of first generation antipsychotics such as chlorpromazine. Little attention was paid to a functional analysis of behavior or the medical contributors to behavior.[53]

Many different medical conditions are associated with self injurious behavior: the differential includes basic medical problems such as eye and ear pain, sinusitis, otitis, dental caries, gastroesophageal reflux, constipation, sleep difficulties, mood disorders, and vision and hearing disorders.[54] These conditions are hard to discern when there are challenges in

communication, gaps in reliable informants who really know the individual's behavior in positive and challenging settings, and a failure to acknowledge the impact during crisis management of providing positive attention to disruptive behaviors and thereby reinforcing their persistence.

What are the general principles for approaching these challenges? The first step is to assess the antecedents to specific patterns of behavior so as to better understand their motivations and thereby specify what consequences might reduce the current challenges. This involves inquiry and observation of the circumstances in which the child does and does not engage in self-injurious behavior.[55]

An important part of this strategy is to simultaneously understand the tempo of the child's self-injurious behaviors. If head banging had started at 2 years and predominantly serves an attention seeking behavior, then the task is to identify ways where one cannot head bang and carry out the task. These situations include being on a swing, jumping on a trampoline, swimming, being on a padded mat, and being in a space like a gym with padded walls.

Another key issue is analysis of where these behaviors do and do not occur, to identify potential positive reinforcers. For example, if there is no head banging during the bus ride to school, then car rides are a positive reinforcer. At school, if there is no head banging during snack time, then food is a positive reinforcer. If the favorite activity is to access a switch or iPad, then cause and effect educational toys are positive reinforcers.

Continued use of a structured intervention framework of applied behavior analysis in combination with the management of daily routines of feeding, dressing, toileting, and maintaining hygiene would allow for a multifaceted strategy that combines positive reinforcers, rewards of attention, responding to positive communications, and understanding how this boy learns. This management plan includes a profile of how the child communicates and signals his likes and dislikes, his favorite tasks, such as listening to music or squeezing an object, and methods to de-escalate disruptive behaviors.

Given that there are behavioral interventions that are helpful but difficult to access, what are the options for health professionals? Most critically, health professionals must recognize that an intervention such as a helmet is not all that is needed for a child with ASD, intellectual disability, limited verbal communication and severe self-injurious behavior. The most important need for families of children with ASD and intellectual disability is for effective management strategies that support the child's functioning and positive behaviors over the course of the day.[56] This includes access to comprehensive behavior therapies and, if needed, judicious psychopharmacology. In examining pharmacological approaches to self-injurious behavior, naltrexone, traditional and atypical neuroleptics, anxiolytics, stimulants, anticonvulsants and SSRIs have been tried. However, there is little evidence to support a magic psychopharmacological bullet.

Given the fragmented access to informed behavior interventions and prescribing clinicians who have expertise in preschool children with ASD and intellectual disability, it should not be surprising that parents try complementary health approaches.[26] When examining a CHA,

it is critically important that health professionals do no harm. It is in this respect that CHA use in vulnerable children requires utmost diligence.

The first question for this parent is to define exactly what the child is receiving. Specifically, how much THC or CBD is in the current product? THC can cause sedation, lethargy, and cognitive blunting.[57] On the other hand, in select populations with refractory epilepsy, CBD can reduce the frequency of monthly seizures by approximately a third,[38] though only 1 in 25 children with refractory seizures become seizure free on these agents.[58]

Second, what do we know about the safety profile of THC/CBD in children? There is a long history of non-regulated supplements with toxicity to children. In addition, they may be expensive and distract the family from educational and behavioral management strategies that improve outcomes over the long term. Families should be informed of the lack of evidence regarding benefits of cannabis in children with autism, intellectual disability, ADHD, anxiety, or disruptive behaviors.

We need good studies of cannabinoids. The previously cited AAP policy statement recommends changing marijuana from a DEA Schedule 1 to Schedule 2 in order to facilitate research.[28]

Given all of the uncertainties about cannabinoids, I would recommend a medication for sedation and anxiety that has more evidence to support its use, such as a benzodiazepine. I would help the mother access appropriate supports across home, school, and the community. I would not report to child protection.

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Abbreviations:

ASD	autism spectrum disorder
CBD	cannabidiol
CHA	complementary health approaches
THC	delta-9-tetrahydrocannabinol

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