

Survey of Current Cannabidiol Use in Pediatric Treatment-Resistant Epilepsy

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Introduction

Severe childhood epilepsies are characterized by a high seizure burden and are often associated with neurodevelopmental delays. When traditional medications fail to control a child's seizures, families look to alternative treatments to help their children. One of these alternative treatments that has become more widespread over the past year involves the use of a compound from the Cannabis plant, Cannabidiol (CBD). CBD is a non-psychoactive compound that has been shown to have anticonvulsive properties in a number of animal models of epilepsy. In limited human adult trials, CBD has shown promise as an anticonvulsant with very few negative side effects. The purpose of this survey was to understand current use of CBD in children with treatment-resistant epilepsy.

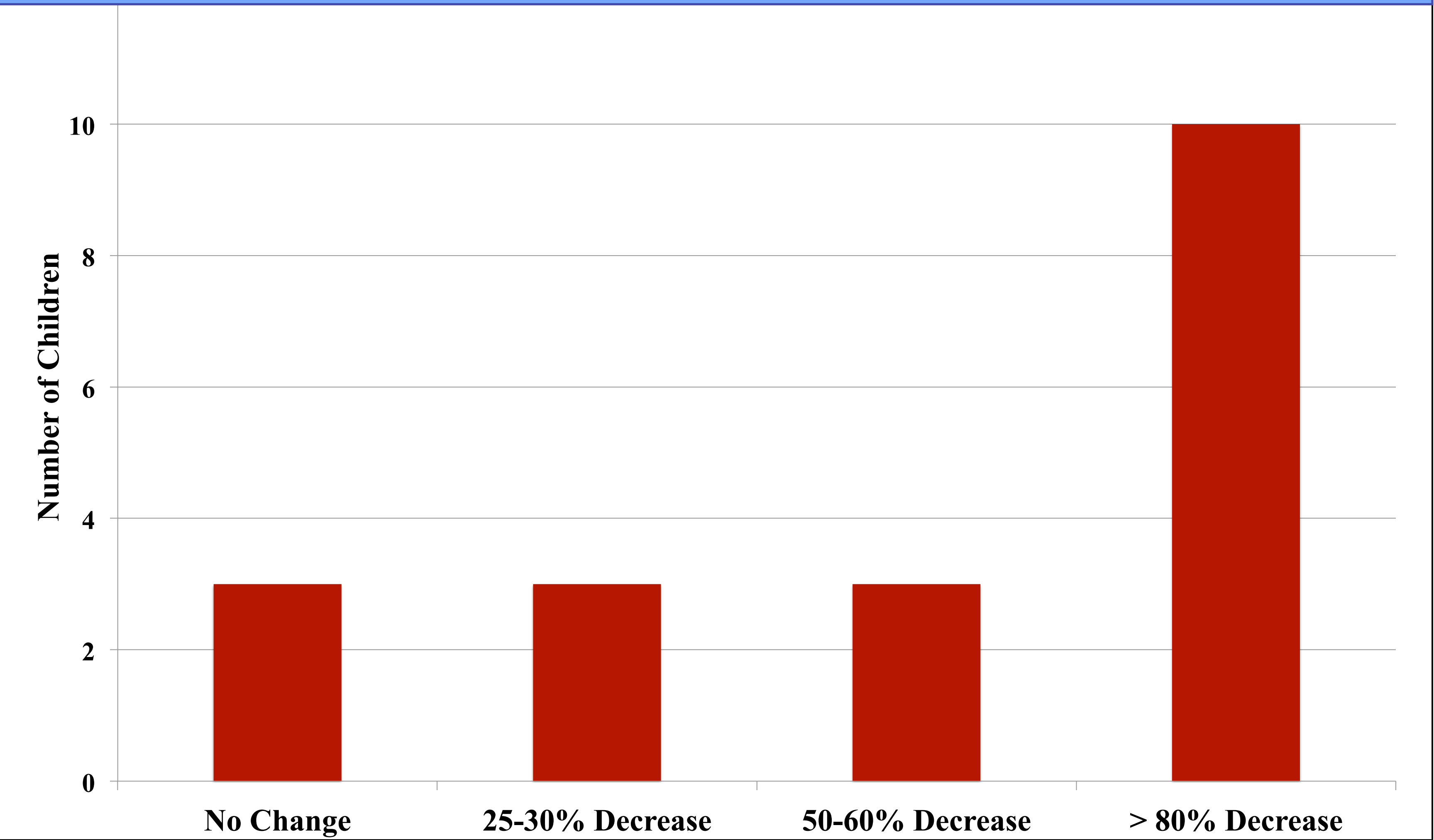
Methods

The Stanford University institutional review board judge the study exempt from requiring full review by the board. Study data were collected and managed using REDCap electronic data capture tools hosted at the Stanford Center for Clinical Informatics. The CBD survey consisted of 24 questions that measured clinical factors, the effect of CBD on the child's seizure frequency and side effects. The CBD survey was presented to a Facebook group composed of parents dealing with issues surrounding the use of CBD to treat seizures in children with treatment-resistant epilepsy. The survey link was posted for two weeks. Twenty parents responded to the survey. Nineteen responses met the inclusion criteria, which were a diagnosis of epilepsy and CBD use. Survey responses were descriptively analyzed.

Results

- Sixteen of 19 parents reported a reduced seizure frequency during CBD treatment
- Three of these parents reported complete seizure freedom during CBD treatment
- A child had tried an average of 12 AEDs before the parent began CBD treatment
- The most often reported side effects were better mood, increased alertness, better sleep and drowsiness
- Common negative side effects often associated with other AEDs were notably absent from parent reports about CBD

Estimated Effect on Seizure Frequency



Clinical Information and Response to CBD

Patient	Diagnosis	Age and Sex	Age at Seizure Onset	Time on CBD	CBD (mg/kg/day)	THC (mg/kg/day)	Seizures before CBD	Seizures after CBD	Estimated Change in Seizure Frequency	Number of AEDs tried before CBD	AEDs discontinued while on CBD
1	Lennox-Gastaut	7y female	<1y	> 1 year	?	?	> 100 per day	8-10 per day	> -80%	8	Banzel, Onfi
2	Dravet Syndrome	14y female	<1y	> 4 months	14	0.5	5 per day	0-1 per day	> -80%	12	
3	Epilepsy in Females with Mental Retardation	12y female	<1y	2-4 months	7	0.5	12 per day	0-1 per day	> -80%	17	
4	Dravet Syndrome	7y male	<1y	> 4 months	8	0.25-0.5	50 per week	50 per week	0	16	
5	Dravet Syndrome	6y female	<1y	> 4 months	4	0.1-0.25	200-300 per week	0-2 per week	> -80%	6	Onfi
6	Dravet Syndrome	16y female	<1y	> 4 months	1-2	0.02-0.1	7 per week	4 per week	-25%	16	Onfi
7	Dravet Syndrome	13y male	<1y	3-4 months	4	0.02-0.1	40 per week	30 per week	-25%	16	Phenobarbital, Depakote
8	Dravet Syndrome		<1y	> 4 months	?	?	3 per week	1-2 per week	-50%	14	Klonipin
9	Dravet Syndrome	male	<1y	> 4 months	3-4	0.04-0.2	100-500 per week	1-2 per week	> -80%	10	STP, Topamax, Depakote
10	Dravet Syndrome		<1y	> 4 months	4	0.2-0.4	200-300 per week	20-50 per week	> -80%	12	STP
11	Dravet Syndrome	8y female	<1y	> 1 year	?	?	5-10 per week	0-3 per week	-60%	10	STP, Onfi, Depakote
12	Dravet Syndrome	7y female	<1y	> 4 months	3-4	0.04-0.2	20+ per week	0-10 per week	-50%	10	Onfi, Zonigran, Depakote
13	Doose Syndrome	9y female	<1y	> 4 months	10-13	0.5	60-250 per day	0	> -80%	15	Lorazepam, Ethosuximide
14	Dravet Syndrome	2y male	<1y	> 4 months	7	0.08-0.4	2 per week	0	> -80%	4	
15	Doose Syndrome		2-5y	2 weeks	< 0.5	0.01-0.05	1-7 per week	1-7 per week	0	13	
16	Myoclonic Absence	11y male	2-5y	1-2 months	6	0.6-0.8	20 per week	4 per week	> -80%	13	
17	Doose Syndrome		2-5y	1-2 months	6	0	15-20 per day	0-3 per day	> -80%	14	Steroids
18	Idiopathic Epilepsy	female	1-2y	< 1 month	28	0.5-0.7	10 per week	8 per week	-25%	5	Valproic Acid
19	Dravet Syndrome	6y female	<1y	> 4 months	1	0.06-0.3	3 per week	3 per week	0	?	

Side Effects

Side Effect	CBD	Other AEDs
Better Mood	15/19 (79%)	4/22 (18%)
Increased Alertness	14/19 (74%)	6/22 (27%)
Better Sleep	13/19 (68%)	5/22 (23%)
Drowsiness	7/19 (37%)	19/22 (86%)
Decreased Self-stimulation	6/19 (32%)	3/22 (14%)
Fatigue	3/19 (16%)	20/22 (91%)
Appetite Decrease	1/19 (5%)	17/22 (77%)
Irritability	--	17/22 (77%)
Insomnia	--	17/22 (77%)
Aggressive Behavior	--	15/22 (68%)
Weight Loss	--	15/22 (68%)
Increased Self-stimulation	--	14/22 (64%)
Appetite Increase	--	10/22 (45%)
Confusion	--	9/22 (41%)
Weight Gain	--	9/22 (41%)
Anxiety	--	7/22 (32%)
Nausea	--	6/22 (27%)
Rash	--	5/22 (23%)
Vomiting	--	5/22 (23%)
Dizziness	--	5/22 (23%)

Conclusions

- Parents are administering CBD to their children as an alternative treatment when traditional anti-seizure medications have failed.
- Parents report a high rate of success in reducing seizure frequency with CBD treatment
- CBD treatment appears to be behaviorally well-tolerated, with some positive side effects not normally noted with other AEDs
- A pharmaceutical-grade formulation of CBD would reduce the risks associated with artisanal preparations that contain THC
- Further study is required for objective measurements of CBD's safety, tolerability and efficacy

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