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Parent use of cannabis for intractable pediatric epilepsy: Everyday empiricism and the boundaries of scientific medicine



Elisa J. Sobo

San Diego State University, United States

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ABSTRACT

Cannabis is an increasingly sought-after remedy for US children with intractable (biomedically uncontrollable) epilepsy. However, like other complementary-alternative medicine (CAM) modalities, and particularly as a federally illegal, stigmatized substance, it is unsanctioned by mainstream medicine. Parents are largely on their own when it comes to learning about, procuring, dispensing, and monitoring treatments. Exploring how they manage is crucial to better assist them. Moreover, it can illuminate how 'research' done on the ground by laypeople variously disrupts and reinforces lay–expert and science–non-science divides. To those ends, in 2016, 25 Southern California parents who used, had used, or sought to use cannabis pediatrically for epilepsy/seizures were interviewed regarding their evidentiary standards, research methods, and aims when trying the drug. Parents generally described their work as experimentation; they saw their efforts as adhering to authorized scientific practices and standards, and as contributing to the authorized medical cannabis knowledge base. Findings subverted assumptions, based on an outdated stereotype of CAM, that cannabis-using parents do not believe in biomedicine. Indeed, parents' desire for their children's biomedical demarginalization, combined with biomedical dependency and a high caregiver burden, fueled a collaborative stance. Implications for understanding the boundaries of science are explored, as are norms for parent agency as ill children's care managers, radicalization among people affected by contested illnesses, and the future of 'medical marijuana.'

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Where are ... doctors getting their information from? They're not getting it from a book. They're learning it from these cannabomoms! - Lillian, age 40

Since 1996, California has allowed residents with qualifying medical conditions access to cannabis. However, due in part to the plant's federal illegality, most biomedical practitioners know little about it. Permission letters generally come from 'referral mill' doctors, whose advice regarding dosing and procurement is necessarily vague. The situation for children is aggravated by pervasive cultural beliefs that cannabis stunts development, is a 'gateway' drug, and foments or indexes household instability. Even with a referral, parents giving minors cannabis-based preparations risk persecution.

Nonetheless, parents of children with intractable epilepsy increasingly turn to the herb. This article shares the stories of twenty-five such parents, giving voice to their discoveries about the

plant's pediatric potential, their concerns about using it, the barriers they have faced in determining an effective regimen, and the ways they have found support. Its aim is to enhance the knowledge base for professionals serving such families. More immediately, it challenges the dominant institutional model of and for 'citizen science,' which minimizes citizen agency. In doing so, this article highlights and contributes to emerging scholarship on self-directed citizen science, particularly regarding 'contested conditions' (those that defy biomedicine's understanding; [Brown et al., 2012:18](#)). It explores how parents' approaches to pediatric cannabis articulate—or not—with the evidentiary ideals of authorized experts, and delineates, through a critical lens, how stakeholders resist, reshape, and reinforce the science–non-science border in biomedicine.

1. Background

Epilepsy is among the most common pediatric neurological disorders. Seizures can be pharmacologically controlled—but only in two-thirds of patients. After "failing" two pharmaceuticals, the chances of another working are only about 5% ([Brodie et al., 2012](#);

E-mail address: esobo@mail.sdsu.edu.

Wirrell, 2013). In such cases,

“uncontrolled [intractable] seizures and exposure to high doses of multiple, ineffective medications result in considerable comorbidity, including intellectual disability; learning and attention problems; physical injury; sudden unexplained death in epilepsy (SUDEP); psychiatric problems such as depression, anxiety disorders, failure to achieve or loss of independence; and poor quality of life” (Wirrell, 2013:19).

1.1. Turning to CAM

Parents use Complementary and Alternative Medicine (CAM; therapies not included in biomedicine’s toolkit) for about one in nine children overall (Barnes et al., 2008); this increases to about three in four for children with lifelong disabilities, intractable epilepsy included (Sanders et al., 2003). For the latter, homeopathy, chiropractic, legal herbal medicine, and now cannabis are popular.

The high fat, low carbohydrate diet now termed ‘ketogenic’ might have been listed, but it traversed the CAM–biomedicine boundary recently, after scientific validation. Actually, it traversed: originally part of conventional medicine, it was pushed out in 1938 by those favoring synthetic anticonvulsants (Freeman et al., 2007). As with most cultural boundaries, that between CAM and biomedicine is responsive to interest-group leverage.

CAM stereotypically entails rejecting Western or biomedical epistemology. Yet, as the above list suggests, multiple epistemologies characterize the CAM domain. Moreover, some modalities are quite reductive, akin to biomedicine (Brosnan, 2016:174). Additionally, a modality that seems oppositional in one way may be in accord with biomedicine in another. But if biomedicine does not control it, it will be classed as CAM.

Sometimes CAM is used for problems beyond biomedicine’s purview, or instead of biomedicine; but in intractable epilepsy, which can entail many comorbidities, CAM is generally used allopathically and alongside biomedicine (see Ricotti and Delanty, 2006). Cannabis use seems mainly intended to manage intractable seizures and offset intolerable side-effects of pharmaceutical treatment (Hartmann et al., 2016; Suraev et al., 2017).

1.2. Cannabis for seizures

Cannabis’s first documented use for seizures was in ancient Mesopotamia. References and instructions next appear in ancient Arabic and Indian medical writings. European and then US use came only after a physician in service to Britain learned about the treatment in India. Ingestible cannabis remained on many official Western medicinal formularies into the early 1900s—not only for epilepsy but for many other ills (Lee, 2012; Russo, 2017; Friedman and Sirven, 2017).

Soon, however, White nationalists noticed people of African and Mexican descent smoking cannabis (Lee, 2012:15–16, 38–40). A 1937 Tax Act effectively criminalized the plant (prejudicially called ‘Marijuana’), enabling racist harassment—and benefitting distillers: alcohol now provided a legal alternative. As pharmacology turned toward synthesized chemical isolates, the American Pharmaceutical Association (APA) and the American Medical Association (AMA), keen on controlling what counted as medicine and who could administer it, got squarely behind the Tax Act also (Lee, 2012:52, 62; Chapkis and Webb, 2008; and see above re: ketogenic diet).

The Controlled Substances Act of 1970 tightened US restrictions; many nations followed suit (Friedman and Sirven, 2017). Like heroin, cannabis was placed into “Schedule I.” These substances are

most restricted, being ascribed the highest abuse and dependence potential, and no accepted medical uses. Present efforts to ‘reschedule’ cannabis federally have failed, partly due to active lobbying by pharmaceutical companies (Ingraham, 2016).

Criminalization created a black market. It also severely limited US scientific research into cannabis’s potential health benefits. Nonetheless, mid-century army investigations regarding its potential for ‘mind control’ and National Institutes of Health research into its imputed dangers led, inadvertently, to findings regarding its anticonvulsive properties (Lee, 2012:125–6, 301). Subsequent small-scale clinical studies overseas (e.g., Israel, Brazil); amassing case, laboratory, and animal studies; and the discovery of a potential mechanism set the stage for the public’s rediscovery of cannabis’s antiepileptic potential (Friedman and Sirven, 2017; Russo, 2017).

Public access to research findings expanded with the internet; and adults with epilepsy began to experiment (Chapkis and Webb, 2008; Lee, 2012:300–303). The state-based trend to legalize cannabis for medical use, supported by various special interest groups each from diverse angles, galvanized many. But the present pediatric groundswell stems mostly from research on one cannabis chemical, cannabidiol (CBD), and a 2013 CNN documentary regarding Charlotte Figi (e.g., Russo, 2017).

Charlotte, a Colorado resident, experienced up to 50 seizures daily. At age five, she required a feeding tube and full assistance with activities of everyday living. Her mother, Paige Figi, learned of a family using a high CBD, low-THC tincture (Maa and Figi, 2014; Warner, 2014). THC (tetrahydrocannabinol) is the cannabis chemical directly associated with getting ‘high.’ CBD entails no ‘high’ but may limit seizures—perhaps particularly when used in whole-plant modalities that leverage synergies between cannabis’s myriad components via an ‘entourage effect’ (Russo, 2011). Figi procured a comparable preparation, to be dropped under the tongue or into the feeding tube. It worked (Maa and Figi, 2014).

Many affected families moved to Denver to access said medicine (Maa and Figi, 2014). Doctors at Children’s Hospital Colorado, now flush with epilepsy patients openly given cannabis, undertook a small, retrospective chart review, which showed some positive results (Press et al., 2015). The demand for CBD-rich cannabis skyrocketed (see Russo, 2017).

Big Pharma took note. Soon, small-scale, early-stage research was underway. However, to approve a drug, the US Food and Drug Administration (FDA) requires randomized, controlled, blinded trials (RCTs); indeed, such trials are a “growth engine” for pharmaceutical marketing (Dumit, 2012:89). Findings from the first RCT, run by GW Pharmaceuticals, just came out (Devinsky et al., 2017)—accompanied by an editorial titled “Real Data at Last” (Berkovic, 2017:2075).

1.3. Boundary work and citizen science

Lay-derived data, brought to GW Pharmaceuticals by parents troubled by potential imprecision in home-made preparations, predicated said trails (personal communication, Carlsbad CA; and see Vogelstein, 2015). Lay research for ‘contested illnesses’ is increasingly frequent. This is variously attributed by scholars to ‘self-responsibilization’ cultivated by the ‘risk society,’ contemporary neoliberalism’s impact on institutional scientific budgets, and ‘scientization.’ The latter not only reinforces a preference among healthcare consumers for scientifically-developed and ostensibly precision-made drugs (part of ‘pharmaceuticalization’; Bell and Figert, 2012); it prioritizes ‘objective’ data and technical solutions, decontextualizing and thus depoliticizing problems—and enabling institutional inaction due to ‘insufficient data’ (Kimura and Kinchy, 2016; Wynne, 1996).

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