Marijuana and Epilepsy Patients: An Interview with Dr. Edward Maa

Ed Maa, chief of the Comprehensive Epilepsy Program at Denver Health and associate professor of neurology at the University of Colorado School of Medicine, is always looking for new ways to improve epilepsy treatments. After a few of his patients talked about using marijuana, he conducted a survey and discovered, to his surprise, that one-third of his patients had tried marijuana in search of relief from their symptoms. Dr. Maa has also worked with key figures involved in the use of the marijuana extract cannabidiol (CBD) to control seizures in children with epilepsy. Dr. Maa, a member of the Epilepsy Foundation of Colorado board, graciously agreed to share his experiences and insights with us in Q&A format.

Q: Why do you think so many of your epilepsy patients are using marijuana?

Ed: In Colorado, marijuana has been constitutionally available to adults with epilepsy for 10 years. I think most of my patients were using it did so in a complementary fashion with their prescribed medications. They had access to it, they thought it might help with their seizures, and I suspect they enjoyed its psychoactive properties as well.

Q: You have collaborated with people who are deeply involved in the Charlotte’s Web story, co-presenting with Dr. Margaret Gedde (who has seen many of the children using the treatment) and co-authoring an article with Paige Figi (Charlotte’s mother). What has that experience been like?

Ed: Of course I was fascinated by this developing story, but as an adult epileptologist, I hadn’t seen any of these children with Dravet syndrome. So I contacted Dr. Gedde to discuss her personal experience with this high-CBD strain of marijuana, how she was dosing it, the side effects, reported efficacy, titration schedules, and interactions with other medications. Those things were of great interest to me and to the medical community at large. Given her large number of cases, we collaborated on a poster at the American Epilepsy Society meeting that year, which I knew would be very informative to epileptologists around the country who were being approached by their patients but had no practical information. My work with Paige was part of a series of papers for an epilepsy journal. I thought it would be valuable to present in a formal way the case that has been made in the CNN headlines.

The curiosity about this phenomenon is not going away anytime soon. What is the rationale behind these parents’ decision to pursue a treatment that has no foundational testing in human pediatric cases? As a parent myself, it was easy to arrive at the same conclusion when I began to understand what Paige went through and the options she had available at the time. Incidentally, the formal studies that are taking place now got a tremendous push forward thanks to these parents’ advocacy.
The responsible folks [using marijuana-related treatments for children with epilepsy] have gone through the traditional Western treatments available to them in the US, and they are managed by pediatric neurologists and a pediatric epileptologist. I think those people have earned the right to look beyond what’s traditionally available. Many have tried to take shortcuts, and I think that’s a bad idea.

**Q: How do your colleagues in the medical realm respond to your interest in this issue?**

**Ed:** As you might expect, it’s all over the board. Some were vehemently opposed to taking a public stance on the topic; many of those have since come around, especially since research dollars have become available. Far more were secretly congratulatory that someone was out there saying this is not a taboo subject and should be investigated like any other potential medication.

**Q: How has the legalization of recreational marijuana in Colorado affected the situation, in your experience? Has legalization made it easier for people with medical needs to access marijuana, or has it increased the risks of misuse?**

**Ed:** In general, it has created more problems than benefits, because recreational marijuana provides a shortcut. Basically, now you can get whatever you need when you want it, without any recommendations or guidance from a physician on things you would typically want your physician to be involved with—the strain selected, the concentration, interaction with other medications, and drug level monitoring.

A second problem is that makers of anti-seizure drugs are avoiding Colorado for clinical trials, because in states with easy access to marijuana, this factor could confound the study results.

**Q: What do you say to patients (either adults or children and their parents) contemplating the use of some form of marijuana for epilepsy?**

**Ed:** I have this conversation now probably about three or four times a week. My typical line is that there are no convincing data available yet on its efficacy. If I know my patient well and know what they have tried already, I have no objection to them trying it, as long as they tell me when they are starting and agree to let me check baseline levels of their other drugs and then do more frequent testing. (As a university faculty member, I am not allowed to provide medical endorsements for patients requesting marijuana.) Should they decide to try it and then complain of a side effect later, I can understand better why it is happening if I have baseline information. The CBD in marijuana slows down the liver metabolism of the enzymes that break down many of our epilepsy drugs, such as Depakote (valproic acid) and Onfi (clobazam). If your system slows down, the levels of those drugs will skyrocket.
Q: Some have contended that the Schedule I classification of marijuana should be changed so as to permit wider research on the substance. What is your view on this issue?

Ed: The Schedule I question is more complicated than I ever expected. In general, if CBD were Schedule II, life would be a lot easier for physicians and researchers. But that might not help with whole-plant preparations like Charlotte’s Web, because they still have some THC [the psychoactive component of marijuana].

Q: How well do you feel the existing dispensary system in Colorado is ensuring quality and consistency of medications?

Ed: I think I would want to see it replaced. I think Colorado is not doing it well, which often happens when you are an early adopter. I am interested in how New Jersey is handling marijuana. New Jersey’s five dispensaries were authorized by the state department of health through an RFP (request for proposal) process, and their products are tested at a state-run lab. Moreover, doctors and patients in New Jersey have access to a strain library that includes the results of lab tests of various samples, to help them determine what strains might work best for them. The challenge in Colorado is that we don’t have a central, state-run lab that we can all consider a standard.

Also, the labeling at dispensaries tends to be deficient. Most of the bottles at dispensaries refer to “milligrams of marijuana” or some other nebulous term. So you don’t really understand what you are getting. I have often asked my patients to go back and ask the dispensary whether lab tests have been run on the sample and whether profiles have been done, and they report that they just get laughed at. As for the makers of Charlotte’s Web, I have not attempted any independent verification, but at least their labeling lists the milligram concentration of CBD you are getting. Generally, my concern is that, unlike with standard pharmaceuticals, we don’t have a way to know with confidence what our patients are taking.

Under the current system, the physician’s role is only to confirm that a patient has a diagnosis [that justifies eligibility for medical marijuana]. Then the patient can submit a fee and the diagnosis, receive a red card in the mail, and go to the dispensary. From that point on, the patient is receiving treatment recommendations from people whose only qualification is that they don’t have a felony. No pharmaceutical or medical background is required.

Q: What is your experience of the effect of marijuana-related medications on your patients?

Ed: We are still in the midst of gathering self-reported seizure diary data from patients who are using Charlotte’s Web. In my own clinic during the past year, I have not seen much impact on my adult patients other than temporizing for a while. As with any other anti-seizure drug, there is a honeymoon period for 4 to 12 months and then the patient often returns to the previous seizure frequency. That is mostly what I’m seeing.
Similarly, the results of the Epidiolex study thus far appear to indicate that it might help some subsets of people but is not an across-the-board panacea for patients with epilepsy.

But there is still hope that these medications will help some people. As we get better access to them and can study them formally, we will be better able to predict who is most likely to respond favorably to them.