

UCLA

UCLA Previously Published Works

Title

Fewer specialists support using medical marijuana and CBD in treating epilepsy patients compared with other medical professionals and patients: Result of Epilepsia's survey

Permalink

<https://escholarship.org/uc/item/6px5d21s>

Journal

Epilepsia, 56(1)

ISSN

0013-9580

Authors

Mathern, Gary W
Beninsig, Laurie
Nehlig, Astrid

Publication Date

2015

DOI

10.1111/epi.12843

Peer reviewed



Fewer specialists support using medical marijuana and CBD in treating epilepsy patients compared with other medical professionals and patients: Result of *Epilepsia's* survey

*Gary W. Mathern, †Laurie Beninsig, and ‡Astrid Nehlig

Epilepsia, 56(1):1–6, 2015

doi: 10.1111/epi.12843



Gary W. Mathern,
Epilepsia Co-Editor in
Chief



Astrid Nehlig,
Epilepsia Co-Editor in
Chief

SUMMARY

Objective: From May 20 to September 1 2014, *Epilepsia* conducted an online survey seeking opinions about the use of medical marijuana and cannabidiol (CBD) for people with epilepsy. This study reports the findings of that poll.

Methods: The survey consisted of eight questions. Four questions asked if there were sufficient safety and efficacy data, whether responders would advise trying medical marijuana in cases of severe refractory epilepsy, and if pharmacologic grade compounds containing CBD should be available. Four questions addressed occupation, geographic region of residence, if responders had read the paper, and if they were International League Against Epilepsy/International Bureau for Epilepsy (ILAE/IBE) members.

Results: Of 776 who started or completed the survey, 58% were patients from North America, and 22% were epileptologists and general neurologists from Europe and North America. A minority of epileptologists and general neurologists said that there were sufficient safety (34%) and efficacy (28%) data, and 48% would advise using medical marijuana in severe cases of epilepsy. By comparison, nearly all patients and the public said there were sufficient safety (96%) and efficacy (95%) data, and 98% would recommend medical marijuana in cases of severe epilepsy. General physicians, basic researchers, nurses, and allied health professions sided more with patients, saying that there were sufficient safety (70%) and efficacy (71%) data, and 83% would advise using marijuana in severe cases. A majority (78%) said there should be pharmacologic grade compounds containing CBD, and there were no differences between specialists, general medical personal, and patients and the public.

Significance: This survey indicates that there is a wide disparity in opinion on the use of medical marijuana and CBD in the treatment of people with epilepsy, which varied substantially, with fewer medical specialists supporting its use compared with general medical personal, and patients and the public.

KEY WORDS: Medical marijuana, Cannabidiol.

Accepted September 10, 2014; Early View publication November 20, 2014.

*Departments of Neurosurgery and Psychiatry & BioBehavioral Medicine, The Mattel Children's Hospital, David Geffen School of Medicine, University of California, Los Angeles, California, U.S.A.; †*Epilepsia*, and ‡Hospital Necker, INSERM U 1129, Paris, France

Address correspondence to Gary W. Mathern, Reed Neurological Research Center, Room 2123, 710 Westwood Plaza, Los Angeles, CA 90095-1769, U.S.A. E-mail: gmathern@ucla.edu

Wiley Periodicals, Inc.

© 2014 International League Against Epilepsy

The subject of the June 2014 print edition of *Epilepsia's* Controversy in Epilepsy series was the use of medical marijuana and cannabidiol (CBD) in treating patients with epilepsy. The series contained pro and con positions on whether to allow the use of these agents, followed by a review article.^{1–4} In conjunction with these articles, the Editors offered readers the opportunity to voice their opinions through an open-access electronic poll about the safety and efficacy of medical marijuana, whether responders

would advise using these compounds in patients with severe medically refractory epilepsy, and if pharmacologic grade materials with known concentration of CBD should be available for use.⁴ This report summarizes the results of the survey.

METHODS

The poll on the use of medical marijuana and CBD in the treatment of people with epilepsy (see Data S1 and Data S2) was advertised through press releases, *Epilepsia*, the International League Against Epilepsy (ILAE), and International Bureau for Epilepsy (IBE) websites, and through *Epilepsia*'s e-Newsletter sent to >18,000 e-mail addresses. Reminders to complete the poll were sent out the last 2 weeks before the poll closed. The survey could be completed anonymously; however, participants were asked to voluntarily provide e-mail contact information to receive results of the poll.

The poll consisted of eight questions, with an opportunity for responders to provide open comments at the end. Four questions related to the Controversy in Epilepsy series articles on the use of medical marijuana and CBD, and four questions on whether the responders read the paper and their demographics. The four questions about medical marijuana asked if responders thought there were sufficient safety and efficacy data to allow use of this agent with or without a prescription (Rx; one question for safety and another for efficacy); would the responder advise patients with severe epilepsy to try marijuana/CBD; and whether pharmacologic grade compounds containing CBD should be available for use in people with epilepsy. These questions are further detailed in the Results section. The other four questions asked general questions as previously published.⁵

1 Have you read the Controversy in Epilepsy series in *Epilepsia* on the use of medical marijuana in treating epilepsy?

Possible answer: Yes or No

2 What category best describes you?

Possible answers: (1) Epileptologist (postresidency training or expertise in epilepsy; includes neurosurgeons; neuroradiologists, neuropsychologists, neuropathologists, and nurses who spend considerable professional time with patients with epilepsy); (2) general neurologist not specializing in epilepsy; (3) general physician (pediatrician, internal medicine, family practice); (4) basic researcher; (5) nurse, social worker, medical student, resident; and (6) patient, family member, and the general public. Because of similar responses, the categories of epileptologist and general neurologist were combined into a single category (Epileptologist/Neurologist), as was general physician, basic researcher, and nurse (General MD/Resident/Allied) to compare with patients and the public (Patients/Public).

3 What geographic location of main residence/professional activities describes you?

Possible answers were based on ILAE regional commissions and included: (1) Africa; (2) Asia/Oceania; (3) Eastern Mediterranean; (4) Europe (includes Eastern Europe, Russia, and Israel); (5) Latin America (south of U.S. border); and (6) North America (U.S.A., Canada, Caribbean).

4 Are you a member of a chapter of the ILAE or IBE?

Possible answer: Yes or No.

Data analysis

Responses were uploaded onto an electronic spreadsheet and tabulated. Responses about the use of medical marijuana and CBD were compared with demographic information using a statistical program (StatView, SAS Institute, Cary, NC, U.S.A.) applying chi-square tests. Statistical significance was set a priori at $p < 0.01$.

RESULTS

The survey opened May 20, 2014 and closed September 1, 2014. The Website was visited 3,466 times, with 776 individuals starting the poll and 529 (68%) completing all of the questions. Comparing those that completed the poll with those that started but did not complete it showed no differences in geographic region (chi-square; $p = 0.89$), if participants were ILAE/IBE members ($p = 0.09$), and by professional/patient category ($p = 0.015$). However, of those that completed the poll, 100% said they read the Controversy in Epilepsy series and Invited Review, whereas 22% that did not complete the poll said they read the series ($p < 0.0001$; $n = 739$).

Demographics of responders

Responders represented primarily patients and the public from North America (58%) and epileptologists and general neurologists from Europe and North America (22%; Table 1). For the question "Which category best describes you?" there were 622 responses (80.1%). The most frequent category was patients/public (58.2%), followed by epileptologist (22.8%), nurse and allied health (6.6%), basic researcher (5.7%), general neurologist (5.1%), and general physician (1.4%). For the question "What geographic location of main residence/professional activities describes you?" there were 617 (79.8%) responses. The most frequent category was North America (80.4%), followed by Europe (16.5%), Asia/Oceania (4.4%), Latin America (3.9%), Africa (0.9%), and Eastern Mediterranean (0.3%). Of the 609 (78.5%) who answered both professional category and geographic location, 58% were patients and the public from North America (Table 1). Of responders, 78.1% (484/619) said they were not members of an ILAE or IBE chapter, and 72.5% (536/739) indicated that they had read the Controversy in Epilepsy series and Invited Review on the use of medical marijuana and CBD in treating patients with epilepsy.

Table 1. Comparison of type of medical personal and patients with geographic region in answering *Epilepsia's* survey on the use of medical marijuana and CBD in treating patients with epilepsy

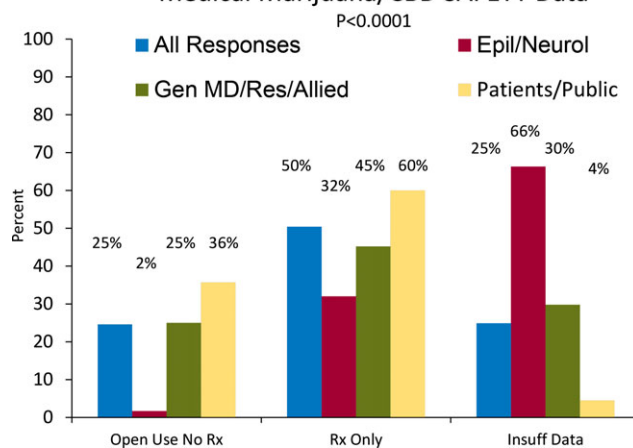
Category	Africa	Asia Oceania	Eastern Med	Europe	Latin America	North America	Total
Epileptologist	3	11	2	39	12	73	140
General neurologist	0	4	0	10	5	12	31
General physician	0	0	0	1	1	7	9
Basic researcher	1	0	0	7	2	26	36
Nurse/allied health	0	3	0	11	0	26	40
Patients/public	2	9	0	33	4	305	353
Total	9	27	2	101	24	449	609

Are there adequate SAFETY data to use medical marijuana for epilepsy?

There was a wide diversity of opinion on the use of medical marijuana in treating people with epilepsy that differed if the responders were specialists (epileptologists and general neurologists), general physicians and allied health professionals (general physicians, basic researchers, nurses and allied health), and patients and the public. The survey asked: "Based on the information from the Invited Review, pro and con positions do you believe: There are sufficient SAFETY data to allow for open nonprescription use of medical marijuana in treating epilepsy (Open Use No Rx); There are sufficient SAFETY data for use of medical marijuana in treating epilepsy but only with prescription and under medical supervision (Rx Only); or The SAFETY data are insufficient and medical marijuana should not be used for treating epilepsy without more studies (Insuff Data)." For all responders, 25% indicated that there were sufficient SAFETY data for nonprescription use, 50% said there were sufficient SAFETY data but only with a prescription, and 25% said there were insufficient SAFETY data (Fig. 1, blue bars).

Further analysis found significant disparity based on the responder's self-described professional category compared with patients and the public. Only 2% of epileptologists and general neurologists said that there were sufficient SAFETY data for unregulated use of medical marijuana, 32% said that there were sufficient SAFETY data but by prescription only, and 66% said that there were insufficient SAFETY data (Epil/Neuro; Fig. 1, red bars). By contrast, 36% of patients and the public said there were sufficient SAFETY data for unregulated use, 45% said there were enough SAFETY data but by prescription, and 4% said that there were insufficient SAFETY data (Patients/Public; Fig. 1, yellow bars). Nonepilepsy medical professionals, which included general physicians, basic researchers, nurses, and allied health professional (Gen MD/Res/Allied; Fig. 1, green bars) answered more in line with patients and the public rather than epileptologists and general neurologists. There were no differences to this question based on geographic category ($p = 0.09$), and if responders had read the series and invited review ($p = 0.20$).

Medical Marijuana/CBD SAFETY Data

**Figure 1.**

Responses from all who answered the survey question (blue bars; $n = 642$) and then separated into epileptologists and general neurologists (Epil/Neuro; red bars; $n = 172$), general physicians, basic researchers, nurses, and social worker (Gen MD/Res/Allied; green bars; $n = 84$) and patients and public (Patients/Public; yellow bars; $n = 353$) to the following question: Based on the information from the Invited Review, pro position, and con position do you believe: There are sufficient SAFETY data to allow for open nonprescription use of medical marijuana in treating epilepsy (Open Use No Rx); There are sufficient SAFETY data for use of medical marijuana in treating epilepsy but only with prescription and under medical supervision (Rx Only); or The SAFETY data are insufficient and medical marijuana should not be used for treating epilepsy without more studies (Insuff Data). Percentages for each group are provided above the bars.

Epilepsia © ILAE

Are there adequate EFFICACY data to use medical marijuana for epilepsy?

The responses were essentially the same for efficacy compared with safety data in using medical marijuana for epilepsy. The survey asked: "Based on the information from the Invited Review, pro and con positions do you believe: There are sufficient EFFICACY data to allow for open nonprescription use of medical marijuana in treating epilepsy (Open Use No Rx); There are sufficient EFFICACY data for use of medical marijuana in treating epi-

lepsy but only with prescription and under medical supervision (Rx Only); or The EFFICACY data are insufficient and medical marijuana should not be used for treating epilepsy without more studies (Insuff Data).” The responses were nearly identical for all responders and by professional category compared with patients and the public on EFFICACY as were found for SAFETY data (compare Figs. 1 and 2). Of responders answering both the SAFETY and EFFICACY question, 86% (525/610) answered in the same category for both questions. Controlling for professional category, there were no differences to the EFFICACY question based on geographic category ($p = 0.23$), and if they had read the series and invited review ($p = 0.56$).

Use of medical marijuana for severe uncontrolled epilepsy

The survey asked: “Would you advise patients with severe, catastrophic epilepsy who have not responded to approved therapy to try medical marijuana?” with a yes or no answer. A large majority (82%; 502/611) said that such patients should be advised to try medical marijuana

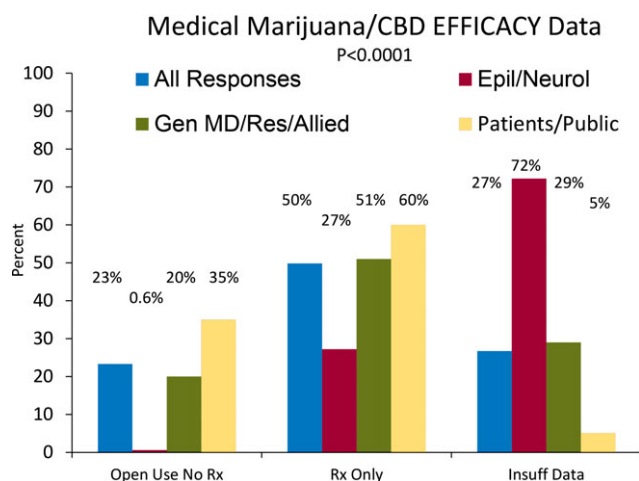


Figure 2.

Responses from all who answered the survey question (blue bars; $n = 616$) and then separated into epileptologist and general neurologist (epil/neurol; red bar; $n = 169$), general physician, basic researcher, nurse, and social worker (Gen MD/Res/Allied; green bars; $n = 83$) and patients and public (Patients/Public; yellow bars; $n = 350$) to the following question: Based on the information from the Invited Review, pro position, and con position do you believe: There are sufficient EFFICACY data to allow for open nonprescription use of medical marijuana in treating epilepsy (Open Use No Rx); There are sufficient EFFICACY data for use of medical marijuana in treating epilepsy but only with prescription and under medical supervision (Rx Only); or The EFFICACY data are insufficient and medical marijuana should not be used for treating epilepsy without more studies (Insuff Data). Percentages for each group are provided above the bars.

Epilepsia © ILAE

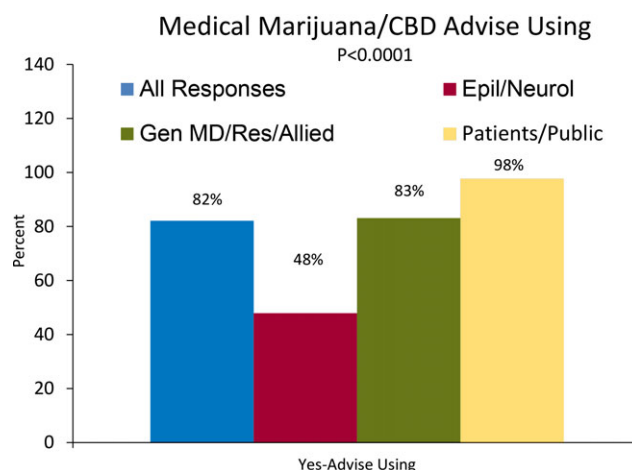


Figure 3.

Responses from all that answered the survey question (blue bar; $n = 611$) and then separated into epileptologist and general neurologist (Epileptologist/Neurologist; red bar; $n = 165$), general physician, basic researcher, nurse, and social workers (Gen MD/Res/Allied; green bars; $n = 83$) and patients and public (Patients/Public; yellow bars; $n = 351$) to the following question: Would you advise patients with severe, catastrophic epilepsy who have not responded to approved therapy to try medical marijuana? Percentages for each group are provided above the bars.

Epilepsia © ILAE

(Fig. 3, blue bar). Again, there was a diversity of opinion, with 48% of epileptologists and general neurologists agreeing with this point of view compared with 83% for general physicians, basic researchers, and allied health professionals and 98% for those who identified themselves as patients and the general public (Fig. 3). There were no differences to this question based on geographic category ($p = 0.59$), and if they had read the series and invited review ($p = 0.87$).

Should pharmacologic grade compounds containing CBD be available?

The survey asked: “What is your opinion about having pharmacologic grade compounds containing CBD available to us in epilepsy patients?” Response could be: Yes, such compounds should be available or No, such compounds are not needed, as growers can provide the medicinal. A large majority (77.6%; 475/612) responded, “Yes, such compounds should be available” with no differences comparing medical personal and patients and the public (Fig. 4). There were no differences in responses to this question based on geographic category ($p = 0.45$), and if they had read the series and invited review ($p = 0.37$).

Survey comments

Written comments were received from 97 responders (12.5%), and are provided unedited in Supporting Informa-

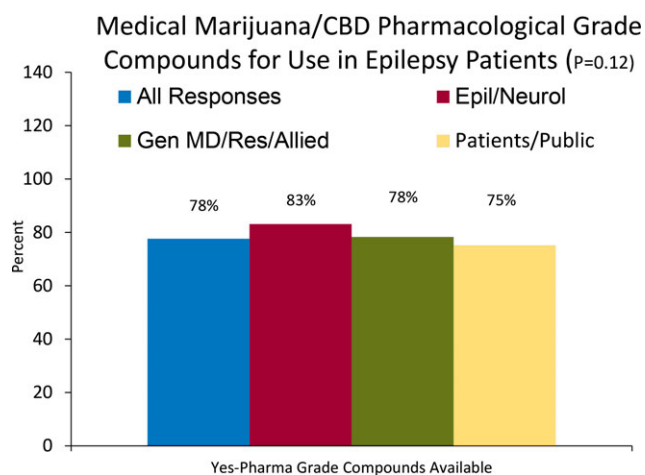


Figure 4.

Responses from all that answered the survey question (blue bar; $n = 612$) and then separated into epileptologist and general neurologist (Epil/Neurol; red bar; $n = 166$), general physician, basic researcher, nurse, and social worker (Gen MD/Res/Allied; green bars; $n = 83$) and patients and public (Patients/Public; yellow bars; $n = 350$) to the following question: What is your opinion about having pharmacological grade compounds containing CBD available to use in epilepsy patients? Response could be: Yes, such compounds should be available or No, such compounds are not needed as growers can provide the medicals. Percentages for each group are provided above the bars.

Epilepsia © ILAE

tion listing first epileptologists and general neurologists, followed by general physicians, basic researchers, nurses, and allied health, and finally patients and the public. The comments are mostly consistent with the results of the poll showing diversity of opinion with specialists supporting the need for properly performed controlled trials, while general physicians often support the use of medical marijuana, and the public stating that the trials take too long and medical marijuana and CBD should be made available immediately for patients with epilepsy.

DISCUSSION

The results of this survey show a disparity of opinion on the use of medical marijuana and CBD for people with epilepsy that varied considerably by medical specialists, general medical personal, and patients and the public. A minority of epileptologists and general neurologists said that there were sufficient safety (34%) and efficacy (28%) data with or without a prescription, and 48% would advise using medical marijuana even in severe cases of medically refractory epilepsy. By comparison, nearly all patients and the public said there were sufficient safety (96%) and efficacy (95%) data to use medical marijuana with or without a prescription, and 98% would recommend medical marijuana in cases

of severe refractory epilepsy. General physicians, basic researchers, nurses, and other allied health professions sided more with patients, saying that there were sufficient safety (70%) and efficacy (71%) data, and 83% would advise using marijuana in severe cases of epilepsy. There was one area of agreement, in that 78% said there should be pharmacologic grade compounds containing CBD for testing and possibly treating patients with epilepsy, without a difference between specialists, general medical personal, and patients and the public. We should emphasize that the results of this survey represent opinion and are not the recommendation of any expert panel or the ILAE, and should be used for informational purposes only.

In hindsight, these findings are probably not surprising based on the views expressed in the original pro and con positions in *Epilepsia*. However, the extent of the difference in opinion was not anticipated. The results of the poll and open comments section indicate that few specialists in epilepsy and neurology would apparently advocate using medical marijuana without proper controlled medical trials and under the supervision of a physician. By comparison, patients and the public often expressed frustration at the slow pace of getting government approval for a controlled substance and conducting trials to get regulatory approval while they watch family members suffer from seizures not responsive to standard medical therapies. Patients and the public who responded to our poll generally wanted open access to medical marijuana for epilepsy patients with or without a prescription. Unless there are changes to the law that allow access and testing of these compounds throughout the world, these differences are not likely to go away, and advocate for producing legitimate data that are helpful for all including physicians and patients. It should be emphasized that this survey was not structured to establish why professionals and patients might hold these opinions and whether their concepts might be mutable through more research and education. This may be the subject for future surveys and studies.

Readers should be aware of the limitations of this report and the survey methods. For example, this was an open-access survey, the responses were unaudited, and we trust that people were honest and forthright in completing the poll's questions. We also do not know if the survey is representative of the entire worldwide epilepsy community, given the limited number of responders outside of North America and Europe representing Africa, Asia, and Latin America. Likewise, we can only report the results of those who were aware of the survey and took the time to complete it. Furthermore, we cannot control for individuals who might have completed the survey more than once if they logged onto the site using different computers and times. These limitations will need to be considered in interpreting our findings. However, this survey indicates that there is a wide diversity of opinion on the use of medical marijuana

and CBD in the treatment of people with epilepsy, which varied substantially, with fewer medical specialists (epileptologists and neurologists) supporting its use compared with general physicians researchers and allied health personal and patients and the public.

DISCLOSURE

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines. None of the authors has any conflict of interest to disclose.

REFERENCES

1. Maa E, Figi P. The case for medical marijuana in epilepsy. *Epilepsia* 2014;55:783–786.
2. Cilio MR, Thiele EA, Devinsky O. The case for assessing cannabidiol in epilepsy. *Epilepsia* 2014;55:787–790.
3. Devinsky O, Cilio MR, Cross H, et al. Cannabidiol: pharmacology and potential therapeutic role in epilepsy and other neuropsychiatric disorders. *Epilepsia* 2014;55:791–802.
4. Mathern G, Nehlig A, Sperling M. Cannabidiol and medical marijuana for the treatment of epilepsy. *Epilepsia* 2014;55:781–782.
5. Mathern G, Beninsig L, Nehlig A. From the Editors: Epilepsia's 2014 Operational Definition of Epilepsy Survey. *Epilepsia* 2014;55:1683–1687.

SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article:

Data S1. Poll questions.

Data S2. Poll comments