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From the Editors: *Epilepsia's* 2014 Operational Definition of Epilepsy Survey

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SUMMARY

Objective: From March 19 to June 30, 2014, *Epilepsia* conducted an open access online survey asking directed questions related to the 2014 Operational Definition of Epilepsy. This study reports the findings of that poll.

Methods: The survey consisted of seven questions. Three questions addressed: (1) Criteria for when a person could be considered to have epilepsy after a single seizure; (2) if individuals with reflex seizures (unprovoked) have epilepsy; and (3) when epilepsy could be considered “resolved.” Four added questions asked if responders were medical personal compared with patients and family members, geographic region of residence based on International League Against Epilepsy (ILAE) regions, and if responders had read the paper and if they were ILAE/International Bureau for Epilepsy (IBE) members.

Results: Of 476 that started the survey, 324 (68%) completed it. As recommended in the ILAE report, 43% agreed that if the chance of a second seizure after a first one was 61–90%, then a person could be considered to have epilepsy. More medical professionals agreed with the 61–90% criteria (55%) compared with patients (21%), while more patients indicated that epilepsy should only be defined after two unprovoked seizures (51%) compared with medical professionals (21%; $p < 0.0001$). The majority indicated that reflex seizures qualify a person as having epilepsy (79%). As recommended in the ILAE report, 51% agreed that the definition of a person with “resolved” epilepsy would be 10 years seizure-free and off medication for the last 5 years. More medical professionals agreed with this definition (59%) compared with patients (37%), while more patients indicated that epilepsy is never resolved (32%) compared with medical professionals (7%; $p < 0.0001$). There were no differences based on geographic residence.

Significance: This survey found that the ILAE recommendations had the highest responses. However, there was clear disagreement with identified differences comparing medical personal with patients. These findings support the notion that there is a need and further opportunities for the ILAE to educate medical professionals and patients and their families on the 2014 Operational Definition of Epilepsy.

KEY WORDS: Definition, Epilepsy, Cure, In remission.



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As part of the publication of International League Against Epilepsy (ILAE) 2014 Operational Definition of Epilepsy, *Epilepsia* sponsored a publically accessible survey. The objective of the survey was to determine how well accepted were components of the report that were considered controversial because they were based on expert opinion and consensus. This report summarizes the results of the definition of epilepsy poll.

METHODS

In conjunction with the publication, the editors of *Epilepsia* provided readers and the public the opportunity to participate in an electronic survey (see Supporting Information).¹⁻⁹ The poll was advertised through press releases, the *Epilepsia* ILAE and IBE Websites, and through *Epilepsia's* e-Newsletter going out to >18,000 e-mail addresses weekly. Reminders to complete the poll were sent out and listed on the Websites the last 2 weeks before it closed. The survey could be completed anonymously; however, we asked those taking the poll to voluntarily provide email contact information if they wanted results provided to them.

The poll consisted of seven questions, with an opportunity for responders to provide written comments at the end. Three of the questions related to the 2014 Operational Definition of Epilepsy, and four questions on whether the responders read the paper and their demographics. The three questions related to the definition of epilepsy asked about criteria to diagnosis if a person can be classified as having epilepsy after a single seizure, whether people with reflex seizures can be considered to have epilepsy, and criteria to consider a person “resolved” of their epilepsy. These questions are further detailed in the Results section. The other four questions were:

1 Have you read the Operational Clinical Definition of Epilepsy in *Epilepsia*?

Possible answer: Yes or No.

2 What category best describes you?

Possible answers: (A) Epileptologist (Postresidency training or expertise in epilepsy; includes neurosurgeons; neuroradiologists, neuropsychologists, neuropathologists, nurses who spend considerable professional time with patients with epilepsy); (B) patients and family members of those with epilepsy; (C) general neurologist; (D) basic researcher; nurses, social workers, medical student, resident, epilepsy fellow; (E) general physician (pediatrician, internal medicine, family practice); and (F) other (and specify).

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

Possible answers were based on ILAE regional commissions and included: (A) Africa; (B) Asia/Oceania; (C) Eastern Mediterranean; (D) Europe (includes Eastern Europe, Russia, and Israel); (E) Latin America (south of U.S. border); and (F); 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 to the three questions related to the definition of epilepsy were compared with demographic information using a statistical program (StatView) applying

chi-square tests. Due to the large sample size and to reduce type I errors, statistical significance was set a priori at $p < 0.001$.

RESULTS

The survey opened April 14, 2014 and closed June 30, 2014. The Website was visited 2,495 times, with 476 starting the poll and 324 (68%) completing all of the questions. When the poll was only partly completed, it generally was the first few questions in the survey. Halfway through the open access, the sequence of questions was reversed so that the incomplete surveys would have similar number of people responding.

Demographics of responders

Responder's represented a diverse group of professionals in epilepsy care along with patients and family members from different parts of the world. For the question, “Which category best describes you?” there were 392 (82%) responses. The most frequent category was epileptologist (40.8%; $n = 172$), followed by patients and family members (30.4%; $n = 128$), general neurologist (8.0%; $n = 34$), basic researcher (3.5%; $n = 15$), nurses and social workers (3.5%; $n = 15$), medical student, resident epilepsy fellow (3.5%; $n = 15$), and general physician (3.0%; $n = 13$). For the question, “What geographic location of main residence/professional activities describes you?” There were 404 (85%) responses. The most frequent category was North America (37.7%; $n = 157$), followed by Europe (34.6%; $n = 144$), Asia/Oceania (14.1%; $n = 59$), Latin America (5.5%; $n = 23$), Africa (3.1%; $n = 13$), and Eastern Mediterranean (1.9%; $n = 8$). Of responders, 38.6% (159/411) said they were members of an ILAE or IBE chapter, and 81.4% (383/470) indicated they had read the 2014 Operational Definition of Epilepsy report in *Epilepsia*.

Diagnosis of epilepsy after a single seizure

The ILAE Definitions Task Force struggled with defining if and under what circumstances a person could be considered to have epilepsy after a single seizure.¹ After much deliberation, the group recommended that a person could be defined as having epilepsy after a single seizure if the probability of a subsequent seizure (second seizure) was similar to the risk after two unprovoked seizures. Two unprovoked seizures separated >24 h apart has been the previously accepted definition of epilepsy, with a range of 60–90% chance of further seizures after the first two.

The survey asked “In your view would you consider someone as having epilepsy if the risk of subsequent seizures after a first seizure was?” and provided a series of probabilities from 10% to 90% plus the answer that a definition of epilepsy required a second unprovoked event (Fig. 1). For all responders, the highest response (43%) was 61–90% chance of a second seizure after the first one as

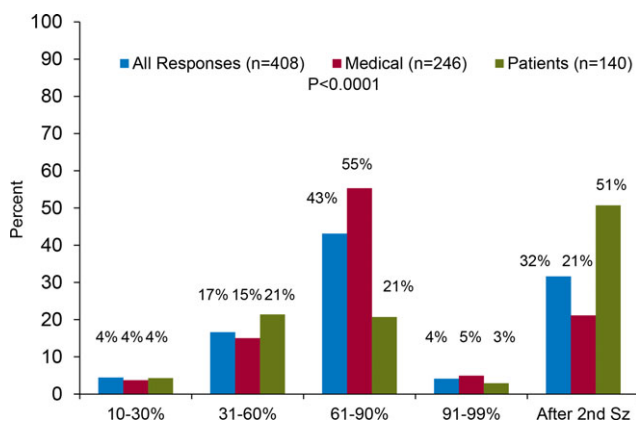


Figure 1.

Responses from all who answered the survey question (blue bars), and then separated into medical professionals (red bar) and patients and families (green bar) to the following question: The ILAE Task Force recommended that besides two unprovoked seizures >24 h apart, a person could be defined as having epilepsy after a single seizure if the probability of subsequent seizures was similar to the risk after two unprovoked seizures (>60–90%). In your view would you consider someone as having epilepsy if the risk of subsequent seizures after a first seizure was: 10–30%, 31–60%, 61–90% (ILAE definition), 91–99%, or only after a second seizure (After 2nd Sz).

Epilepsia © ILAE

recommended by the ILAE. The next highest response (32%) was that epilepsy could only be defined as having two unprovoked seizures. Of note, 17% of responders were more liberal than the ILAE recommendations by saying that they would accept a definition of epilepsy if the risk of a second seizure after a first one was from 31% to 60% (Fig. 1).

Further analysis found that there were differences if responders self-described themselves as medical professionals (Fig. 1 red bars; epileptologist, general neurologist, general physician, nurse, medical student, resident, and epilepsy fellow combined) compared with patients and family members (Fig. 1, green bars). More medical professionals (55%) agreed that if the risk of a subsequent seizure after an initial one was from 61% to 90% a person could be defined as having epilepsy compared with 21% from patients and families. By comparison, 51% of patients and families indicated that epilepsy should be defined only after a second unprovoked seizure compared with 21% for medical professionals. There were no differences to this question based on self-described geographic location ($p = 0.06$).

Are reflex seizures epilepsy?

Another area of possible contention was whether a person with reflex seizures, which are provoked, could be defined as having epilepsy. A large majority of responders (79.3%; 308/388) indicated that they agreed that reflex seizures qualify a person as having epilepsy. There were no differences by self-reported professional category or geographic location ($p > 0.32$).

When can epilepsy be considered resolved

Another discussion for the Task Force was whether people with epilepsy can ever be considered resolved or cured, and if so by what criteria. The Task Force eventually decided that there are circumstances in which the risk of future seizures was sufficiently reduced to consider individuals nearly cured, and used the term “resolved” for this condition. However, criterion for when a person is “resolved” of their epilepsy has never been appropriately defined in the literature. The Task Force eventually recommended that the term “resolved” be used for those who have remained seizure-free for at least 10 years, with no seizure medicines for the last 5 years.

The survey asked responders to select the definition they felt most comfortable for defining epilepsy as “resolved” with a choice of: (1) Seizure-free for 5 years on or off seizure medications; (2) seizure-free for 5 years and off seizure medications for the last 3 years; (3) seizure-free for 10 years on seizure medications; (4) seizure-free for 10 years with no seizure medications for the last 5 years (ILAE recommended definition); (5) seizure-free for 10 years off seizure medications for the last 7 years; or (6) epilepsy can never be considered “resolved.”

Responses were mostly consistent with the Task Force’s recommendation (Fig. 2). The majority of all responders (51%) agreed that the definition of a person with “resolved” epilepsy would be 10 years seizure-free and off medication for the past 5 years. This was followed by seizure-free for 5 years off medications for 3 years (17%), and epilepsy is never resolved (16%). There were differences when comparing medical professionals with patients and family. More medical professionals (59%) responded accepting the ILAE recommendation of 10 years seizure-free and off medications for 5 years compared with patients and families (37%), while 32% of patients and families responded that epilepsy is never resolved compared with medical professionals (7%). There were no differences based on geographic location of responders ($p = 0.43$).

Survey comments

Written comments were received from 140 responders (29.4%) in the survey, and are provided unedited in Supporting Information. Most were directed at whether epilepsy should be considered a disease versus a disorder, which was discussed in the original 2014 definition paper.¹

DISCUSSION

Within the limitations of any open access publically accessible survey, this report shows that while most agreed with the ILAE recommendations as expressed in the 2014 Operational Definition of Epilepsy, there was differences of opinion, especially when comparing medical professionals with patients and families.¹ Of the 476 that started the survey, 43% agreed that if the chance of a second seizure after

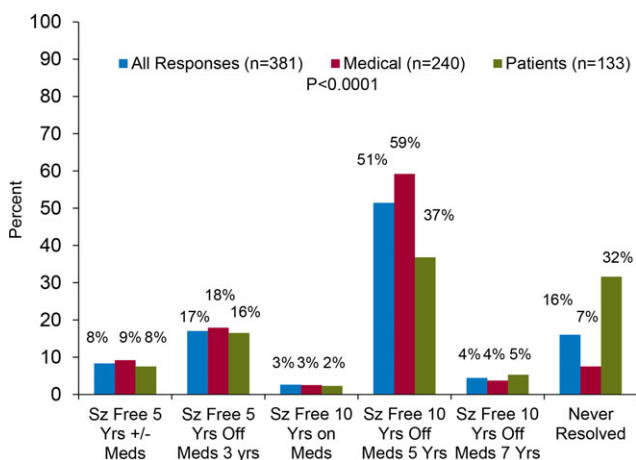


Figure 2.

Responses from all that answered the question (blue bars) and then separated into medical professionals (red bar) and patients and families (green bar) to the following question: The ILAE Task Force recommended the term “resolved” be used for those with epilepsy who have remained seizure-free for at least 10 years, with no seizure medicines for the last 5 years. Please select the definition you feel most comfortable for defining epilepsy as “resolved”: Seizure-free for 5 years on or off seizure medications, seizure-free for 5 years and off seizure medications for the last 3 years, seizure-free for 10 years on seizure medications, seizure-free for 10 years with no seizure medications for the last 5 years (ILAE definition), seizure-free for 10 years off seizure medications for the last 7 years, or epilepsy can never be considered resolved. *Epilepsia* © ILAE

a first one was 61–90%, then a person could be considered to have epilepsy (Fig. 1). However, 17% felt that the risk of the second seizure after a first one could be from 31% to 60%. More medical professionals agreed with the 61–90% criteria (55%) compared with patients and families (21%), and more patients indicated that epilepsy should be defined only after a second unprovoked seizure (51%) compared with medical professionals (21%). The majority in the survey indicated that reflex seizures qualify a person as having epilepsy (79%). As recommended in the ILAE report, 51% agreed that the definition of a person with “resolved” epilepsy would be 10 years seizure-free and off medication for the last 5 years (Fig. 2). However, 17% indicated that a person’s epilepsy could be considered resolved if they were seizure-free for 5 years and off medications for 3 years. More medical professionals agreed with this definition (59%) compared with patients (37%), and more patients responded that epilepsy is never resolved (32%) compared with medical professionals (7%). There were no differences based on the geographic residence of the responders based on ILAE regional categories.

Our findings, although supporting that many people agreed with the ILAE definitions, also showed a diversity of opinion, with many responders not accepting the ILAE

recommendations. These findings support the notion that there is controversy involving the new definitions, and suggest that there are opportunities for the ILAE to engage medical professionals and the public about the definition of epilepsy after a first seizure and when to consider a person’s epilepsy is “resolved.” This would seem especially important for patients and their families, as many supported that epilepsy could be defined only after having two unprovoked seizures, and that epilepsy could never be considered resolved or cured. Hence, our survey suggests that patients and families may be more conservative in their view of the definition of epilepsy compared with medical professionals. Engagement might be through forums to exchange ideas and concepts via the Internet, and through educational sessions and epilepsy congresses. Furthermore, it might be worthwhile to repeat this or a similar survey in the future to determine if added education or adjustments of attitudes over time alter the responses to the 2014 Operational Definition of Epilepsy.

Readers should be aware of the limitations of a publicly accessible survey, such as the one we are reporting. For example, the responses were unaudited and we must 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 epilepsy community. We can only report the results of those that were aware of the survey and took the time to complete it. Likewise, 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. However, the responses related to the demographic questions are in line with the readership profile of *Epilepsia*, and statistical analysis midway, and 3 weeks before the close of the survey showed similar findings, supporting that there were no obvious problems in conducting the survey that influenced the results.

In conclusion, this survey found that those who completed the poll accepted most of the ILAE recommendations, as presented in the 2014 Operational Definition of Epilepsy. However, there are areas for which there is clear disagreement, and differences in responses were noted comparing medical professionals and patients and families for criteria on if and when a person could be defined as having epilepsy after a single seizure and if and when a person’s epilepsy can be considered “resolved.” These findings suggest that there are opportunities for the ILAE to better educate medical professionals and patients and their families on the 2014 Operational Definition of Epilepsy.

DISCLOSURE

None of the authors has any conflict of interest to disclose. 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.

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SUPPORTING INFORMATION

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

Data S1. The operational clinical definition of epilepsy.

Data S2. 2014 ILAE definition of epilepsy poll comments.