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Should consciousness describe seizures and what terms should be applied? *Epilepsia's* survey results

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SUMMARY

Objective: From May to September 2014, *Epilepsia* conducted an online survey seeking opinions on whether consciousness should be used in describing focal and generalized seizures, and what terms should be applied to describe focal seizures with loss of awareness and amnesia. This study reports the findings of that survey.

Methods: Two questions asked if consciousness should be used to classify seizures and what terms should be applied. Another four questions addressed demographic information.

Results: Of 209 individuals that started the poll, 147 (70.3%) completing it, and most that completed it were epileptologists (66%) from Europe (41%) and North America (27%). A majority (64%) indicated that the presence or absence of consciousness should be used to describe focal and generalized seizures, whereas 23% said it should not be used. When asked what term should be used to describe focal seizures with altered awareness and amnesia, 36% said focal impaired consciousness seizures (FICS), 30% selected complex partial seizures (CPS), and 16% answered focal dyscognitive seizures.

Significance: This survey indicates that most responders prefer that consciousness be considered in the description of focal and generalized seizures, despite the difficulty in determining awareness clinically. Furthermore, responders could not agree on a single term that could be used to define focal seizures with loss of awareness and amnesia.

KEY WORDS: Seizure, Epilepsy, Classification, Focal, Dyscognitive, Impaired consciousness, Awareness, Amnesia.

The 1989 International League Against Epilepsy (ILAE) Classification of Seizures and Epilepsy included loss of consciousness and awareness as part of describing epileptic

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events using the terms simple and complex partial. In the report of the Commission on Classification and Terminology, consciousness was removed to simplify the classification of seizures into focal and generalized, and in considering that recognizing loss of consciousness and awareness during seizures was often challenging and inaccurate.¹

The debate about describing consciousness and level of awareness during seizures has not been resolved and was the subject of *Epilepsia's* Controversy in Epilepsy series in the August 2014 print edition. The series involved a position paper, which presented that consciousness should be a component in describing seizures.² This was followed by a paper that described the difficulty in labeling consciousness

during seizures and what different terms might mean.³ The pro and con positions were followed by commentaries.^{4,5} In conjunction with these articles, the Editors included an editorial and offered readers the opportunity to voice their opinions on this subject through an open access electronic poll.⁶ This report summarizes the results of the survey on using consciousness in describing seizures and what terms might be used.

METHODS

The survey on whether consciousness should be used in the classification of seizures (see Supporting Information Data S1) was disseminated through the print edition and *Epilepsia's* e-Newsletter. Reminders to complete the poll were sent out through the e-Newsletter several weeks before the poll closed. The survey could be completed anonymously; however, participants were asked to voluntarily provide email contact information to receive results.

The poll consisted of six questions, with an opportunity for responders to provide comments. Two questions related to the Controversy in Epilepsy articles, and four questions on whether the responders read the paper and their demographics. The questions related to the Controversy series asked if consciousness should be used in the classification of seizures, and what terms should be applied for focal seizures with altered awareness and amnesia. These questions are further detailed in the Results section. Four general questions addressed demographics as published previously.⁷

1 Have you read the Controversy in Epilepsy series on Consciousness of Epilepsy in *Epilepsia*?

Possible answer: Yes or No.

2 What category best describes you?

Possible answers as described previously included⁷: (A) epileptologist; (B) general neurologist not specializing in epilepsy; (C) general physician; (D) basic researcher; (E) medical student, resident, epilepsy fellow; (F) nurse, social worker, nurse practitioner; and (G) patient and family member of those with epilepsy.

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 the International Bureau for Epilepsy (IBE)?

Possible answer: Yes or No.

Data analysis

Responses were uploaded onto an electronic spreadsheet and tabulated. Responses related to the questions concerning consciousness in epilepsy were compared with demographic information using a statistical program (StatView,

Cary, NC, U.S.A.) applying chi-square tests. Statistical significance was set a priori at $p < 0.05$.

RESULTS

The survey opened May 28, 2014, and closed October 1, 2014. The website was visited 1,155 times; 209 individuals started the poll and 147 (70.3%) completed all of the questions. Compared with participants who completed the poll, those who did not showed no differences in responses to the questions about medical specialty ($p = 0.08$), geographic residence ($p = 0.71$), and if they were members of an ILAE or IBE chapter ($p = 0.76$). Perhaps not unexpectedly, more people who completed the poll said they had read the Controversy articles on consciousness in epilepsy (88.6%) compared with those who did not complete the survey (72.4%; $p = 0.0045$).

Demographics of responders

Responders described themselves as mostly epileptologists (66%) from Europe (41%) and North America (27%). There were 164 responses (78.5%) for the question, "Which category best describes you?" The most frequent category was epileptologist (66.5%), followed by general neurologist (10.4%), basic researcher (7.9%), patient (6.7%), student (3.6%); nurse and social worker (3.0%), and general physician (1.8%). For the question, "What geographic location of main residence/professional activities describes you?" there were 164 (78.5%) responses. The most frequent was Europe (40.8%) followed by North America (26.8%), Asia/Oceania (16.4%), Latin America (12.8%), Eastern Mediterranean (1.8%), and Africa (1.2%). Of responders, 60.3% (99/164) said they were members of an ILAE or IBE chapter, and 56.8% (116/204) indicated that they had read the Controversy in Epilepsy series on using consciousness in describing seizures.

Should consciousness be used to describe seizures?

The survey asked the following: The 2010 ILAE organization of the epilepsies classified seizures as focal or generalized without considering alterations of consciousness. In your opinion: (A) Seizures should be described as focal or generalized without considering consciousness (current ILAE recommendation); (No cons ILAE); (B) Focal and generalized seizures should include alteration of consciousness in describing the events (Include cons); or (C) Only focal seizures should include alteration of consciousness in describing the events (Focal only). The majority (64%) answered that consciousness should be used to describe focal and generalized seizures (Fig. 1; Answer B). Responses did not differ based on professional category ($p = 0.32$), geographic region ($p = 0.76$), if they had read the series ($p = 0.98$), if the responder was a member of an ILAE or IBE chapter ($p = 0.63$), and if they fully completed the survey ($p = 0.32$).

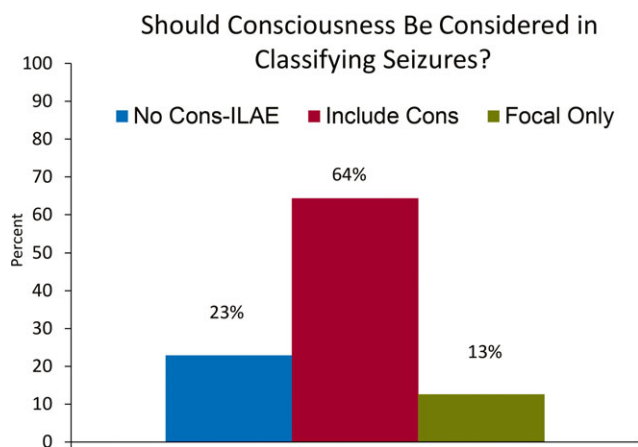


Figure 1.

Responses to the question: The 2010 ILAE organization of the epilepsies classified seizures as focal or generalized without considering alterations of consciousness. In your opinion: (A) Seizures should be described as focal or generalized without considering consciousness (current ILAE recommendation; no cons-ILAE); (B) Focal and generalized seizures should include alteration of consciousness in describing the events (Include cons); or (C) Only focal seizures should include alteration of consciousness in describing the events (Focal only). Percentages for each answer are provided.

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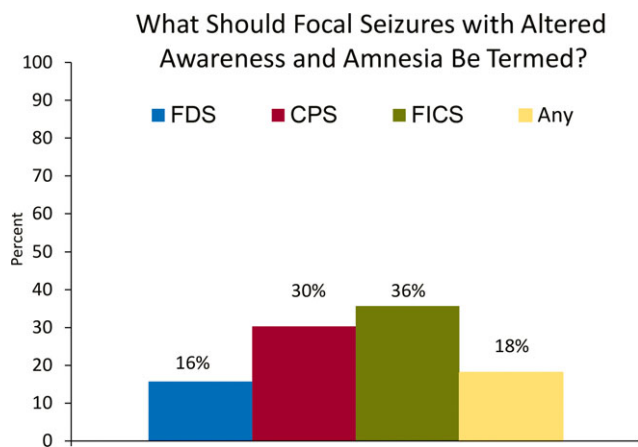


Figure 2.

Responses to the question: Focal seizures with altered awareness and amnesia should be termed: (A) Focal dyscognitive seizures (FDS); (B) Complex partial seizures (CPS); (C) Focal impaired consciousness seizures (FICS); or (D) Any of the above (Any). Percentages for each answer are provided.

Epilepsia © ILAE

What terms should be used to describe seizures with altered awareness?

The survey asked: Focal seizures with altered awareness and amnesia should be termed: (A) Focal dyscognitive seizures (FDS); (B) Complex partial seizures (CPS); (C) Focal impaired consciousness seizures (FICS); or (D) Any

of the above (Any). There was a diversity of responses, with 36% saying FICS and 30% indicating CPS (Fig. 2). Responses did not differ based on professional category ($p = 0.69$), geographic region ($p = 0.28$), if they had read the series ($p = 0.70$), if the responder was a member of an ILAE or IBE chapter ($p = 0.79$), and if they fully completed the survey ($p = 0.08$).

Survey comments

No written comments were received from responders to this survey.

DISCUSSION

The results of this survey from mostly epileptologists (66%) from Europe and North America (68%) indicated that a majority of responders (64%) said that consciousness should be considered in the description of generalized and focal seizures despite the difficulty in determining awareness as expressed in the Controversy series (Fig. 1).³ However, responders could not agree on a single term that could be used to define focal seizures with loss of awareness and amnesia with, 36% saying focal impaired consciousness seizures (FICS) and 30% indicating complex partial seizures (CPS). We should emphasize that the results of this survey represent opinion and should be used for informational purposes only.

Readers should be aware of the limitations of this report. This was an open access survey, the responses were unaudited, and we trust that people honestly completed the poll. Likewise, we can only report the results of those who were aware of the survey and took the time to complete it. These limitations will need to be considered in interpreting our findings. However, this survey indicates that most felt that consciousness should be considered when classifying seizures, although no single term could be agreed upon to describe focal seizures with altered awareness and amnesia. Further discussion and consensus is needed among those in the epilepsy community to clarify these questions.

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. Consciousness of epilepsy.