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### Title

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### Authors

Mathern, Gary W  
Beninsig, Laurie  
Nehlig, Astrid

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## Reasons for discrepancy between incidence and prevalence of epilepsy in lower income countries: *Epilepsia's* survey results

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

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Gary W. Mathern,  
*Epilepsia* Co-Editor in  
Chief



Astrid Nehlig,  
*Epilepsia* Co-Editor in  
Chief

### SUMMARY

**Objective:** From July to August 2014, *Epilepsia* conducted an online survey seeking opinions that explained the discrepancy between the incidence and prevalence of epilepsy in lower income countries. Data on cumulative incidence suggest a higher rate of active epilepsy than reported in lifetime prevalence surveys. This study reports the findings of that poll addressing the proposal in our Controversy in Epilepsy series that it could be from increased death rates.

**Methods:** The survey consisted of a question addressing possible reasons to explain the discrepancy between the incidence and prevalence of epilepsy. Another four questions addressed demographic information.

**Results:** There were 34 responders who completed the survey. Half (50%) of the responders felt that the discrepancy between cumulative incidence and lifetime prevalence was due to lack of uniform definitions and misclassification of patients in study design, 23.5% said the discrepancy was due to a higher mortality from diseases and conditions such as trauma and infections associated with epilepsy, 23.5% indicated that the stigma of epilepsy prevented people from acknowledging their disease in prevalence surveys, and 2.9% felt it was from poor access to qualified medical personal and utilization of medical treatments that increased death rates directly related to epilepsy.

**Significance:** Within the limitations of sample size, the results of this survey support that the discrepancy between the incidence and prevalence of epilepsy in lower income regions of the world is due to problems in acquiring the data and stigma rather than higher mortality from diseases associated with epilepsy and repeated seizures.

**KEY WORDS:** Seizure, Epilepsy, Epidemiology, Prevalence, Incidence.

In our Controversy in Epilepsy series (July 2014), we addressed the question to explain the discrepancy between cumulative incidence and lifetime prevalence of epilep-

psy in lower income regions of the world. Cumulative incidence predicts a higher lifetime prevalence of epilepsy as reported in epidemiologic surveys. What explains the discrepancy? Bell et al. proposed the provocative hypothesis that more people with epilepsy die from poor medical management and the underlying diseases causing their seizures, and thus are not identifiable at the time of prevalence surveys.<sup>1</sup> In response, Beghi and Hesdorffer suggested that there are several possible explanations for the discrepancy and identified that the patients with epilepsy can be misclassified in surveys, there is a lack of uniform definitions applied in epidemiologic studies, and

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

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that stigma could play a role in people not acknowledging their epilepsy in surveys.<sup>2</sup> In conjunction with these articles, the Editors offered readers the opportunity to voice their opinions through an open access electronic poll on the reasons for the discrepancy between the incidence and prevalence of epilepsy.<sup>3</sup> This report summarizes the results of the survey.

## METHODS

The poll on the discrepancy between the incidence and prevalence of epilepsy (see 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 the last two 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 five questions, with an opportunity for responders to provide comments. One question related to the Controversy in Epilepsy series articles on the discrepancy between the incidence and prevalence of epilepsy, and four questions whether the responders read the paper and their demographics. The question about the discrepancy asked for the reader's opinion on what might explain the difference between the cumulative incidence and lifetime prevalence of epilepsy, and is further detailed in the Results section. The other four questions asked general questions as previously published.<sup>4</sup>

**1** Have you read the Controversy in Epilepsy series on the discrepancy between the incidence and prevalence of epilepsy in *Epilepsia*?

Possible answer: Yes or No

**2** What category best describes you?

Possible answers: (1) Epileptologist; (2) general neurologist not specializing in epilepsy; (3) general physician; (4) basic researcher; (5) nurse, social worker, medical student, resident; and (6) patient and family member.

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

Possible answers were based on International League Against Epilepsy (ILAE) regional commissions and included the following: (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 International Bureau for Epilepsy (IBE)?

Possible answer: Yes or No.

## Data analysis

Responses were uploaded onto an electronic spreadsheet and tabulated. Responses about the discrepancy between the incidence and prevalence of epilepsy were compared with

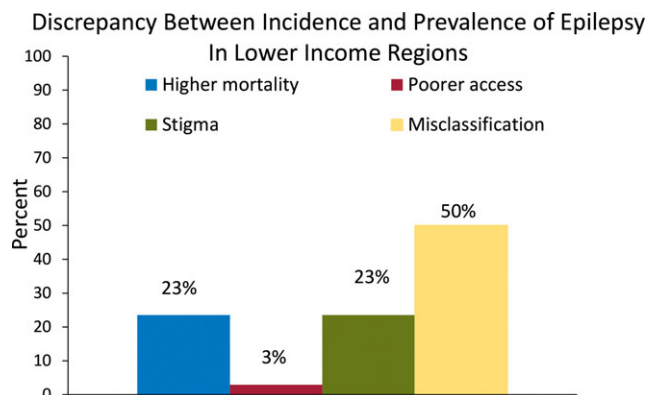
demographic information using a statistical program (Stat-View, SAS Institute, Cary, NC, U.S.A.) applying chi-square tests. Statistical significance was set a priori at  $p < 0.05$ .

## RESULTS

The survey opened May 28, 2014 and closed September 1, 2014. The website was visited 389 times, with 61 individuals starting the poll and 34 completing all of the questions. The 27 who did not complete the poll answered only the first question. Hence, this survey reports the findings from the 34 who completed it.

### Demographics of responders

Responders represented primarily medical personal from Europe and North America. For the question, "Which category best describes you?" there were 34 responses. The most frequent category was epileptologist (52.9%), followed by general neurologist (17.6%), nurses and social workers (11.7%), patients (8.8%), basic researcher (5.8%), and general physician (2.9%). For the question, "What geographic location of main residence/professional activities describes you?" there were 34 responses. The most frequent category was Europe (47.0%) followed by North America (32.3%), Asia/Oceania (14.7%), Latin America (2.9%), and



**Figure 1.**

Response to the question: Based on the information from Bell et al. and Beghi and Hesdorffer, select which answer is the most likely factor in your opinion that explains the discrepancy between the cumulative incidence and lifetime prevalence of epilepsy in lower income regions of the world. Answers were: (A) Higher premature mortality from epilepsy-related diseases and conditions (trauma, brain infections, and HIV) explains the reduced lifetime prevalence (Higher mortality); (B) Poorer access and utilization of treatments such as antiepileptic drugs (AEDs) increase death rates from SUDEP in people with epilepsy (Poorer access); (C) The stigma of epilepsy prevents people from acknowledging their disease in surveys (Stigma); and (D) The misclassification and lack of uniform definitions in collecting incidence and prevalence data on people with epilepsy explain the difference in reported data (Misclassification). Percentages for each answer are provided.

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Eastern Mediterranean (2.9%). Of responders, 73.5% (25/34) said they were members of an ILAE or IBE chapter, and 54.0% (33/61) indicated they had read the Controversy in Epilepsy series on the discrepancy between incidence and prevalence of epilepsy in lower income countries.

### What explains the difference between the cumulative incidence and lifetime prevalence of epilepsy in low-income regions of the world?

The survey asked: Based on the information from Bell et al. and Beghi and Hesdorffer, select which answer is the most likely factor in your opinion that explains the discrepancy between the cumulative incidence and lifetime prevalence of epilepsy in lower income regions of the world? Of the responders (n = 34), 50% felt that it was due to misclassification and lack of uniform definitions in collecting such data, 23.5% said it was due to a higher mortality from diseases and conditions associated with epilepsy such as trauma and brain infections, 23.5% indicated that the stigma of epilepsy prevented people from acknowledging their disease in surveys, and 2.9% felt it was from poor access and utilization of epilepsy treatments that increased death rates from sudden unexpected death in epilepsy (SUDEP; Fig. 1). Further analysis found that these results did not differ based on professional category (p = 0.39), geographic regions (p = 0.49), if they had read the series (p = 0.84), and if the responder was a member of an ILAE or IBE chapter (p = 0.24).

### Survey comments

No written comments were received from responders, to this survey.

## DISCUSSION

Within the limitations of a relatively small sample size, the results of this survey show a diversity of opinion to explain the discrepancy between the cumulative incidence and lifetime prevalence of epilepsy in lower income regions of the world. Half of responders felt the discrepancy was due to misclassification and lack of uniform definitions in collecting data, 23.5% said it was from a higher mortality from diseases and conditions such as trauma and infections

associated with epilepsy, 23.5% indicated that the stigma of epilepsy prevented people from acknowledging their disease in surveys, and 2.9% felt it was from poor access and utilization of epilepsy treatments that increased death rates. 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 and the survey methods. 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. Likewise, we can only report the results of those who were aware of the survey and took the time to complete it, and the sample size was smaller than previous surveys from *Epilepsia*. These limitations will need to be considered in interpreting our findings. However, this survey indicates that most felt that the discrepancy between incidence and prevalence was due to misclassification and lack of uniform definitions in collecting data rather than an increase in death rates from seizures or their causes.

## 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 discrepancy between accumulative incidence and lifetime prevalence of epilepsy.