

A Report from the ILAE Commission on Epidemiology

Ettore Beghi and Dale C Hesdorffer, Co-Chairs

The ILAE Commission on Epidemiology was established in 2009. Co-Chairs are Dale C Hesdorffer (New York, USA) and Ettore Beghi (Milano, Italy). Commission members include Allen Hauser (Past Chair), Ley Sander (Treasurer), Charles Newton (Secretary), Torbjorn Tomson (Educational Officer), Giancarlo Logrosino (Information Officer), Ding Ding, David Thurman, and Marco Medina (Executive Committee Liaison).

The Epidemiology Commission tasks for this term reflect the primary issues of epidemiology for epilepsy and are an evolution of the effort of the previous Commission from 2001-2005. Because the goals involve multiple areas of expertise, much of the work has been done in collaboration with other ILAE Commissions (Classification, Diagnostic Methods, Education, Pediatrics, and Psychobiology). Within this framework, the action plan of the Epidemiology Commission for the 2009-2013 term includes five primary themes:

1. Standardizing terms and methods for epilepsy research.
2. Examining the issues surrounding increased mortality in epilepsy.
3. Determining the scope of epilepsy comorbidities.
4. Evaluating the reliability of epilepsy classification.
5. Developing a classification for status epileptics.

The Commission completed a position paper outlining standard definitions, study designs, and instruments to improve the quality of epidemiological research on epilepsy and to facilitate comparison of the burden of epilepsy worldwide (Thurman et al, 2011). We hope that the availability of such standardized materials will facilitate the development of studies that can have broad application to our understanding of epilepsy.

The Mortality Task Force is engaged in work on prevention of epilepsy-related deaths. To this end, we have published two articles on a pooled analysis of the available evidence on the risk factors for sudden unexplained death (SUDEP) (Hesdorffer et al, 2011 & 2012). The Task Force is currently engaged in a systematic review of death in epilepsy with a focus upon preventable causes where there is potential for prevention strategies to reduce mortality in epilepsy. This work is based on published information. So far the articles have been selected, the data forms for article abstraction completed, and the forms filled in for all articles. Additional work still underway includes calculation of the cumulative risk for SUDEP and development of a model to assess SUDEP risk that could be used by clinicians.

The Comorbidity Task Force is working on two systematic reviews to determine and describe the scope of psychiatric and cognitive comorbidities in epilepsy. Questions being examined for the comorbidity with psychiatric disorders include:

- Is the phenomenology of a psychiatric disorder different with and without epilepsy?



Ettore Beghi



Dale C Hesdorffer

- Does psychiatric comorbidity occur in the pre- and post ictal period more than during other periods?
- Is the psychiatric disorder more common in epilepsy than in the general population?
- Is the psychiatric disorder associated with an increased risk for developing epilepsy?
- Is epilepsy associated with an increased risk for developing a psychiatric disorder?

Questions being examined for the comorbidity with cognitive problems include:

- Is the phenomenology of deficits in cognitive domains different with and without epilepsy?
- Does a deficit in a cognitive domain occur in the pre- and post ictal period more than during other periods?
- Is the cognitive domain deficit more common in epilepsy than in the general population?
- Is deficit in the cognitive domain associated with an increased risk for developing epilepsy?
- Is epilepsy associated with an increased risk for developing a deficit in the cognitive domain?

We have screened 3,000 article abstracts and selected 2,500 for review. We have created an abstraction form and connected it with a database. Currently, we are piloting the abstraction in six psychiatric comorbidity articles and six cognitive comorbidity articles.

The Reliability Task Force is evaluating the reliability of the classification of epilepsy according to ICD-10, ICD-11, and the NIH consensus forms for seizure type and etiology. Seventy-one case reports were created covering children and adults. These were evaluated three times, each time with incremental information, and the reliability was compared across participating epileptologists. A manuscript has been prepared. A second examination of reliability was undertaken in Latin American with seven pediatric epileptologists and seven adult epileptologists reviewing 26 case

reports each. These data are being analyzed and a manuscript will be prepared.

The Status Epilepticus Task Force from the Commission on Epidemiology joined forces with the Status Epilepticus Task Force of the Commission on Classification to develop a joint statement covering the clinical and the epidemiological definition of Status Epilepticus. This statement is almost ready for submission to the ILAE Executive Committee.

Task Force Members:

Mortality TF:

Giancarlo Logrosino and David Thurman (Co-Chairs)
Dale Hesdorffer, Ettore Beghi, Allen Hauser, Ley Sander, Charles Newton, Fulvio Scarza, and Torbjorn Tomson

Comorbidity TF:

Dale Hesdorffer (Chair), Ettore Beghi, Roberto Tuchman, Andres Kanner, Michael Trimble, Paola Torelli and Christoph Helmstaedter

Reliability TF:

Ettore Beghi (Chair), Dale Hesdorffer, Donna Bergen, Allen Hauser, Peter Bergin, Jacqueline French, Marco Medina, Charles Newton, Douglas Nordli, Nathalie Jetté, and Giuseppe Capovilla

Status Epilepticus TF:

Shlomo Shinnar (Chair), Giancarlo Logrosino, Ingrid Scheffer, Ding Ding, Ed Dudek

References

Hesdorffer DC, Tomson T, Benn E, Sander JW, Nilsson L, Langan Y, Walczak TS, Beghi E, Brodie MJ, Hauser A; ILAE Commission on Epidemiology; Subcommission on Mortality. Combined analysis of risk factors for SUDEP. *Epilepsia*. 2011 Jun;52(6):1150-9.

Hesdorffer DC, Tomson T, Benn E, Sander JW, Nilsson L, Langan Y, Walczak TS, Beghi E, Brodie MJ, Hauser WA; for the ILAE Commission on Epidemiology; Subcommission on Mortality. Do antiepileptic drugs or generalized tonic-clonic seizure frequency increase SUDEP risk? A combined analysis. *Epilepsia*. 2012 Feb;53(2):249-252.

Thurman DJ, Beghi E, Begley CE, Berg AT, Buchhalter JR, Ding D, Hesdorffer DC, Hauser WA, Kazis L, Kobau R, Kroner B, Labiner D, Liow K, Logrosino G, Medina MT, Newton CR, Parko K, Paschal A, Preux PM, Sander JW, Selassie A, Theodore W, Tomson T, Wiebe S; ILAE Commission on Epidemiology. Standards for epidemiologic studies and surveillance of epilepsy. *Epilepsia*. 2011 Sep;52Suppl 7:2-26.



Research

Education

The Journals of the ILAE

For subscription information, visit
www.ilae.org/Visitors/Publications/Index.cfm

