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Epilepsy Registries Task Force

Jakob Christensen (Denmark), Co-chair Wendyl D'Souza (Australia), Co-chair Sandra Helmers (USA), Dale Hesdorffer (USA), David Thurman (USA), Donna Bergen (USA)

Aims

To accomplish its mission, the Commission on Epidemiology seeks to promote standard methods for epidemiological research in epilepsy and for describing the epidemiological evidence on the burden of epilepsy and potential preventive measures. The principal responsibility of the Commission on Epidemiology is to develop and disseminate knowledge of the global burden of epilepsy and its risk factors from a public health and prevention perspective.

Accordingly, the Commission seeks:

- to review available epidemiological evidence, assess the strength of such evidence, and summarize this evidence for the planning and management of relevant ILAE programs, where requested;
- to identify needed epidemiological research, to promote improvements in research methods, and to strengthen such research capacity, including research to inform epilepsy prevention and control programs of the ILAE;
- to thereby enhance research and prevention programs in world regions where the burden of epilepsy and its adverse consequences are highest, especially lower income countries;
- to educate the epilepsy community and health ministries and departments about the burden of epilepsy, and to promote discussions of program development toward the prevention of epilepsy and its adverse consequences.

Commission Activities from June 2013 through June 2014

In the first year of its new term, the Commission on Epidemiology reexamined its mission and appointed 4 new or continuing Task Forces to support this mission. In a meeting convened in December 2013, the Commission defined the goals of these Task Forces as described in the following section.

Accomplishments (2013-2014)

The Prevention Task Force represents a new initiative whose purpose is to assess opportunities for epilepsy prevention and to develop strategies toward implementing prevention measures. The Task Force will address both primary prevention (i.e., the prevention of epileptogenic brain insults such as injury, stroke, or infection), early secondary prevention (i.e., the interruption of epileptogenesis following a brain insult), and secondary prevention (i.e., timely access to appropriate care following the onset of epilepsy). To this end, activities of the Task Force will include:

- Systematic reviews—studies of incident epilepsy, addressing causes and modifiable risk factors in both higher and lower income countries; studies of epilepsy treatment gaps and treatment non-adherence; studies of effectiveness of epilepsy prevention strategies, including primary prevention, as well as early secondary and secondary prevention.

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- Recommendations based on these reviews to identify priorities for epilepsy prevention programs, identify major gaps in understanding causes and risk factors in different world regions.

The Epilepsy Registry Task Force, also a new initiative, was proposed to explore opportunities to develop epilepsy registries, promote the development of new and existing registries, and promote methods to facilitate the international sharing and comparison of data across registries. Such registries have value in providing data to better understand:

- the public health burden and clinical spectrum of epilepsy,
- the distribution of epilepsy types in populations, and
- clinical and demographic determinants of outcomes. As conceived, the objectives for this Task Force were ambitious; however, funding to proceed with the range of activities to achieve them was not approved, due to financial constraints and other considerations. Accordingly, this Task Force is re-considering its objectives to reduce their number and extent.

The Mortality Task Force continues from the previous Commission term. Its purpose is to describe the mortality risk and causes of death among people with epilepsy, and to assess and recommend strategies to prevent premature death in epilepsy. To this end, the Task Force has undertaken systematic reviews to identify incidence and causes of death in epilepsy, separately assessing these in higher-income countries and lower- and middle-income countries. These data have been compiled and analyzed, and manuscript reports are now in preparation. Based upon these reviews of causes of death in epilepsy and risk factors for preventable causes of death, the Task Force will seek to develop potential prevention strategies in collaboration with the Prevention Task Force.

The Comorbidity Task Force also continues from the previous Commission term. Its purpose is to identify and assess the burden of comorbidities among people with epilepsy. This assessment is now focused primarily on psychiatric comorbidities; as time and resources permit, cognitive comorbidities may be addressed subsequently. To this end, the Task Force is in the process of a systematic review to identify psychiatric comorbidities of epilepsy. The publication of this report will enable further work, described as follows.

Recommendations for Future Work

The work of recent and current Task Forces of the Commission on Epidemiology is ultimately intended, to a large extent, to help promote the primary and secondary prevention of epilepsy and its adverse consequences.

The Prevention Task Force will be addressing this aim directly. Its systematic reviews will yield published recommendations that the Commission will promulgate in coordination with other ILAE Commissions, WHO, PAHO, and other relevant agencies to promote research and public health interventions for epilepsy. The work of the Mortality Task Force will also lead to the development of prevention strategies that may be similarly promulgated. And the findings of the Comorbidity Task Force will be translated into prevention work in several ways: first, to increase awareness through publication, educational symposia, and dissemination of materials to health ministries, and also by the development of assessment and training materials for clinicians to help them identify comorbidities, understand their impact, and improve their treatment.