The solutions to these different needs often seem in conflict with each other. Informatics is introduced as a discipline that may provide the necessary tools to construct an internally consistent conceptual and terminological system responsive to these many different settings and purposes and able to accommodate changes over time.

KEY WORDS: Classification, Epidemiology, Etiology, Informatics.

The International League Against Epilepsy (ILAE) Classifications of seizures (Commission, 1981) and epilepsies (Commission, 1989) were laudable efforts to standardize terminology and concepts for epilepsy and facilitate communication. Based on an understanding and the technologies from the 1800s and early 1900s they have become, in many important ways, obsolete in the age of genomic technology, advanced imaging, new neurophysiologic capabilities, and combined (e.g., coregistration) techniques. Changing them is no simple task as they are enshrined in texts, hospital billing codes, and the World Health Organization’s International Classification of Diseases (ICD) system. A 2010 report (Berg et al., 2010) wrought some havoc and distress in the community when it recommended abandoning the old terms and, in fact, the entire classification structure for epilepsies. At the same time, most who gave the matter careful thought acknowledged that change was long overdue even if they did not fully endorse the changes proposed. At the 2011 American Epilepsy Society (AES) meeting, the Epidemiology Special Interest Group addressed the need for terminology primarily as regards underlying causes or etiology of epilepsy. Speakers included Donna Bergen (Bergen et al., 2012), representing the ICD committee tasked with providing a new disease classification scheme for epilepsy (ICD-11) and Ingrid Scheffer, Chair of the ILAE Classification and Terminology Commission (Scheffer, 2012).

We also heard from stakeholders ranging from a neurologist who practices most of the year in rural Zambia to a neurosurgeon practicing in a well-known, American tertiary center. The needs of epidemiologists and clinical triallists were also represented. This supplement, the result of a gracious invitation from Prof. Phillip Schwartzkroin, co-editor-in-chief of Epilepsia, contains brief commentaries from the speakers and should provide the interested reader with an appreciation of the range of issues that must be accommodated in any future attempts to develop a terminology and classification approach that can be all inclusive and useful to all.

From my own perspective, there is much to be done. Even as it was being written, it was clear that the genetic versus structural-metabolic distinction presented in the 2010 report was inadequate; we said as much in that report. However, the “much to be done” implies some serious work. I am concerned that there will be attempts to make quick changes to what was intended as a transition from old terminology (idiopathic, symptomatic, cryptogenic) and replace it with a final solution such as genetic, structural, metabolic, and immune. In such a scheme, one quickly loses track of and will likely confuse precipitating cause versus pathophysiologic mechanisms through which a cause may have its effect.

Birbeck (2012) endorsed the notion that any classification be flexible and multidimensional. This will be essential to the success of any future efforts in this area. Exactly how to do that and how to ensure that information used in developing a classification is grounded in evidence and can grow as new evidence emerges is, to many, a mystery. It is for that reason that Guo-Qiang Zhang, Satya Sahoo,
and Samden Lhatoo were asked to contribute to this discussion and to reflect upon and introduce to us the brave new world of informatics and ontologies (Zhang et al., 2012). Strange words, off-putting for some, but behind them a burgeoning system for managing the extraordinary complexity of information with which we are now faced and for improving communication across a broad array of clinical and laboratory settings. Their analogy to the Amazon.com model for classifying a book versus how a physical bookstore would locate the same book provides an easy way for us non-initiates to get oriented to these new concepts and what they can offer us. Rapidly, one can see how, as Peter Camfield (2012) suggests, all epilepsies that are associated with substantial risk of severe developmental consequences can be identified and grouped together, but this can and should be done independently of their precipitating cause or underlying pathophysiology, which is not the same thing as developmental outcome. This does not preclude grouping epilepsies by type of presenting seizure, most relevant in adults as Jakob Christensen points out (Christensen & Sidenius, 2012), but still important in children, nor does it stop someone else regrouping based upon age at onset or the two together. Similarly, in classifying causes, the genetic counselor may wish to identify all causes of epilepsies with a primary genetic component, whereas the neurosurgeon may wish to identify all causes associated with potentially resectable lesions (some will have a genetic basis, others not). Others approaching this from a public health perspective may be interested in causes easily preventable through basic public health maneuvers (vaccination, seat belts, clean water, pest control, and so on). There are no conflicts, and all of this is possible.

We have a good deal of work to do, but we also have the means for accomplishing that work and for continuing it forward. Discussions such as the one at AES, where we were pleased to see a large engaged audience participating in the exchanges, are an essential component to this progress. Such engagement will continue to contribute to future progress, especially as the new possibilities afforded by informatics become appreciated and these newer approaches are incorporated into everyday thinking.

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