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INTERNATIONAL CLASSIFICATION OF DISEASES (ICD-11) AND NEUROLOGIC DISORDERS: THE FUTURE

When the WHO's Topic Advisory Group for Neurology (TAG) started work on revision of the *ICD-10* diagnostic codes in June 2009, the issues were daunting. The existing classification was produced a generation ago and the need to move to the digital age was becoming imperative. Appreciating modern advances in genetics and immunology, and the consequent changes in understanding of the pathophysiology of disorders of the nervous system, WHO's charge to the TAG was to produce a comprehensive, up-to-date disease classification, while providing published or consensus evidence for each coding change. In addition, the task would be to focus on ways to reduce the treatment gap while considering the utility of the *ICD-11* when used in primary care and nonspecialist settings. The project mushroomed over the 3 years since our first meeting and continues to do so. The work was made even more difficult as the group needed to add "content models" for the major codes for the first time (i.e., providing a definition for each disorder, along with appropriate diagnostic tests and outcome). The *ICD-11* is meant to be updated as new knowledge develops, rather than waiting some years for another whole-scale revision, but this process has yet to be defined.

An unprecedented collaboration among many international neurologic and neurosurgical associations is exemplified in the work of the TAG. The WHO appointed 7 ad hoc members from across the world. There are also representatives from the major global neurologic organizations: Alzheimer's Disease International, International Brain Research Organization, International Child Neurology Association, International Headache Society, International League Against Epilepsy, International Neuropsychological Society, Movement Disorders Society, Multiple Sclerosis International Federation, World Federation of Neurosurgical Societies, World Federation of Neurology, and the World Stroke Organization.

The task is formidable. In addition to the genetic revolution of the previous 2 decades and changes in the understanding of neurologic disorders, there has been

massive progress in neurosurgical and neurointerventional procedures. Adopting a new *ICD* coding system by the WHO member states is voluntary and costly. Users across the world need an easily usable coding system that is scientifically accurate and applicable to their own environment. The reason maintaining and distributing the *ICD* codes are core functions of the WHO is that the system is used as an international language by which accurate mortality and morbidity health statistics are reported yearly to the WHO. The same statistics are used in most countries by ministers of health and other health care planners who must allocate resources for the prevention and care of diseases, injuries, and disabilities.

The TAG began by organizing its tasks and working groups, and the existing *ICD-10* was analyzed in detail. The *ICD-10* is organized in 10 "blocks" based on organ systems or major categories such as injuries, and many conditions are located in categories no longer considered appropriate. The neurology TAG therefore reviewed the *ICD-10* to construct the draft of a new *ICD-11* chapter reflecting scientific advances, important traditions in clinical practice, and increased clinical utility by the non-specialist as well as in primary care. The balance between highly specialized institutions and use in primary care is paramount.

There are many clearly defined sections that have already been in use internationally and were easy to integrate in the classification. The Headache and Epilepsy Working Groups already have the International Headache Society and the International League Against Epilepsy classifications with which to work.

However, there are areas to be added; for example, prion diseases were not in the *ICD-10* and need to be included. Another crucial issue is that some major neurologic conditions are placed in widely scattered chapters of the *ICD-10*, so the easy epidemiologic tracking of the global burden of neurologic disorders has been virtually impossible. The most important is cerebrovascular diseases, the major cause of neurologic death and disability worldwide, which in the *ICD-10* is classified with cardiovascular diseases in the chapter on circulatory disorders. This anomaly has made statistics on neurologic mortality and morbidity ambiguous or undetectable. With the

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agreement of the internal medicine TAG, cerebrovascular diseases will be moved to the neurology chapter of the *ICD-11*, which will facilitate monitoring of the incidence and cost of these brain disorders globally.

Other placements present challenges. Reflecting clinical specialization, there are separate TAGs for neurology and for psychiatry. As studies of functional brain imaging, neurochemistry, and neurogenetics expand our understanding of the pathophysiologic aspects of brain disorders, the distinction between neurology and psychiatry appears to many increasingly arbitrary.¹ The *ICD-11* should take this into account and include a method of classification to satisfy all or at least reflect the changes in neuroscience in the past few decades.² The *ICD-11* placement of “dementia” is another example of such challenges. There is the issue of nomenclature as well: “dementia” vs “neurocognitive disorders.” How dementia and its many etiologies should be classified is not an easy issue to tackle and is the subject of discussion and debate.

The most logical placement of functional neurologic disorders is also being addressed. The diagnosis of paralysis, blindness, gait disorders, and other neurologic signs and symptoms without physical causes is part of every neurologist’s practice, but psychiatrists are often involved in management. The neurologic basis of such phenomena can now be studied with functional brain imaging, however, and the large number of patients with pseudoseizures found in epilepsy clinics requires the diagnostic and technical skills of neurologists and psychiatrists. Whether the practitioner seeking a diagnostic code for such problems should find it in the *ICD* chapters on neurology or psychiatry has implications not just for ease of coding but in some health systems for coverage of medical care. The argument for neurology is under discussion and has not as yet been resolved. It may be argued that it does not really matter in which chapter a code lies as long as the disorder is captured and entered in the *ICD*. But such categorizations may have implications for the patient’s perspective on his or her illness, and may easily produce

misleading statistics for the disorders dealt with by various specialties. All health economists and governments depend on accurate statistics related to the burden of disease to formulate financial allocations and specialty development.

Similar “cross-border” discussions are being held with TAGs on otorhinolaryngology in relation to neuro-otology, ophthalmology in relation to neuro-ophthalmology, and trauma in relationship to neurosurgery. The draft *ICD-11* codes will be open to the public and available online for comment.

For many still-unresolved issues, there will be field trials in selected WHO research locations or sponsored by neuroscience organizations. These will include use of the codes by various types of health care providers and coders, and will shed light on the utility of the classifications.³ The main objective is to produce a classification that clearly defines the burden of neurologic disease across the world.

AUTHOR CONTRIBUTIONS

Raad Shakir: drafting/revising the manuscript, analysis or interpretation of data, acquisition of data. Donna Bergen: drafting/revising the manuscript.

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DISCLOSURE

R. Shakir is the Chair of the Topic Advisory Group for the revision of *ICD-10* chapter on diseases of the nervous system established by the WHO. D. Bergen is a member of the Topic Advisory Group for the revision of *ICD-10* chapter on diseases of the nervous system established by the WHO. Statements in this article represent the views of the authors and not the official views of the Topic Advisory Group or the WHO. Go to Neurology.org for full disclosures.

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