Revising the ICD: stroke is a brain disease

The tenth revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) was long overdue. The ICD-10 was based on outdated medical knowledge and concepts from the 1980s. Since then, science and practice have changed beyond recognition. The WHO neurology topic advisory group (TAG) for the revision of the ICD-10 was formed in 2009. In the ICD-10, cerebrovascular diseases were inconsistently and confusingly spread over several different chapters. In March, 2011, the Neurology and Circulatory TAGs, with contribution of WHO classification representatives and relevant WHO departments, agreed that in the ICD-11, all types of strokes should form a single block, and that this block should be placed in the nervous system diseases chapter. The decision was based on a transparent process, reflecting the fact that all manifestations of cerebrovascular diseases are related to brain dysfunction, stroke being the second leading cause of disability-adjusted life-years (DALYs) globally. The relationship with dementia and particularly Alzheimer’s disease is becoming clearer. Public health advocacy has a focus on recognition of acute neurological symptoms warranting immediate medical intervention and subsequent commencement of life-saving therapies. The long-term cost of care and rehabilitation is of paramount global importance. The purpose of the ICD-11 is to produce a classification that reflects the advances in knowledge and concepts of the 21st century. On Sept 9, 2016, WHO classification staff unilaterally decided to break their agreed decision made 5 years earlier and move the newly created cerebrovascular block from neurology to circulatory disease. This backward step did not follow the expected transparency and openness of WHO decision making. It came totally out of the blue and even the WHO departments that are responsible for neurosciences and non-communicable diseases, as well as the Neurosciences TAG, were not informed, let alone consulted. The medical rationale for stroke being a disease of the brain is overwhelming. This decision needs to be reversed henceforth in order to safeguard patient care and provide correct figures and finances for healthcare provision.

The ICD-11 should be useful for all users, helping them to manage and report disorders according to modern concepts. After all, the main purpose of any enduring classification should be the interests of patients, which are not served without acknowledging that stroke is a brain disease. We expect the WHO Department of Health and Information Systems to be our ally in helping all those responsible for collecting health data across the world to understand the reasons for improvements to the ICD. In the end, this is the purpose of all of us who seek to mitigate the effects of non-communicable diseases such as stroke, working with WHO as the lead.

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