Defeating epilepsy: A global public health commitment

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**SUMMARY**

This article points out that defeating epilepsy is a global public health commitment and a new challenge. This is because: epilepsy causes a heavy burden and very high treatment gap; in the field of life sciences and medicine, the 21st century would be the “Century of Brain Science”; a number of national brain research initiatives provide a great opportunity to reveal the secret of epilepsy; the Global Campaign against Epilepsy and the Mental Health Gap Action Programme made great contributions in the epilepsy control work worldwide; the historical WHA68.20 resolution gives great strength to promote defeating epilepsy.

**KEY WORDS:** Defeating epilepsy, Disease burden, Brain research, GCAE, mhGAP.

In the 21st century, all stakeholders are newly challenged to defeat epilepsy and, at the same time, bring this common but severe illness out of shadows. The birth of the journal *Epilepsia Open* gives us a new and wider platform for professional knowledge exchange, thus facilitating these efforts.

**HEALTH AND ECONOMIC BURDEN OF EPILEPSY**

On a global basis, epilepsy continues to cause a large burden of disease, and the treatment gap for this condition remains unfortunately and surprisingly large. More than 50 million people worldwide have epilepsy, making it one of the most common neurological diseases globally. Nearly 80% of people with epilepsy live in low- and middle-income countries (LAMICs).

Treatment gaps for active epilepsy exceed 75% in most low-income countries and 50% in most lower-middle- and upper-middle-income countries. In stark contrast, many high-income countries have a treatment gap of less than 10%. This disparity is especially unfortunate in view of the fact that epilepsy treatment is inexpensive.

In many parts of the world, people with epilepsy and their families suffer from stigma and discrimination because of ignorance, misconceptions, and negative attitudes surrounding the disease. They face serious difficulties in, for example, education, employment, marriage, and reproduction. Epilepsy affects people of all ages, genders, races, and income levels, and poor populations and those living in vulnerable situations—in particular, in LAMICs—bear a disproportionate burden, which poses a threat to public health and economic and social development.

In a recent study that compared the global burden of disease imposed by 220 conditions affecting all organs and systems, severe epilepsy ranked fourth in terms of disability weight. The lives of people with epilepsy can be devastated...
by many factors, including recurrent seizures, a heavy burden of comorbidities, and the side effects of antiseizure medications. Worldwide, the number of cases of sudden unexpected death in epilepsy can be estimated at 60,000 per year, or eight cases per million, with epilepsy ranking second only to stroke among selected neurological diseases in terms of years of potential life lost.

In LAMICs, even higher mortality and morbidity rates can be ascribed to status epilepticus and seizure-related accidents, particularly drowning.

**Epilepsy in the 21st Century**

In the life sciences and medicine, knowledge of the human body has reached a very high level, except for understanding of the human brain. In 1990, the US Congress designated the 1990s the “Decade of the Brain” to enhance public awareness of the benefits to be derived from brain research. Epilepsy was notably mentioned in the presidential proclamation that formally initiated the Decade of the Brain. During this decade, scientists in the life sciences and medicine foresaw that the 21st century would be the “Century of Brain Science.”

From the beginning of the 21st century, the research on brain science in the global technology sector has been booming. In 2013, US president Barack Obama announced at the White House an initial $100 million investment to shed light on how the brain works and to provide insight into diseases such as Alzheimer’s and epilepsy. This brain mapping project is called Brain Research through Advancing Innovative Neurotechnologies, or the BRAIN Initiative. President Obama said: “As humans we can identify galaxies light years away, we can study particles smaller than the atom, but we still haven’t unlocked the mystery of the three pounds of matter that sits between our ears.”

Research on brain science is now advancing rapidly; in addition to the U.S.A.’s BRAIN Initiative, the European Union’s Human Brain Project (HBP) and national brain research projects in China, Australia, Japan, Canada, Israel, and other countries have been initiated, and large international corporations have also shown great interest.

Research on epilepsy may provide a special, even unique shortcut to explore the secrets of the human brain, because epilepsy research studies the function of the human brain in vivo (e.g., by electroencephalogram), which other laboratory studies cannot substitute for. Modern research on epilepsy integrated brain structure and function, including electrical functioning, chemical signal transmission, ion channels, neuronal networks, neuroimaging, and magnetic performance, to localize brain function and protect and reveal learning and recognition activities of the brain. This research provides us a great opportunity to defeat epilepsy and, in the process, unlock the mysteries of the human brain.

**The Global Campaign Against Epilepsy (GCAE) and the World Health Assembly Resolution**

For years, the World Health Organization (WHO) has led the global movement against epilepsy. In 1997, WHO joined with the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) to launch the Global Campaign Against Epilepsy (GCAE). The GCAE made substantial progress in encouraging countries to prioritize epilepsy in public health planning, which resulted in WHO Regional Declarations in all six WHO regions and the successful completion of a number of demonstration projects. The campaign also clearly showed the incremental power of collaboration between WHO and civil society organizations in advancing a public health agenda.

WHO, as a partner in the GCAE, has carried out demonstration projects to scale up epilepsy care in a number of countries. For example, the project in China estimated that the number of people with epilepsy in the country was almost 9 million, with a treatment gap of 63%. The project, carried out in rural areas of six noncontiguous provinces, successfully implemented management of convulsive forms of epilepsy by training physicians. This approach reduced the treatment gap by about 13% and was shown to be cost-effective.

Because of the public health importance of epilepsy and the fact that few neurologists and other specialist health care providers reside in the majority of LAMICs, epilepsy is included as a priority condition in the Mental Health Gap Action Programme (mhGAP) that WHO developed. A key part of mhGAP is the evidence-based guideline to facilitate delivery of interventions by nonspecialist health care providers in LAMICs and to assist with the scale-up of care for mental, neurological, and substance use (MNS) disorders identified as conditions of high priority in LAMICs, specifically depression, psychosis (including schizophrenia and bipolar disorders), epilepsy, child mental disorders, dementia, alcohol use disorders, drug use disorders, and self-harm/suicide. The WHO mhGAP has made great contributions to epilepsy control work worldwide.

At the political level, in 2015 the World Health Assembly (WHA) discussed the issue of epilepsy and adopted a resolution on the global burden of epilepsy and the need for coordinated action at the country level to address its health, social, and public knowledge implications. This resolution urges the 194 WHO member states to strengthen leadership, governance, and policies in consideration of the specific needs of people with epilepsy and to make financial, human, and other resources available to implement evidence-based plans and actions. It also requests that the WHO develop a set of technical recommendations guiding member states in the development and implementation of epilepsy programs and services and provide technical support to member states.
in actions for epilepsy management, especially in LMICs.5,14

This WHA resolution, which comes almost 20 years after the establishment of the GCAE, is a landmark and creates new opportunities in the long-standing collaboration among the WHO, ILAE, and IBE in addressing the needs of people with epilepsy.5,14

To promote prevention and control of epilepsy, we need coordinated actions at the national level to strengthen effective leadership and governance. These actions, as recommended by the WHA resolution, should consider the specific needs of people with epilepsy; introduce and implement national health care plans for epilepsy; integrate epilepsy management into health and social care, particularly in community-based services; support the establishment and implementation of strategies for the management of epilepsy, including access to safe, effective, and quality-assured antiepileptic medicines; promote public awareness and education about epilepsy; develop interventions to prevent the causes of epilepsy; improve investment into epilepsy research; and increase research capacity. To accomplish those actions, political commitments by governments are vitally important, as shown by previous successful GCAE projects in a number of LMICs.14

Scientific journals can play a role in stimulating and publishing public health–oriented research and in facilitating the use of research findings in changing policy and practice.

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DISCLOSURE

The authors have no conflicts of interest to declare. We confirm that we have read the Journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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