

Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications

Report by the Secretariat

BURDEN AND IMPACT OF EPILEPSY

1. Epilepsy is one of the most common serious chronic neurological diseases affecting people of all ages globally. It is characterized by recurrent seizures. It has many causes. In some cases, there is an underlying genetic basis. Other common causes of epilepsy include brain damage from prenatal or perinatal injuries (for example, a loss of oxygen or trauma during birth); congenital abnormalities or brain malformations; head injury; stroke; neurological infections, such as meningitis, encephalitis and neurocysticercosis; and brain tumour. In about half the cases of epilepsy, the cause cannot be identified.
2. More than 50 million people worldwide have epilepsy, more than three quarters living in low- and middle-income countries. An estimated 2.4 million new cases occur each year. Epilepsy accounts for 0.5% of the total global burden of disease.
3. The risk of premature death in people with epilepsy is 2–3 times higher than for the general population in high-income countries and more than six times higher in low- and middle-income countries. People with epilepsy often suffer from comorbidities such as depression and anxiety, associated intellectual disabilities, especially in children, and physical injuries (for instance, fractures and burns).
4. People with epilepsy are often subjected to stigmatization and discrimination because of misconceptions and negative attitudes surrounding the disease. Some common misconceptions are “possession by evil spirits”, “epilepsy is contagious” or its equivalence to “madness”. Stigmatization leads to human rights violations and societal exclusion. For example, in some settings children with epilepsy may not be allowed to go to school and adults may not find suitable employment or be able to marry.

5. In addition to its social implications, epilepsy results in huge economic costs. In the WHO European Region, for example, these costs have been estimated at €20 000 million per year.¹

CHALLENGES AND GAPS IN EPILEPSY CARE

6. Up to 75% of people with epilepsy can live a normal life, free from seizures, if they are appropriately treated with antiepileptic medicines. Treatment with first-line antiepileptic medicines (phenobarbital, phenytoin, carbamazepine and valproic acid) is among the identified “best buys” for neurological diseases with the cost of treatment with phenobarbital as low as US\$ 5 per person per year.² All the medicines are included in the WHO Model List of Essential Medicines.

7. Despite the availability of affordable treatment, up to 90% of people with epilepsy may not be properly diagnosed or treated in resource-poor settings. The so-called “treatment gap” (the percentage of people with epilepsy whose seizures are not being appropriately treated at a given point in time) is estimated to be 75% in low-income countries and substantially higher in rural areas than in urban areas.

8. Such a wide treatment gap may result from a combination of, for instance, inadequate capacities of health care systems and inequitable distributions of resources, particularly in resource-poor and rural areas. Factors that widen the gap, many of which are interconnected, include an insufficiency of staff, poor access to antiepileptic medicines, societal ignorance and misconceptions, poverty, and low prioritization for the treatment of epilepsy.

9. Only limited numbers of specialist health professionals are available in low- and middle-income countries; for example, the median number of neurologists in low-income countries is only 0.03/100 000 population. Epilepsy can be treated at primary health care level but very often the health care workers there are not adequately trained to diagnose or treat epilepsy.

10. Many barriers to accessing antiepileptic medicines exist. The price often remains unjustifiably high, even for generic medicines. Data and information necessary for planning, forecasting and budgeting are often lacking. Certain regulatory policies prevent wider use of some antiepileptic medicines, particularly those associated with the procurement of phenobarbital. Although national essential medicines lists frequently include first-line antiepileptic medicines, their inclusion does not guarantee availability in public health care facilities.

11. An analysis of availability, price and affordability of antiepileptic medicines in public hospitals and primary health care facilities from surveys in 46 Member States estimated the average availability of generic oral antiepileptic medicines as less than 50%. Prices charged to patients in the public sector for generic carbamazepine and phenytoin were 4.95 and 17.50 times higher than international reference prices, respectively. The lowest-paid government worker in the countries surveyed would

¹ International League Against Epilepsy, International Bureau for Epilepsy, World Health Organization. Global campaign against Epilepsy. Epilepsy in the WHO European Region: fostering epilepsy care in Europe. Hoofddorp, The Netherlands: Global Campaign Against Epilepsy, 2010 (see http://www.who.int/mental_health/neurology/epilepsy/euro_report.pdf?ua=1, accessed 24 November 2014).

² Abegunde D. Essential medicines for non-communicable diseases: background paper. Geneva: World Health Organization (http://www.who.int/medicines/areas/policy/access_noncommunicable/EssentialMedicinesforNCDs.pdf, accessed 24 November 2014).

spend between 1.1 and 2.6 days' wages to buy a month's supply of phenytoin; the comparable figure for carbamazepine was between 2.7 and 16.2 days' wages.¹

12. Lack of knowledge or misperceptions about epilepsy may affect health-seeking behaviour. People with epilepsy may not access treatment from health care facilities and instead might seek help from other sources that may be ineffective. They also may not seek regular follow-up care or adhere to medications as prescribed.

INTERNATIONAL CONTEXT AND THE SECRETARIAT'S ACTIVITIES

13. In 2003, the Health Assembly noted the report on the control of neurocysticercosis with its references to epilepsy,² and, in resolution WHA66.8 in May 2013, it adopted the comprehensive mental health action plan 2013–2020, which builds on the work of WHO's mental health gap action programme and notes that actions taken to promote mental health and prevent mental disorders are relevant for the prevention of epilepsy and other neurological disorders. Other resolutions are also pertinent to coordinated action on epilepsy include United Nations General Assembly resolution 66/2 adopting the Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases, the Health Assembly's resolution WHA66.10 which endorsed the global action plan for the prevention and control of noncommunicable diseases 2013–2020, resolutions 68/269 and WHA57.10 on road safety, resolution WHA66.12 on neglected tropical diseases, resolution WHA67.10 on newborn care and resolution WHA67.15 on violence.

14. In 1997, WHO and two international nongovernmental organizations, the International League Against Epilepsy and the International Bureau for Epilepsy, launched the *Global Campaign Against Epilepsy: Out of the Shadows* in order to raise awareness and strengthen efforts to improve care and reduce the impact of epilepsy. Under the auspices of the global campaign, demonstration projects have been undertaken in Argentina, Bolivia (Plurinational State of), Brazil, China, Georgia, Pakistan, Senegal, Timor-Leste and Zimbabwe. For example, the project in China was implemented in six provinces between 2000 and 2004 to test the feasibility of diagnosis and treatment of epilepsy at the primary health care level. The results showed that trained primary health care physicians could diagnose and treat people with epilepsy, and that the care model could significantly reduce the epilepsy treatment gap.³ This project has been extended to 18 provinces and covers a population of 75 million.

15. In 2005, WHO published a compilation of relevant information about resources for care of mental and neurological conditions in the world.⁴ The publication emphasized that globally the available resources for epilepsy care are insufficient for the large number of people needing such care and the known substantial burden associated with the disease. In addition, large inequities exist across regions and income groups of countries, with low-income countries having extremely meagre resources.

¹ Cameron A, Bansal A, Dua T, Hill SR, Moshe SL, Mantel-Teeuwisse AK et al. Mapping the availability, price, and affordability of antiepileptic drugs in 46 countries. *Epilepsia*, 2012; 53:962-969.

² See document WHA56/2003/REC/3, summary record of the fourth meeting of Committee A.

³ Epilepsy management at primary health level in rural China: WHO, International League Against Epilepsy, International Bureau for Epilepsy. Geneva: World Health Organization; 2009.

⁴ WHO, International Bureau for Epilepsy, International League Against Epilepsy. Atlas: epilepsy care in the world 2005. Geneva: World Health organization; 2005.

16. In 2008, WHO launched the WHO Mental Health Gap Action Programme, which includes epilepsy as a priority mental health and neurological condition. The Programme's objective is to expand services for mental, neurological and substance use disorders in low- and middle-income countries using an innovative and multifaceted approach. The Secretariat has issued normative materials such as the Programme's intervention guide for mental, neurological and substance use disorders in non-specialized health settings and related training materials, which cover epilepsy care management.¹

17. The WHO Programme on Reducing the Epilepsy Treatment Gap builds on the experience with non-specialist primary health care providers to diagnose, treat and follow up people with epilepsy. It also mobilizes nongovernmental organizations and community groups among others to raise awareness about epilepsy and support people with epilepsy and their families, and supports health system strengthening to ensure sustainable access to antiepileptic medicines, reinforce referral systems, and enable better monitoring of epilepsy. Pilot initiatives have been initiated in Ghana, Mozambique, Myanmar and Viet Nam.²

18. Regional conferences on public health aspects of epilepsy have been organized in all six WHO regions, with the participation of some 1300 delegates from more than 90 countries. Regional reports on epilepsy and declarations have also been issued by different WHO regions. The regional reports emphasize the need for action on public education, legislative reform, investment in research, support for organizations or associations on epilepsy, information exchange, and community-based control and prevention programmes.³

19. In 2011, the Region of the Americas approved and has subsequently been implementing the Strategy and Plan of Action on Epilepsy for 2012–2021.⁴ The strategy defines priority areas for epilepsy, including the need to promote programmes and legislation for the care of people with epilepsy and the protection of their human rights; establish networks of health services for people with epilepsy, with emphasis on primary health care and the provision of antiepileptic medicines; educate and sensitize the general population, including people with epilepsy and their families; and strengthen the ability to produce, assess and use information on epilepsy.

20. Also in 2011, the European Parliament approved the written declaration on epilepsy.⁵ The declaration calls for the European Commission and Council to encourage research and innovation in the area of prevention and early diagnosis and treatment of epilepsy; prioritize epilepsy as a major disease that imposes a significant burden across Europe; encourage measures to ensure equal quality of life, including access to education, employment, transport and public health care for people with epilepsy, for instance by stimulating the exchange of best practice; and encourage effective health

¹ mhGAP intervention guide for mental, neurological and substance use disorders in non-specialized health settings, available at http://www.who.int/mental_health/publications/mhGAP_intervention_guide/en/ (accessed 21 November 2014).

² http://www.who.int/mental_health/neurology/epilepsy/en/.

³ For links to regional reports and declarations, see http://www.who.int/mental_health/publications/epilepsy_neurological_disorders/en/ (accessed 21 November 2014).

⁴ See resolution CD51.R8 and document CD51/10: http://www.paho.org/hq/index.php?option=com_docman&task=doc_download&gid=24657&Itemid=270&lang=en (accessed 21 November 2014).

⁵ European Parliament. Written declaration on epilepsy. Brussels, European Parliament, 0022/2011, 2011 (<http://www.ilae.org/Visitors/initiatives/documents/writtendeclaration.pdf>, accessed 21 November 2014).

impact assessments on all major European and national policies. It calls on Member States of the European Union to introduce appropriate legislation to protect the rights of all people with epilepsy.

IMPROVING EPILEPSY CARE: WHAT IS NEEDED

21. Several actions can be taken at country level to make progress in dealing with the global public health issue of improving epilepsy care. These are outlined in paragraphs 22–30 below.

22. **Strengthen effective leadership and governance.** National policies and legislation need to be formulated, strengthened and implemented in order to promote and protect rights of people with epilepsy and to prohibit discrimination in, for example, education, employment, marriage, reproduction, driving regulations and recreation.

23. **Improve provision of epilepsy care.** Policies on general health, mental health or noncommunicable diseases should include consideration of care for people with epilepsy. Budgets should be allocated that are commensurate with the human and other resources that have been identified as necessary to implement agreed-upon evidence-based plans and actions. Stakeholders from all relevant sectors, including people with epilepsy and their carers and family members, should be engaged in the development and implementation of policies, laws and services.

24. **Integrate epilepsy management into primary health care.** In order to help to reduce the epilepsy treatment gap, non-specialist health care providers should be trained and supported so that epilepsy can be diagnosed and treated in primary health care settings. A strong and functional referral system should be made available.

25. **Increase access to medicines.** Strategies should be formulated and implemented to make antiepileptic medicines more available, accessible and affordable. Strategic options are: to include essential antiepileptic medicines in national formularies; to strengthen supply chains and systems of selection, procurement and distribution; and to improve access to controlled medicines such as phenobarbital. It is estimated that extending the coverage of treatment with antiepileptic medicines to 50% of epilepsy cases would reduce the current epilepsy burden by between 13% and 40%.

26. **Support strategies for prevention of epilepsy.** Many of the causes of epilepsy in low- and middle-income countries are preventable, and the health and social sectors should be supported to assist in reducing the incidence of epilepsy. Effective implementation of relevant United Nations General Assembly and Health Assembly resolutions (see paragraph 13 above) could help to prevent many cases of epilepsy. Examples include promoting safe pregnancies and births, control of cysticercosis, prevention of head trauma, and prevention of stroke.

27. **Increase public awareness and education.** In order to help to reduce misconceptions and negative attitudes, and to influence more people with epilepsy to seek treatment, public education activities related to epilepsy should be strengthened, and community leaders, grassroots public health workers, and people with epilepsy and their families should be educated about the disease. The Secretariat should provide support to Member States in harnessing the potential contribution of traditional medicine to the health and well-being of people with epilepsy. These actions should help to reduce stigmatization of and discrimination against people with epilepsy.

28. **Strengthen health information and surveillance systems.** Data on epilepsy should be captured, collated, routinely reported, analysed and disaggregated by sex and age in order to measure progress in increasing access to services for people with epilepsy. National data systems and exchange

of information between countries should also be reinforced, for instance collaboration on data collection.

29. **Improve investment in epilepsy research and increase research capacity.** Surveillance should be improved and comprehensive, accurate epidemiological estimates made of the burden of epilepsy, particularly in low- and middle-income countries. Informed and effective decision-making should be facilitated through the development of standardized and validated research tools. In addition to epidemiological research, priority should be given to research areas such as genetics; health system evaluation; diagnostics, prevention, treatment and rehabilitation; and scientific investigation of traditional medicine approaches to epilepsy treatment. The research capacity of low- and middle-income countries should be built through expanded academic collaboration and establishing centres of excellence in such countries.

30. **Collaborate with civil society and other partners.** National epilepsy-related organizations should be established in order to improve care for people with epilepsy and to strengthen advocacy. These bodies could include professional societies, charitable foundations, epilepsy centres, and associations of patients and their families.

ACTION BY THE EXECUTIVE BOARD

31. The Board is invited to take note of the report and provide further guidance on the need for a coordinated action at the country level to address the health, social and public knowledge implications of the global burden of epilepsy.

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