

Epilepsy

Report by the Director-General

1. Following a discussion by the Executive Board at its 144th session and based on an earlier recommendation by the Officers of the Executive Board,¹ the Board agreed to include the subject of epilepsy on the agenda of the 146th Executive Board.² The present report is submitted in response to that decision.

EPIDEMIOLOGY AND BURDEN OF EPILEPSY

2. Epilepsy is one of the most common serious chronic neurological conditions affecting people of all ages globally, with peaks in incidence rates in children and in adults over the age of 60. It is characterized by abnormal electrical activity in the brain, causing seizures or unusual behaviour, sensations and sometimes loss of awareness. Common causes include prenatal or perinatal injuries, congenital abnormalities or brain malformations, head injuries, stroke, neurological infections such as meningitis, encephalitis and neurocysticercosis, and brain tumours. In some cases, there is an underlying genetic reason for the condition; in about half of the cases, however, there is no identifiable cause.

3. Around 50 million people worldwide have epilepsy, of whom nearly 80% live in low- and middle-income countries. More than 5 million new cases are diagnosed each year, and this is expected to increase further. Epilepsy accounts for more than 0.5% of the total global burden of disease.³

4. The risk of premature death in people with epilepsy is up to three times higher than in the general population. 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).

5. In many parts of the world, people with epilepsy and their families are subjected to stigmatization and discrimination as a result of the misconceptions and negative attitudes that surround epilepsy, including the belief that epilepsy is the result of possession by evil spirits or that it is contagious. Stigmatization leads to human rights violations and social exclusion. In some settings, children with epilepsy may not be allowed to attend school, while adults with the condition may not be able to find suitable employment or to marry.

¹ See document EB144/1 (annotated).

² See document EB144/2019/REC/2, summary records of the seventeenth meeting, section 1.

³ Epilepsy: a public health imperative. Geneva: World Health Organization; 2019 (https://www.who.int/mental_health/neurology/epilepsy/report_2019/en/, accessed 12 October 2019).

6. As well as having social implications, epilepsy can constitute a significant financial burden. In the WHO European Region, for example, the cost of epilepsy has been estimated at €20 billion per year.¹

CHALLENGES AND GAPS IN EPILEPSY CARE

7. Up to 70% of people with epilepsy could live seizure-free, if treated with antiseizure medicines. First-line antiseizure medicines (phenobarbital, phenytoin, carbamazepine and valproic acid) are a highly cost-effective use of health resources. The annual cost of phenobarbital is as low as US\$ 5 per person.² All first-line medicines are included in the WHO Model List of Essential Medicines.

8. The treatment gap (percentage of people with epilepsy whose seizures are not being appropriately treated at a given point in time) is, however, estimated at 75% in low-income countries and is substantially higher in rural than in urban areas. Wide treatment gaps may result from a combination of lack of capacity in health care systems, inequitable distribution of resources and low priority accorded to epilepsy care. Factors that widen this gap include:

- *Shortage of staff.* Specialist health professionals are scarce in low- and middle-income countries: the median number of neurologists in low-income countries is only 0.03/100 000 population.³ Although epilepsy could be treated at the primary health care level, staff are often not adequately trained to diagnose and treat it.
- *Limited access to antiseizure medicines.* The price of antiseizure medicines, including generic medicines, is often high and is several times higher in low-income countries than in high-income countries. Data and information necessary for planning, forecasting and budgeting are often lacking. Certain regulatory policies prevent wider use of antiseizure medicines, particularly phenobarbital. Although national lists of essential medicines often include first-line antiseizure medicines, this does not guarantee access to them in public health and primary care facilities, where they are often not available.
- *Lack of knowledge, misperceptions and stigma.* These mean that people with epilepsy may not present to health care facilities, instead seeking help from other sources that may be ineffective. Further, they may not attend regular follow-up care, or adhere to medications as prescribed.

9. Approximately 25% of epilepsy cases could be prevented by broader public health responses in maternal and newborn health care, communicable disease control, injury prevention and cardiovascular health. These include: screening for pregnancy complications and ensuring the presence of trained birth attendants to help prevent perinatal injuries; immunization against pneumonia and meningitis; malaria control programmes in endemic areas; early and effective management of febrile convulsions; initiatives

¹ International League Against Epilepsy, International Bureau for Epilepsy and WHO. Epilepsy in the WHO European Region: fostering epilepsy care in Europe. Hoofddorp, The Netherlands: Global Campaign Against Epilepsy; 2010 (https://www.who.int/mental_health/neurology/epilepsy/euro_report.pdf?ua=1, accessed 12 October 2019).

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 12 October 2019).

³ Atlas: country resources for neurological disorders – 2nd ed. Geneva: World Health Organization; 2017 (https://www.who.int/mental_health/neurology/atlas_second_edition/en/, accessed 13 October 2019).

to reduce road traffic injuries, violence and falls; and health and community interventions to prevent high blood pressure, diabetes, obesity and tobacco use.

INTERNATIONAL COMMITMENTS FOR DEALING WITH EPILEPSY

10. In May 2015, the Health Assembly adopted resolution WHA68.20 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. The resolution urged Member States, *inter alia*, to: introduce and implement national health care plans of action for epilepsy management; ensure public awareness of and education about epilepsy; and to improve investment in epilepsy research and increase research capacity. In 2018, the Secretariat reported on progress towards implementing the resolution.¹

11. Other relevant international commitments have been undertaken through the adoption of the following Health Assembly and United Nations General Assembly resolutions: WHA66.8 (2013) on the comprehensive mental health action plan 2013–2020, WHA66.10 (2013) on the follow-up to the Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases, WHA57.10 (2004) on road safety and health, 68/269 (2014) on improving global road safety, WHA66.12 (2013) on neglected tropical diseases, WHA67.10 (2014) on newborn health action plan, WHA67.15 (2014) on strengthening the role of the health system in addressing violence, in particular against women and girls, and against children, and WHA69.19 (2016) on the global strategy on human resources for health: workforce 2030. Health Assembly document A56/10 also addressed the control of neurocysticercosis, which is an important cause of epilepsy.

12. Commitments at the regional level include the Region of the Americas Strategy and Plan of Action on Epilepsy for 2012–2021,² endorsed by PAHO's 51st Directing Council in resolution CD51.R8 (2011), and the European Parliament written declaration on epilepsy.³

13. The outcome documents of United Nations high-level meetings also provide strategic relevance for accelerating the global epilepsy response. The political declarations emanating from the high-level meetings of the General Assembly on the prevention and control of non-communicable diseases in 2011 and 2018 (resolutions 66/2 and 73/2, respectively) recognized that mental and neurological disorders, including epilepsy, are an important cause of morbidity and contribute to the global burden of noncommunicable diseases. They drew the attention of policy-makers to the need to integrate epilepsy into action on noncommunicable diseases and mental health.

PRINCIPAL WHO RESPONSE

Advocacy and awareness rising

14. Together with two international nongovernmental organizations, the International League Against Epilepsy and the International Bureau for Epilepsy, WHO has been leading the Global Campaign Against Epilepsy since 1997. The Campaign, which aims to raise public awareness and support health ministries in identifying needs and promoting education, training, treatment, services, and research, is

¹ Document A71/41 Rev.1.

² Available at https://www.who.int/mental_health/neurology/epilepsy/paho_strategy.pdf (accessed 13 October 2019).

³ Available at <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//NONSGML+WDECL+P7-DCL-2011-0022+0+DOC+PDF+V0//EN&language=EN> (accessed 13 October 2019).

being run in several Member States, spanning all WHO regions. In China, it has been extended to 240 communities in 19 provinces, serving 120 million members of the rural population.

15. In June 2019, in collaboration with the International League Against Epilepsy and the International Bureau for Epilepsy, WHO published a global report, *Epilepsy: a public health imperative*.¹ The report summarizes the available evidence on the burden of epilepsy and the public health response required at the global, regional and national levels. In line with Health Assembly resolution WHA68.20 (2015) 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, the report calls for sustained and coordinated action to ensure that every person with epilepsy has access to the care and treatment they need and the opportunity to live free from stigma and discrimination anywhere in the world.

16. During the Seventy-second World Health Assembly in May 2019, Member States organized a high-level side event to highlight epilepsy as a public health priority, during which investment in reducing the epilepsy burden was strongly encouraged, and participants advocated for action to bridge gaps in epilepsy knowledge, care and research.

17. In the African Region, where the treatment gap for epilepsy is particularly significant, the Secretariat facilitated a regional workshop in Ghana (September 2015), in which policy-makers, experts, people living with epilepsy, non-State actors and other stakeholders from 17 Member States were represented. In the Region of the Americas, a regional workshop was held in Honduras (August 2015) to discuss successful experiences, progress, and lessons learned.

Service development

18. Since 2008, the WHO Mental Health Gap Action Programme (mhGAP), which includes epilepsy as a priority neurological condition, has been using innovative and multifaceted approaches to expand services in more than 100 low- and middle-income countries. Normative products have been issued under the aegis of the Programme, such as the mhGAP Intervention Guide and related training materials, which cover epilepsy care management.²

19. The WHO Programme on Reducing the Epilepsy Treatment Gap builds on experience gained with non-specialist primary health care providers to ensure diagnosis, treatment and follow up for people with epilepsy. It mobilizes nongovernmental organizations and community groups to raise epilepsy awareness and support people with epilepsy and their families; and it supports efforts to strengthen health systems in order to ensure sustainable access to antiseizure medicines, reinforce referral systems and enable better monitoring of epilepsy. Pilot initiatives have been launched in Ghana, Mozambique, Myanmar and Viet Nam, resulting in a considerable increase in access: epilepsy treatment is now accessible for 6.5 million more people.³

¹ Epilepsy: a public health imperative. Geneva: World Health Organization; 2019 (<https://apps.who.int/iris/handle/10665/325293>, accessed 15 October 2019).

² mhGAP intervention guide for mental, neurological and substance use disorders in non-specialized health settings (https://www.who.int/mental_health/mhgap/mhGAP_intervention_guide_02/en/, accessed 13 October 2019).

³ WHO highlights scarcity of treatment for epilepsy in low-income countries. In: WHO/Mental health [website]. Geneva: World Health Organization; 2019 (http://www.who.int/mental_health/neurology/epilepsy/en/h, accessed 13 October 2019).

IMPROVING EPILEPSY CARE

20. Despite the efforts outlined above, the global treatment gap remains high. This is particularly the case in low-resource settings, where, despite acknowledgement of the global burden of epilepsy, antiseizure medicines are not readily available and most governments have not set up national programmes or allocated funds to implement policies and plans for epilepsy.

21. With political will and a combination of innovative strategies, epilepsy diagnosis and treatment can be integrated into primary health services in cost-effective ways, even in low-resource settings.

Actions to accelerate progress at the country level

22. The burden of epilepsy can be reduced by promoting the condition as a public health priority and by strengthening effective leadership and governance. Policies on national health, mental health and noncommunicable diseases should take account of care for people with epilepsy. Appropriate and integrated epilepsy care requires funding. Budgets should be commensurate with the human and other resources needed to implement agreed evidence-based plans and actions. Stakeholders from all relevant sectors, including people with epilepsy and their families, should be involved in the development and implementation of policies, laws and services. Better data and information systems are needed to make the case for prioritizing epilepsy on global public health agendas.

23. Efforts are needed to improve public attitudes, reduce stigma and protect the rights of people with epilepsy. To correct misconceptions and counter negative attitudes towards people with epilepsy, and to influence more people with epilepsy to seek treatment, public education activities related to epilepsy should be strengthened for community leaders, grassroots public health workers, and people with epilepsy and their families. This would help to reduce stigmatization of and discrimination against people with epilepsy. Legislation should promote and protect the rights of people with epilepsy and prohibit discrimination against them in respect of, for example, education, employment, marriage and family planning, obtaining a driving licence, and recreation.

24. Investment in health and social care systems would improve accessibility to comprehensive epilepsy care by integrating epilepsy management into primary health care. 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. Access to cost-effective antiseizure medicines should be enhanced globally. Strategies should be formulated and implemented to make antiseizure medicines more available, accessible and affordable. Strategic options are: to include essential antiseizure 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 antiseizure treatment to 50% of epilepsy cases would reduce the current epilepsy burden by between 13% and 40%.¹

26. Acquired epilepsies should be prevented through improved care for common causes, such as perinatal injury, central nervous system infections, stroke and traumatic brain injuries. 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 the

¹ Chisholm D, WHO-CHOICE. Cost-effectiveness of first-line antiepileptic drug treatments in the developing world: a population-level analysis. *Epilepsia*. 2005;46(5):751-9.

aforementioned United Nations General Assembly and Health Assembly resolutions could help to prevent many cases of epilepsy. For example, promotion of safe pregnancies and births, control of cysticercosis, prevention of head trauma and prevention of stroke would all support reduced incidence of the condition.

27. Health information systems should be strengthened. Improved and harmonized metrics for collecting and reporting incidence and prevalence of epilepsy, disaggregated by income, age, sex and other measures of inequity, as well as associated premature mortality, are needed to better understand the burden of disease. Sufficient population and health care system data are required to monitor epilepsy care, inform guidelines on quality of care and direct adequate resources to ensure universal health coverage. National data systems and exchange of information between countries should be enhanced, for instance through collaboration on data collection.

28. The attention given to epilepsy in research agendas should be increased through capacity-building, investment and training for epilepsy research. Informed and effective decision-making should be facilitated through the development of standardized and validated research tools. Implementation research to scale up epilepsy care is needed as a matter of urgency. The research capacity of low- and middle-income countries should be built through expanded academic collaboration and by establishing centres of excellence in those countries.

ACTION BY THE EXECUTIVE BOARD

29. The Board is invited to note the report. In its discussions, the Board may wish to focus on:

- ways to close the treatment gap, which remains significant despite the availability of cost-effective treatment (antiseizure medication);
- actions that may be taken by Member States, the Secretariat and other partners to tackle the health, social and public impact of epilepsy.

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