Access to drugs to treat and manage neurological disorders “grossly inadequate,” says WHO report

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Patients at the Pharmacy of Kakuma Mission Hospital, Kenya, 2018. © WHO / Sebastian Liste

“Anti-seizure medications are not just treatments, they are lifelines,” says Ivana Garcia, a patient with epilepsy from Argentina. However, a new WHO report [1] on improving access to medicines for neurological disorders highlights a sustained lack of access to treatment, particularly in low-resource and rural areas.

Neurological disorders, such as epilepsy or Parkinson’s disease, severely impact a person's quality of life and are the leading cause of disability and years of life lost worldwide. Fortunately, effective treatments exist that enable patients to manage their symptoms and live fulfilling lives, but multiple barriers exist to accessing neurological care.

Many barriers to access to medicines

Using epilepsy and Parkinson’s disease as tracer conditions (easily diagnosable conditions used to represent the broader disease area) the report [1] highlights the main barriers affecting access to medicines for neurological disorders in a ‘fishbone diagram’.

Improving access to medicines for neurological disorders, WHO, 2024

Elements directly influencing access to treatment include:

- **Stigma** and insufficient public awareness of neurological disorders;
- **Inadequate health coverage** for neurological disorders and high drug costs leading to out-of-pocket spending;
- **Under-registration** of essential medicines for neurological disorders, particularly in the African, Eastern Mediterranean and Western Pacific regions;
- Lack of availability of a ‘**neurological workforce**’, trained to identify and manage neurological conditions, especially in low-resource settings and rural areas.

Other elements impact the broader health system and include the availability of reliable data, challenges along supply chains, drug safety, and regional manufacturing.

The report is a timely and welcome addition to the WHO’s work on noncommunicable diseases (NCDs). It fits within the framework of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022-2031 (IGAP), which aims for 80% of countries to provide essential medicines and technologies for managing neurological disorders in primary care by 2031. It also aligns with the WHO’s broader Roadmap for Access to Medicines, Vaccines and Other Health Products (2019).

The report also highlights the impact of unique situations on access. These include emergency contexts such as pandemics or armed conflicts, limited access to paediatric medicines, and ‘controlled medicines’, which are regulated due to the risk of misuse and therefore more difficult to access.

> **“These medicines are crucial not just for controlling symptoms, but for improving quality of life,” says Omotola Thomas, a patient with Parkinson’s disease.**

Patients living with neurological disorders share their experiences in the report, providing valuable insight into the everyday challenges of living with such a condition. At the report launch event, Ivana Garcia, the patient from Argentina living with epilepsy, described the fear that gripped her when she ran out of her antiseizure medications in her rural village in Argentina. ‘There is a huge inconsistency in access to these medications, especially in low-resource settings and rural areas.’ she explains, adding that ‘without access, the risk of frequent severe seizure increases, leading to physical and psychological injuries and fatalities.’

> **Omotola Thomas, founder of Parkinsons Africa, highlighted the possible life-threatening impact of the problem on families. “Families have to choose between buying medicines and meeting other basic needs, such as food or housing,” she explained in the launch event.**

To tackle these challenges, the WHO proposes eight actions that span various aspects of the health system, including policy and regulatory environments, health infrastructure, and education systems:

1. **Strengthen leadership**: Experts should equip global leaders with evidence-based arguments and strong investment cases to prioritise neurological disorders.
2. **Promote appropriate selection and use of medicines**: Regularly update national essential medicine lists and treatment guidelines to include essential neurological medicines and ensure proper use and coverage.
3. **Strengthen regulatory environments**: Establish robust regulatory systems to ensure quality, safety, affordability, and reduce shortages, while promoting international collaboration and efficient registration processes.
4. **Strengthen supply chains and procurement systems**: Improve coordination and standard operating procedures across the supply chain to prevent stockouts and ensure timely distribution of medicines.
5. **Improve financing and affordability**: Integrate medicines into national benefit packages, implement fair pricing policies, regulate pharmaceutical mark-ups, encourage pooled procurement and quality generics, ensure price transparency, and incentivise local manufacturing.
6. **Build workforce capacity**: Empower non-specialists and the supply chain workforce through training and clinical guidance to effectively diagnose and manage neurological disorders.
7. **Strengthen data and health information systems**: Collect data on disease burden, treatment access, and supply chain metrics for evidence-based decision-making and to avoid stockouts.
8. **Encourage coordination, partnerships and convening**: Foster collaboration among stakeholders, including WHO, non-government organisations, patient communities, health ministries, regulators, and the private sector, with meaningful engagement of affected individuals.

Addressing the neurological care gap

Neurological disorders, recognised in the 2018 High-Level Meeting on NCDs as a ‘fifth NCD’ with mental health, are the second leading cause of global mortality after cancer, cardiovascular disorders, diabetes, and respiratory disease. These diseases often occur in tandem. Addressing the neurological treatment gap, or the difference between the number of people with a condition and the number of people with the condition being appropriately treated, is central to reducing the global burden of NCDs.

This report is a stark reminder of the need to scale up efforts to meet the IGAP’s objective for 80% of countries to provide essential medicines and technologies for managing neurological disorders in primary care by 2031. The NCD community looks forward to renewed discussions on this topic ahead of the fourth High-Level Meeting (HLM4) on NCDs in 2025, to ensure that people living with neurological conditions have access to the care they need and are not left behind.

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