Why are patients with epilepsy not getting treatment?

The global burden of epilepsy is huge. In 2016, 45·9 million people worldwide were reported to have epilepsy, and epilepsy accounted for 126 055 deaths and 13·5 million disability-adjusted life-years. Although around 70% of patients with epilepsy respond to antiepileptic drugs, only one quarter of them get the treatment they need in low-income and middle-income countries. In these countries, this so-called treatment gap—undertreatment of a disease in the presence of effective treatment—is mostly due to socioeconomic factors (eg, limited access to diagnosis or treatment), sociocultural factors (eg, cultural beliefs), or both. In high-income countries, where antiepileptic drugs are readily accessible, there is also a treatment gap, but its extent and causes are not fully understood.

To elucidate the issues around undertreatment of epilepsy in high-income countries, Patrick Kwan and colleagues undertook a retrospective analysis of newly diagnosed patients with epilepsy. Their findings, which have not undergone peer-review yet, were presented at the last Annual Meeting of the American Epilepsy Society, held Nov 30–Dec 4, 2018, in New Orleans (LA, USA), and showed that 232 (36%) of 636 patients, diagnosed by a neurologist at a First Seizure Clinic in Western Australia, did not receive immediate treatment and that 14% (93) patients declined treatment. Among the most common reasons for treatment not being offered in this cohort were the presence of seizure precipitating factors (eg, flashing lights), presentation after a single seizure, and waiting for additional tests, while concerns about the need for treatment, presence of seizure precipitating factors, and potential adverse effects led patients to decline treatment. A report of aggregated data from the 2013 and the 2015 National Health Interview Surveys by the US Centers for Disease Control and Prevention, published on Apr 20, 2018, has also revealed that of 2·6 million patients with epilespy in the USA annually, about 260 000 (10%) did not take antiepileptic drugs, only two out of three patients were being cared for by a neurologist or epileptologist, and that 1 310 400 (56%) of those who were on antiepileptic medication had recurrent seizures. Notably, higher adherence to antiepileptic medication was reported in patients who had seen an epileptologist in the past year, compared with those who did not; however, adherence did not result in better seizure control.

Although the reasons for undertreatment differ between low-income and middle-income countries and high-income countries, an accurate and prompt diagnosis is a prerequisite for starting treatment and improving quality of life in patients with epilepsy anywhere. Untreated epilepsy is a crucial public-health issue; patients with untreated epilepsy face potentially poor health outcomes and life-threatening conditions (eg, status epilepticus). Accurate diagnosis of epilepsy is crucial not only to prevent mistreatment, but also to facilitate therapeutic choice. However, a diagnosis of epilepsy does not necessarily mean that treatment is needed or should be given immediately. There are several reasons for not starting treatment. These include, among others, the presence of provoking factors, the expected risk of relapse and, not least, finding the balance between indication, risks, and benefits of a treatment. Thus, it is not surprising that some patients are left untreated in light of their individual risk–benefit ratio.

However, an important, and perhaps the most worrying, contributor to undertreatment of epilepsy in western countries might be the lack of confidence of some patients in their diagnosis and recommended treatment plan. A good physician–patient relationship is essential to discuss the risks of treatment and of non-treatment. Although antiepileptic drugs remain the most efficient intervention to prevent seizures, non-pharmacological management (eg, avoiding sleep deprivation) might be beneficial in some patients with epilepsy. Treatment adherence is a major part of seizure control, but is affected by many factors (eg, comorbid disorders). Allowing patients with epilepsy to participate in the clinical decision process can promote their adherence to treatment and reduce the effects that the disease may have on their lives.

Patient education is essential to ensure that the need for epilepsy treatment is fully understood. There is also a need for increased public engagement to improve awareness that epilepsy is a condition that anybody can get, and to aid recognition of the various symptoms, ranging from subtle seizures to disruptive seizures. Initiatives similar to the stroke campaigns could reduce stigma and help patients to receive an earlier and accurate diagnosis and the adequate treatment to improve their quality of life. ■ *The Lancet Neurology*

For the **global burden of epilepsy** see **Articles** *Lancet Neurol* 2019; in press

For more on **epilepsy in low-income and middle-income countries** see https://www.who.int/en/news-room/fact-sheets/detail/epilepsy

For the **Annual Meeting of the American Epilepsy Society** see https://meeting.aesnet.org/

For the **study on the treatment gap in Western Australia** see https://www.aesnet.org/meetings_events/annual_meeting_abstracts/view/502100/

For the **CDR report** see *MMWR Morb Mortal Wkly Rep* 2018; **67:** 437–42