

The treatment of epilepsy in developing countries: where do we go from here?

Robert A. Scott,¹ Samden D. Lhatoo,² & Josemir W.A.S. Sander³

Epilepsy is the most common serious neurological disorder and is one of the world's most prevalent noncommunicable diseases. As the understanding of its physical and social burden has increased it has moved higher up the world health agenda. Over four-fifths of the 50 million people with epilepsy are thought to be in developing countries; much of this condition results from preventable causes. Around 90% of people with epilepsy in developing countries are not receiving appropriate treatment. Consequently, people with epilepsy continue to be stigmatized and have a lower quality of life than people with other chronic illnesses. However, bridging the treatment gap and reducing the burden of epilepsy is not straightforward and faces many constraints. Cultural attitudes, a lack of prioritization, poor health system infrastructure, and inadequate supplies of antiepileptic drugs all conspire to hinder appropriate treatment. Nevertheless, there have been successful attempts to provide treatment, which have shown the importance of community-based approaches and also indicate that provision for sustained intervention over the long term is necessary in any treatment programme. Approaches being adopted in the demonstration projects of the Global Campaign Against Epilepsy — implemented by the International League Against Epilepsy, the International Bureau for Epilepsy, and the World Health Organization — may provide further advances. Much remains to be done but it is hoped that current efforts will lead to better treatment of people with epilepsy in developing countries.

Keywords: Epilepsy/drug therapy/epidemiology; Anticonvulsants/supply and distribution; Phenobarbital/therapeutic use; Cost of illness; Clinical protocols; Sustainability; Developing countries (*source: MeSH*).

Mots clés: Epilepsie/chimiothérapie/épidémiologie; Anticonvulsivants/ressources et distribution; Phénobarbital/usage thérapeutique; Coût maladie; Protocole thérapeutique; Durabilité; Pays en développement (*source: INSERM*).

Palabras clave: Epilepsia/quimioterapia/epidemiología; Anticonvulsivos/provisión y distribución; Fenobarbital/uso terapéutico; Costo de la enfermedad; Protocolos clínicos; Sostenibilidad; Países en desarrollo (*fuente: BIREME*).

Bulletin of the World Health Organization, 2001, **79**: 344–351.

Voir page 349 le résumé en français. En la página 350 figura un resumen en español.

Introduction

Epilepsy is the most common serious neurological disorder and is one of the world's most prevalent noncommunicable diseases. It is estimated that the

condition affects approximately 50 million people, around 40 million of them living in developing countries (1). The incidence of epilepsy in low-income countries may be as high as 190 per 100 000 people (2). Consequently, in the context of the large and rapidly increasing populations in these countries, epilepsy is a significant health and socioeconomic burden requiring urgent attention (3). In this connection it is worth noting the World Health Organization's (WHO's) aim of easing the burden of mental and neurological illnesses that affect 400 million people (4).

This burden has been quantified in terms of disability-adjusted life years (DALYs). As a result of setting up this measure it has become increasingly important to recognize the adverse impact and burden of noncommunicable diseases (3) and to formulate strategies for combating them (Table 1). The use of DALYs has been criticized, because, for example, it is subjective and based on guesstimates (5), and because the same weight is given to all

¹ Assistant Scientific Project Leader for the demonstration projects of the ILAE/IBE/WHO Global Campaign Against Epilepsy; based at the Institute of Neurology, University College London, England.

² Clinical Research Fellow for the Epilepsy Research Group at the Institute of Neurology, University College London, England.

³ National Society for Epilepsy Professor of Neurology and Clinical Epilepsy at the Institute of Neurology, University College London, and Honorary Consultant Neurologist at the National Hospital for Neurology and Neurosurgery, London, and the Chalfont Centre for Epilepsy, Chalfont St Peter, Buckinghamshire, England. Correspondence should be sent to this author at the WHO Collaborative Centre for Research and Training in Neurosciences, Institute of Neurology, University College London, 33 Queen Square, London WC1N 3BG, England (tel: + 44 20 7813 0588; fax: + 44 20 7813 0676; email: lsander@ion.ac.uk).

Ref. No. 00-0857

income groups — i.e. the poor are not prioritized (6, 7). However, even in developing and transitional countries, noncommunicable diseases account for a high proportion of the total mortality and disease burden (8). It has also been argued that a sinister tactic of some powerful interest groups may be at work to ensure that DALYs are not used and noncommunicable diseases are not treated (9).

Epidemiology of epilepsy in developing countries

The reported prevalence rates of active epilepsy in developing countries range from 5 to 10 per 1000 people (10–12). Reliable incidence figures are harder to establish because prospective studies have to contend with difficult and often insurmountable logistical problems concerning accurate case ascertainment. However, the more stringent studies have found annual incidence rates of up to 190 per 100 000 people in developing countries and of 50–70 per 100 000 people in industrialized countries (13).

These epidemiological estimates raise an interesting question, as yet unanswered. As prevalence rates for active epilepsy appear to be similar in both developing and industrialized countries, and given that there is a much higher incidence of epilepsy in developing countries, a significant proportion of the afflicted population may be dying from the seizure disorder or its underlying cause. Of course, an alternative explanation is that many people with epilepsy in developing countries go into spontaneous remission. Unfortunately, although many epidemiologists strongly suspect that the former explanation is the more probable, no comprehensive mortality studies have been conducted to resolve this issue.

The high incidence figures are, to a significant degree, attributable to symptomatic epilepsies caused by a host of parasitic and infectious diseases that are largely absent in industrialized countries. Neurocysticercosis, for example, is frequently found in people with epilepsy in developing countries (2, 14, 15), and a study in Peru concluded that it was one of the major causes of seizures in Latin America (16). Malaria may indirectly lead to epilepsy through febrile seizures, as may malnutrition and underresourced health care at the pre-, peri-, and postnatal levels. In a study of infants with epilepsy in Nigeria, for example, 48% of cases were identified as being caused by birth asphyxia, infections or hypoglycaemia (17). In South Africa, it was found that 50% of children with recurrent seizures had had their first seizure before the age of two years, and that 32% and 11% of the patients studied had a history of perinatal complications and meningitis, respectively (18).

The experience of epilepsy: the treatment gap and social aspects

A large proportion of the 50 million people affected by epilepsy remains untreated (19). It is estimated, for

example, that approximately 5 million of the 10 million people with epilepsy in India are untreated (12). Such a treatment gap was defined by a workshop of the International League Against Epilepsy (ILAE) as the difference between the number of people with active epilepsy (two or more unprovoked seizures on different days in the previous year) and the number whose seizures are being appropriately treated in a given population at a given point in time, expressed as a percentage (20). It should also be noted that while four-fifths of the potential market for antiepileptic drugs is in the developing world, up to 90% of people with epilepsy in developing countries receive no treatment at all (21–23). There may be various reasons for this, some of which are described in the next section, but poverty may be viewed as the root cause of the treatment gap.

Various psychosocial issues are also linked to epilepsy (1). A Canadian study (24) found that people with epilepsy had more days off work, a lower annual income and a lower quality of life than people with other chronic illnesses. Children with epilepsy had a lower performance at school than other pupils, including those suffering from other chronic diseases that affected their attendance at school (25). The burdens produced by epilepsy go beyond the individual affected by the condition. In China, for example, epilepsy has been reported to threaten the aspirations of the entire family as well as the opportunities of the individual with epilepsy (26).

The Global Campaign Against Epilepsy was established by the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE), and WHO in order to tackle the kinds of problem outlined above (1). The aim is to bridge the treatment gap and bring epilepsy out of the shadows so that the physical and socioeconomic burdens of epilepsy on individuals and society as a whole are reduced.

Factors responsible for inadequate treatment of people with epilepsy

Various studies in developing countries have shown that many constraints and difficulties hinder the adequate treatment of epilepsy. These factors, outlined below, are not restricted to one particular social sector but exist in the economic, political, and cultural frameworks of societies.

Different perceptions and understanding

Cultural beliefs vary from country to country and may influence individuals' health-seeking strategies. For example, people may not seek treatment with antiepileptic drugs if epilepsy is not seen as a condition that can be treated by western medicine. This is equally true of people in both industrialized and developing countries (27–33). In both settings a lack of knowledge about the cause and treatment of epilepsy, possibly dependent on levels of education,

Table 1. **The percentage of total disability-adjusted life years (DALYs) lost worldwide to selected health problems in 1998**

Health problems	DALYs lost %
Infectious and parasitic diseases	23.4
Neuropsychiatric disorders (including unipolar and bipolar affective disorders, psychosis, epilepsy, dementia, Parkinson disease, multiple sclerosis)	11.5 (23 in high-income countries; 11 in low-income countries)
Unintentional injuries	11.3
Cardiovascular diseases	10.3
Respiratory infections	6.2
Perinatal infections	5.8
Malignant neoplasms	5.8

Source: ref. 3.

may lead to a degree of stigmatization of people with epilepsy (34–37). Differences in perception, lack of knowledge, and illiteracy can also lead directly to problems of compliance with medication regimens.

Lack of prioritization

Despite its importance and the existence of an often-effective remedy, epilepsy is not generally recognized as a public health priority (10, 38). Where there are low budgets for health, resources are inevitably prioritized for conditions perceived to be more important than epilepsy, such as infectious diseases. Data showing the cost-effectiveness of treating epilepsy rather than other health problems would be invaluable in convincing health planners of the need to prioritize epilepsy treatment. Unfortunately, there appear to be no studies on this issue: urgent research on the subject is therefore required.

Lack of infrastructure and structural adjustment programmes

These issues are linked to and may further accentuate the lack of prioritization discussed above. China, Malawi, and Senegal annually spend US\$ 15, 5.8 and 13.5 per capita, respectively, on health care (39). Bearing in mind that a person's annual treatment with phenobarbitone costs around US\$ 2–3 in China (37), it is unlikely that antiepileptic drugs could be provided solely by government-funded schemes in these countries. Equally, if privately paid for, drug treatment could cause financial hardship, although even the more expensive antiepileptic drugs may be affordable to those who are rich.

Developing countries' inadequate health systems may be further constrained through the adoption of stabilization programmes of the International Monetary Fund or structural adjustment programmes of the World Bank (40–44). This has been particularly true in sub-Saharan Africa where incomes, exports, investment, health expenditure, and education expenditure have fallen while debt, ecological damage, malnutrition, and morbidity have risen (45–47).

Supply of antiepileptic drugs

Ideally, the choice of antiepileptic drug for each patient should be based on seizure type and/or syndrome as well as the individual person's needs. Unfortunately, in most developing countries both the choice and supply of drugs are limited. Figures for Europe, Latin America, and North America have shown their respective market shares for antiepileptic drugs to be 27.3%, 5.9%, and 54.3% (37). As the population sizes and the prices of antiepileptic drugs in these regions are similar, it is clear that relatively small quantities of these drugs are available in Latin America (37). An analysis of the market also shows that while older and cheaper drugs, such as phenobarbitone, have declined in market share in industrialized regions, their market share in Latin America and other developing regions is higher and increasing faster than that of newer antiepileptic drugs. Furthermore, in inadequate and poorly-resourced health care systems, whether under structural adjustment or not, any type of antiepileptic drug is usually in short supply. In such systems the normal determinants for drug treatment are the drug's cost and availability (4).

The profitability of antiepileptic drugs for pharmaceutical companies and distributors can be an additional factor in their supply and use. The profit margin on a drug such as phenobarbitone may be too small to make it commercially viable for the companies producing it or for pharmacies (23, 27). Although the profit may be too low for producers, paradoxically the price may be too high for consumers. In India in 1988, for example, a year's supply of phenobarbitone cost US\$ 20–30 when average annual incomes were around US\$ 110 (27). In view of such problems concerning the supply of antiepileptic drugs, it has been argued that the non-availability of antiepileptic drugs is the most important obstacle to the care of people with epilepsy (23, 48, 49).

Choice of drug

Phenobarbitone has become WHO's front-line antiepileptic drug in developing countries (50), where it is the most commonly prescribed antiepileptic drug (51). This may in part be because phenytoin, carbamazepine, and valproate are up to 5, 15, and 20 times as expensive, respectively (23, 48, 49). Questions have, however, been raised about its suitability with respect to its efficacy and the profile of adverse events (23). It is of little use in absence seizures and has several disadvantages in some childhood epilepsies (37, 51). Indeed, ILAE commissions have argued that the WHO essential drugs' list needs to be discussed further, as the status of phenobarbitone seems to be based on economic factors rather than on efficacy and suitability (48).

However, various studies have shown that this may not necessarily be true. A study in rural India (52, 53) found that 65% of patients who received phenobarbitone were successfully treated, and that the same proportion responded to phenytoin. Adverse events were also similar in type and

frequency in both groups. This confirmed an earlier study in Indonesia (54) which concluded that, despite some disadvantages, phenobarbitone should still be used as the front-line drug in epilepsy treatment in developing countries. Studies in Ecuador (55) and Kenya (56, 57) compared phenobarbitone to carbamazepine and found that there were no significant differences in either efficacy or safety. Therefore, given the cost advantages, phenobarbitone may still be deservedly the front-line drug in WHO's strategy concerning epilepsy treatment.

Approaches in Malawi, Kenya, and West Bengal, India: success and sustainability

Malawi

A simple treatment model was designed by a doctor working at Embangweni Hospital in northern Malawi to address some of the above constraints (34). It incorporated wide publicity of accessible services; easily available, free, and simple treatment with phenytoin or phenobarbitone; adequate supply of medication; frequent follow-up; and continuity of follow-up. The need to balance efficacy with cost and simplicity of use was considered to be very important. In view of the low ratio of physicians to population, health workers had to be used. The number of physicians per 1000 people was less than 0.05 in 1980 and there was no change by 1998; for Kenya the corresponding values were 0.1 and less than 0.05, and for the United Kingdom they were 1.6 and 1.6 (39).

The education of the local population and people with epilepsy was crucial. Those with the condition were informed in culturally relevant terms that epilepsy was caused by a dysfunction or a lesion in the brain and that sufficient time was therefore required for healing to occur. Consequently, long-term treatment was probably required, the control of seizures would probably take some time, and drug doses would have to be changed. They were also informed that there could be side-effects and that, although alcohol should be avoided, there were no dietary restrictions.

After 8 months, 11 individuals were receiving treatment in hospital. Following a publicity campaign, however, 70 additional people received antiepileptic drugs over the following 3 months. As some of these people walked over 20 miles to attend the hospital clinic, two mobile clinics were set up to facilitate attendance. After two years, 461 patients were registered at the hospital and the mobile clinics. Of the 254 people who began treatment in the 18 months of the programme, 68% were still attending after 6 months. After 6 months of treatment, 56% of patients had no seizures, whereas before treatment, 88% had one seizure per month.

Kenya

WHO has recommended that community health workers diagnose and treat tonic-clonic seizures

(58). This is in broad agreement with the views expressed at a workshop of the International Community-based Epilepsy Research Group (ICBERG) held in New Delhi, India, in 1989 (59). Adopting this key-informant approach, the study in a rural district of the Rift Valley in South-West Kenya ensured effective case ascertainment, and used a simple model of treatment and follow-up (56, 57). The informants were selected from families, or were teachers, traditional healers, chiefs, or community figures who helped to identify people who had seizure-like symptoms. In this way, 529 people from the population of 850 000 in Nakuru, south-west Kenya, were identified as having active seizures and 302 of them were recruited to the study. A health worker was allocated to each person with epilepsy and educated them about the condition and the importance of compliance. A non-specialist physician conducted a monthly hospital follow-up of these people on simple regimens of carbamazepine or phenobarbitone, and easy, urgent access was facilitated for people experiencing side-effects.

A compliance rate of 82% of the 302 people occurred in the 12 months of follow-up. Of these, 53% were seizure-free for 6–12 months, 25% of them being without seizures for 12 months. A further 26% had reductions in seizure frequency. The two drugs were equally effective and, importantly, the duration of epilepsy before medication made no difference to subsequent efficacy.

Community-based approach. The authors suggested that the reduction in seizures had much to do with the community-based approach. Community health workers identified appropriate people with epilepsy. The treatment protocols were suitable for use by non-physicians and enabled the health workers to take a leading role in diagnosis, education, adjustment of drug doses, monitoring treatment, and ensuring compliance. A psychiatrist confirmed their diagnoses and reviewed their work. This review established that community health workers identified tonic-clonic seizures correctly. As expected, however, there were difficulties in diagnosing rarer forms of seizure.

This study model established an important precedent for treatment projects led by community health workers. It emphasized the feasibility of delivering appropriate care in developing countries through the primary health care system.

Sustainability. Although both this model and that from the study in Malawi efficiently treated people with epilepsy, were initially successful, and provided methods which could be adopted elsewhere, an additional constraint has jeopardized their achievements in the longer term. The programmes came to a halt after the people who had established them moved away. Consequently, these examples have more similarities with failing vertical interventions, such as those associated with malaria or trypanosomiasis (60), than with the community-based approach that they were trying to adopt.

The sustainability of a programme depends on community participation and therefore needs to be societal as well as integrated into primary health care (61–64). Furthermore, WHO has proposed that dialogue take place between health professionals and important groups in society, such as traditional healers, who express fundamental community attitudes and often hold the key to successful community liaison (65). The Malawian and Kenyan experiences have provided invaluable insights into field situations, but the knowledge obtained should be built on by further involvement of communities.

Issues of sustainability are not only essential to an intervention's success but also have important ethical aspects (66). Antiepileptic drugs were provided in many of the above studies but it is unclear what happened to the people with epilepsy after the studies were completed. If drugs were provided free of charge, did this continue? If not, had patients been warned that they would have to pay for their treatment? Did drug costs rise after treatment? Were patients able to access a similar level of care after a study was completed? Moreover, if drug supplies cease after the perceived life-cycle of an intervention, patients who have been treated may face an increased risk of status epilepticus. This means that what begins as a study or intervention model may end up increasing mortality.

West Bengal, India

A study in rural West Bengal (67) provides pointers to resolving issues of sustainability. Workers in two local nongovernmental organizations (NGOs) received training in case ascertainment and informing communities about epilepsy. The NGOs were already involved in community-based health care and the epilepsy service was integrated into the rest of their health care provision. This offered a low-cost alternative to other forms of intervention and meant that epilepsy services became part of organizations already committed to their communities in the long term. When the study was finished, therefore, the epilepsy service continued to be provided.

Further approaches to bridging the treatment gap

A programme in India

An Indian programme, established by the National Institute of Mental Health and Neurosciences in Bangalore (12), provides an interesting approach that attempts to circumvent many of the anticipated problems of treatment programmes in developing countries. A national workshop on public health aspects of epilepsy estimated that around 10 million people with epilepsy were living in India (a prevalence rate of 1 in 100 people) (12). For the country's population of one billion (1 000 000 000), however, there are only 500 neurologists, and many health professionals lack adequate expertise in the diagnosis and management of epilepsy. The following two-

pronged approach has therefore been proposed: firstly, a *top-down strategy* of strengthening district hospitals, ensuring an uninterrupted supply of antiepileptic drugs, and using mobile teams for remote rural areas; and secondly, a *bottom-up strategy* of training health professionals in case detection, diagnosis and management (the concomitant setting up of a national programme will ensure political and operational support).

In 1999, three workshops for district medical officers covered training in the diagnosis of epilepsy, management and psychosocial aspects, and a manual on epilepsy was provided. The officers' knowledge of epilepsy and its treatment was evaluated before and after training, and further assessment was planned after a year. Wider-reaching workshops are intended for 2000–01 with the aim of covering all the country's states. The aim is to achieve a state model of epilepsy treatment.

A Chinese approach

Some 5 million people suffer from epilepsy in China and there are about 400 000 new cases each year (68). A demonstration treatment project under the Global Campaign Against Epilepsy has begun its implementation in seven counties of five provinces in northern and eastern China; each county has a population of between 500 000 and 600 000 (68). Some of the key aspects of the programme are focused on knowledge, attitudes, and practices. It is intended to bring about a change in traditional and cultural attitudes so that stigma of epilepsy is reduced and more people are prepared to receive treatment. In order to make treatment more successful, village doctors will be trained to diagnose and treat epilepsy correctly and a protocol for the use of phenobarbitone has been developed (68). The study period for the project is intended to last five years and if the project is successful it is hoped that its approach will be adopted throughout China's provinces.

Conclusion (see Box 1)

Epilepsy, one of the most important noncommunicable neurological illnesses, is particularly under-resourced and undertreated in the developing world. Epidemiological studies have made it clear that the magnitude of the problem makes it a public health priority. Large numbers of people are at risk of morbidity and mortality, mainly because of difficulties with treatment infrastructure and the availability of suitable drugs. However, people with epilepsy need more than drug treatment because their local cultural context adds a social and economic burden to the physical burden of their seizures. The education of health workers, patients, and the wider community is therefore essential.

Projects in Africa have shown that intervention models are effective if there are adequate resources and commitment. Any intervention should, however, be fully integrated into the context of primary health care delivery. Personnel should be trained and

Box 1. Key points relating to epilepsy treatment in developing countries

- Four-fifths of the 50 million people with epilepsy are in developing countries.
- 90% of these people do not receive appropriate treatment. This is called the treatment gap.
- Incidence rates far exceed prevalence figures. This could be associated with high mortality.
- High incidence rates partly result from many preventable causes that are largely absent in the developed world, e.g. neurocysticercosis.
- People with epilepsy are often socially, educationally and economically disadvantaged because of their condition.
- Epilepsy treatment is constrained by cultural perceptions, a lack of prioritization, poor infrastructure, and uncertain supplies of drugs.
- Programmes in India, Kenya, and Malawi provide community-based approaches that offer evidence of effective treatment strategies.
- Demonstration projects of the ILAE/IBE/WHO Global Campaign Against Epilepsy may provide further approaches and galvanize public support for people with epilepsy.

committed to epilepsy treatment to the same extent as required for any other illness or health problem. Local communities should be brought into the planning and implementation process so that long-term sustainability is further fostered. In this regard it may be more appropriate to involve existing local or national NGOs in epilepsy service provision rather than establish new epilepsy organizations or work with governments whose health priorities may be altered by electoral concerns. Sustainability may also be improved through the use of support groups (69).

Furthermore, a top-down commitment to resources and political patronage should be adopted in order to ensure that epilepsy remains on the agenda and that drug supplies can be assured. There should also be a commitment to dealing with the many preventable causes of epilepsy in developing countries, such as neurocysticercosis. Epilepsy should therefore be integrated into wider public health programmes, such as those concerned with sanitation, safe water, nutrition, and mother and child health. Such commitments are not only required, however, from public health practitioners but also from people directly involved in epilepsy treatment so that prevention becomes part of their activities as well.

The treatment gap can only be properly closed if poverty and inequalities of income are dealt with at the local, national, and global levels. At the local level this may mean ensuring that primary health care operates within a community development framework where, for example, there are literacy and income-generating programmes.

The methods and results of the Malawian and Kenyan projects have been encouraging and it is hoped that the proposed Indian and Chinese approaches will lead to further progress. The interventions to be established in Argentina, China, Senegal, and Zimbabwe under the Global Campaign Against Epilepsy should also permit long-term models to be established and evaluated. These interventions were publicly announced at the launch of the Second Phase of the Global Campaign at WHO in Geneva, Switzerland, in February 2001, and it is hoped that it will be possible to use these approaches across the world in bridging the epilepsy treatment gap and reducing the burden of the condition.

These approaches may also prove to be of value in the treatment of other noncommunicable diseases. However, in contrast to other chronic noncommunicable diseases, such as diabetes and heart disease, there is a high social burden and stigma attached to epilepsy. These psychosocial issues would not, therefore, have to be included in programmes for other diseases.

Although mortality among people with epilepsy is high (70), the chances of remission are also high (71) and therefore the probability such people being young, fully contributing members of society is higher than with heart disease, where the afflicted population is more often elderly and non-contributing. Unfortunately, it is difficult to provide more concrete proposals at present. However, after the Global Campaign Against Epilepsy has been operating for some years its relevance to other noncommunicable diseases should be re-examined, to discover what lessons have been learnt and which approaches may be appropriate. ■

Acknowledgements

The authors thank Deb K. Pal for his helpful comments.

Conflict of interests: none declared.

Résumé**Traitement de l'épilepsie dans les pays en développement : où allons-nous ?**

L'épilepsie est la plus courante des affections neurologiques graves et l'une des maladies non transmissibles les plus répandues dans le monde. Avec l'évolution des connaissances concernant son poids médical et social, l'épilepsie est maintenant mieux placée sur l'agenda mondial de la santé. On estime que plus des 4/5 des 50 millions de personnes touchées par l'épilepsie, une affection due en grande partie à des causes évitables,

vivent dans les pays en développement ; dans ces pays, plus de 90 % des personnes atteintes ne reçoivent pas un traitement approprié. Elles continuent donc à être stigmatisées et ont une moins bonne qualité de vie que les malades atteints d'autres affections chroniques. Cependant, réduire les écarts en matière de traitement et la charge que représente l'épilepsie n'est pas une tâche aisée et se heurte à de nombreux obstacles. Les attitudes

culturelles, l'absence de priorités, les carences de l'infrastructure sanitaire et l'insuffisance de l'approvisionnement en médicaments antiépileptiques concourent à empêcher les malades de recevoir un traitement approprié. Plusieurs tentatives ont néanmoins été couronnées de succès; elles ont montré l'importance des approches à base communautaire et indiquent également que tout programme de traitement nécessite une intervention de longue durée. Les approches adoptées

par les projets de démonstration de la Campagne mondiale contre l'épilepsie, et mises en œuvre par la Ligue internationale contre l'épilepsie, le Bureau international de l'épilepsie et l'Organisation mondiale de la Santé, pourraient offrir de nouvelles avancées. Il reste beaucoup à faire mais on peut espérer que les efforts actuels conduiront à améliorer le traitement des personnes atteintes d'épilepsie dans les pays en développement.

Resumen

Tratamiento de la epilepsia en los países en desarrollo: ¿qué camino seguir?

La epilepsia es el más común de los trastornos neurológicos graves, y una de las enfermedades no transmisibles de mayor prevalencia en el mundo. Conforme se ha progresado en el conocimiento de la carga física y social que representa, la enfermedad ha ido cobrando también importancia entre las prioridades sanitarias mundiales. Se estima que más de las cuatro quintas partes de los 50 millones de personas que sufren epilepsia viven en países en desarrollo, y que una gran parte de esos casos se deben a causas prevenibles. Aproximadamente un 90% de las personas con epilepsia de los países en desarrollo no están siendo tratadas correctamente. El resultado es que esas personas siguen siendo estigmatizadas y tienen una menor calidad de vida que otros enfermos crónicos. Sin embargo, reducir la carga de epilepsia y las diferencias en cuanto a su tratamiento no resulta fácil, pues hay que afrontar

muchos problemas. Las actitudes culturales, la falta de prioridades, una deficiente infraestructura sanitaria y un suministro inadecuado de medicamentos antiépilepticos son todos ellos factores que se confabulan para impedir un tratamiento idóneo. Así y todo, han tenido éxito algunos intentos en ese sentido, que han demostrado la importancia de los enfoques comunitarios, así como la necesidad, en todo programa de tratamiento, de una intervención sostenida a largo plazo. Los enfoques que se están adoptando en los proyectos de demostración de la Campaña Mundial contra la Epilepsia — aplicados por la Liga Internacional contra la Epilepsia, la Oficina Internacional para la Epilepsia y la Organización Mundial de la Salud — pueden posibilitar nuevos avances. Queda mucho por hacer, pero cabe esperar que los esfuerzos actuales conduzcan a un mejor tratamiento de las personas con epilepsia en los países en desarrollo.

References

1. *The Global Campaign Against Epilepsy*. Geneva, World Health Organization, 2000 (Information Pack for the launch of the Global Campaign's Second Phase, 12–13 February 2001).
2. **Placencia M et al.** The characteristics of epilepsy in a largely untreated population in rural Ecuador. *Journal of Neurology, Neurosurgery, and Psychiatry*, 1994, **57** (3): 320–325.
3. *The global burden of mental and neurological problems*. Geneva, World Health Organization, 1999 (WHO Fact Sheet No. 217).
4. *Raising awareness, fighting stigma, improving care*. Geneva, World Health Organization, 1999 (WHO Press Release WHO/67).
5. **Cooper RS et al.** Disease burden in sub-Saharan Africa: what should we conclude in the absence of data? *Lancet*, 1998, **351**: 208–210.
6. **Gwatkin R.** The global burden of disease. *Lancet*, 1997, **350**: 141 (letter).
7. **Gwatkin DR, Guillot M, Heuveline P.** The burden of disease among the global poor. *Lancet*, 1999, **354**: 586–589.
8. **Reddy KS.** The burden of disease among the global poor. *Lancet*, 1999, **354**: 1477–1478 (letter).
9. A manipulated dichotomy in global health. *Lancet*, 2000, **355**: 1923 (editorial).
10. **Bertolote JM.** Epilepsy as a public health problem — the role of the World Health Organization and of cooperation between WHO and nongovernmental organizations. *Tropical and Geographical Medicine*, 1994, **46** (3): S28–S30.
11. **Aziz H et al.** Comparative epidemiology of epilepsy in Pakistan and Turkey: population-based studies using identical protocols. *Epilepsia*, 1997, **38**: 716–722.
12. **Gourie-Devi M, Satischandra P, Gururaj G.** Report of national workshop on public health aspects of epilepsy for senior health personnel of state health departments in India. *Annals of Indian Academy of Neurology*, 1999, **2**: 43–48.
13. **Sander JWAS, Shorvon SD.** Epidemiology of the epilepsies. *Journal of Neurology, Neurosurgery, and Psychiatry*, 1996, **61** (5): 433–443.
14. **Pal DK, Carpio A, Sander JWAS.** Neurocysticercosis in developing countries. *Journal of Neurology, Neurosurgery, and Psychiatry*, 2000, **68** (2): 137–143.
15. **Carpio A, Escobar A, Hauser WA.** Cysticercosis and epilepsy: a critical review. *Epilepsia*, 1998, **39** (1): 1025–1040.
16. **García HH et al.** Epilepsy and neurocysticercosis in a village in Huaraz, Peru. *Clinical Neurology and Neurosurgery*, 1999, **101** (4): 225–228.
17. **Asindi AA et al.** Neonatal seizures in Nigerian infants. *African Journal of Medical Sciences*, 1995, **24**: 243–248.
18. **Leary PM, Morris S.** Recurrent seizures in childhood: Western Cape profile. *South African Medical Journal*, 1998, **74**: 579–581.
19. **Ellison RE et al.** A study of approaches to antiepileptic drug treatment in four countries in the developing world. In: Dreifuss F et al., eds. *Advances in epileptology — XVIth Epilepsy International Symposium*. New York, Raven Press, 1988.
20. **Meinardi H et al.** The treatment gap in epilepsy: the current situation and ways forward. *Epilepsia*, 2001, **42**: 136–149.
21. In the shadow of epilepsy. *Lancet*, 1997, **349**: 1851 (editorial).
22. **Kale R.** Bringing epilepsy out of the shadows. *British Medical Journal*, 1997, **315**: 2–3.
23. **Shorvon SD, Farmer PJ.** Epilepsy in developing countries: a review of epidemiological, sociocultural and treatment aspects. *Epilepsia*, 1988, **29** (Suppl. 1): S36–S45.
24. **Wiebe S et al.** Burden of epilepsy: the Ontario health survey. *Canadian Journal of Neurological Sciences*, 1999, **26** (4): 263–270.
25. **Boekaerts M, Roder I.** Stress, coping, and adjustment in children with chronic disease: a review of the literature. *Disability and Rehabilitation*, 1999, **21** (7): 311–337.

26. Kleinman A et al. The social course of epilepsy: chronic illness as social experience in interior China. *Social Science and Medicine*, 1995, **40** (10): 1319–1330.
27. Kshiragar NA, Shah PU. Management of epilepsy in developing countries. In: Pedley TA, Meldrum BS, eds. *Recent advances in epilepsy*. Edinburgh, Churchill Livingstone, 1992.
28. Meinardi H, Pachlatko C. The economic impact of epilepsy in developing countries. In: Engel J Jr, Pedley TA, eds. *Epilepsy: a comprehensive textbook*. Philadelphia, Lippincott-Raven Publishers, 1997.
29. Canger R, Commaggia C. Public attitudes towards epilepsy in Italy: results of a survey and comparison with USA and West German data. *Epilepsia*, 1985, **26** (3): 221–226.
30. Caveness WF, Gallup GH Jr. A survey of public attitudes towards epilepsy in 1979 with an indication of trends over the past 30 years. *Epilepsia*, 1980, **21** (5): 509–518.
31. Nyame PK, Biritwum RB. Epilepsy: knowledge, attitudes and practice in a literate urban population, Accra, Ghana. *West African Journal of Medicine*, 1997 **16** (3): 139–145.
32. Santos IC et al. Public awareness and attitudes towards epilepsy in different social segments in Brazil. *Arquivos de Neuro-psiquiatria*, 1988, **56** (1): 32–38.
33. Bener A, Al-Marzooqi FH, Sztrihai L. Public awareness and attitudes towards epilepsy in the United Arab Emirates. *Seizure*, 1998, **7** (3): 219–222.
34. Watts AE. A model for managing epilepsy in a rural community in Africa. *British Medical Journal*, 1989, **298**: 805–807.
35. Osuntokun BO. Epilepsy in the African continent. In: Penry JK, ed. *Epilepsy — the VIIIth International Symposium*. New York, Raven Press, 1977: 365–378.
36. Hamdi H, Al-Husaini AA, Al-Hadithi F. The epilepsies: clinical and epidemiological aspects/availability and desirability of services. In: Penry JK, ed. *Epilepsy — the VIIIth International Symposium*. New York, Raven Press, 1977: 393–399.
37. ILAE Commission. Epilepsy in the tropics: II. clinical presentations, pathophysiology, immunologic diagnosis, economics and therapy. *Epilepsia*, 1996, **37** (11): 1128–1137.
38. *Child mental health and psychosocial development*. Geneva, World Health Organization, 1977 (WHO Technical Report Series, No. 613).
39. World Bank. *World development indicators 2000*. New York, Oxford University Press, 2000.
40. Kanji N, Kanji M, Manji F. From development to sustained crisis: structural adjustment, equity and health. *Social Science and Medicine*, 1991, **33** (9): 985–993.
41. Logie D, Rowson M. Poverty and health: debt relief could help achieve human rights objectives. *Health and Human Rights*, 1998, **3** (2): 82–97.
42. Banerji D. A simplistic approach to health policy analysis: the World Bank team on the Indian health sector. *International Journal of Health Services: planning, administration, evaluation*, 1994, **24** (1): 151–159.
43. Manfredi C. Can the resurgence of malaria be partially attributed to structural adjustment programmes? *Parassitologia*, 1999, **41**: 389–390.
44. Chaullet P. After health sector reform, whither lung health? *International Journal of Tuberculosis and Lung Disease*, 1998, **2** (5): 349–359.
45. Mosley P. Structural adjustment: a general overview 1980–89. In: Balasubramaniam V, Lall S, eds. *Current issues in development economics*. London, Macmillan, 1991.
46. *Alternative framework to structural adjustment: programme for socioeconomic recovery and transformation*. Addis Ababa, United Nations Economic Commission for Africa, 1989.
47. Mosley P, Weeks J. Has recovery begun? "Africa's adjustment in the 1980's" revisited. *World Development*, 1993, **21** (10): 1583–1606.
48. IIIrd and IVth ILEA Commission on Antiepileptic Drugs. Availability and distribution of antiepileptic drugs in developing countries. *Epilepsia*, 1985, **26** (2): 117–121.
49. Adamolekun B, Meinardi H. Problems of drug therapy of epilepsy in developing countries. *Tropical and Geographical Medicine*, 1990, **42** (2): 178–181.
50. *Initiative of support to people with epilepsy*. Geneva, World Health Organization, 1990 (unpublished document WHO/MNH/MND/90.3).
51. De Silva M et al. Randomised comparative monotherapy trial of phenobarbitone, phenytoin, carbamazepine or sodium valproate for newly diagnosed childhood epilepsy. *Lancet*, 1996, **347**: 709–713.
52. Pal DK et al. Randomised controlled trial to assess acceptability of phenobarbital for childhood epilepsy in rural India. *Lancet*, 1998, **351**: 19–23.
53. Pal DK et al. Antiepileptic drugs in developing countries. *Lancet*, 1998, **351**: 1210–1211 (letter).
54. Ismael S. The efficacy of phenobarbital in controlling epilepsy in children. *Paediatrica Indonesiana*, 1990, **30** (3–4): 97–110.
55. Placencia M et al. Antiepileptic drug treatment in a community health care setting in northern Ecuador: a prospective 12 month assessment. *Epilepsy Research*, 1993, **14** (3): 237–244.
56. Feksi AT et al. Comprehensive primary health care anti-epileptic drug treatment programme in rural and semi-urban Kenya. *Lancet*, 1991, **337**: 406–409.
57. Feksi AT et al. A comprehensive community epilepsy programme: the Nakuru project. *Epilepsy Research*, 1991, **8**: 252–259.
58. *Community control of epilepsy: report on an informal consultation for the development of strategy and protocol*. Geneva, World Health Organization, 1985 (unpublished report, Division of Mental Health).
59. Shorvon SD et al. *The management of epilepsy in developing countries — an ICBERG manual*. London, Royal Society of Medicine, 1991.
60. Unger J-P, Killingsworth JR. Selective primary health care. *Social Science and Medicine*, 1986, **22** (10): 1001–1013.
61. Chowdhury A M et al. Control of tuberculosis by community health workers in Bangladesh. *Lancet*, 1997, **350**: 169–172.
62. Heggenhougen HK, Shore L. Cultural components of behavioural epidemiology: implications for primary health care. *Social Science and Medicine*, 1986, **22** (11): 1235–1245.
63. Justice J. Can socio-cultural information improve health planning? A case study of Nepal's assistant nurse-midwife. *Social Science and Medicine*, 1984, **19** (3): 193–198.
64. Mubbashar MH. *Community based interventions in neuropsychiatry*. Forum 3 Document, Global Forum for Health Research, Geneva, 1999 (Internet communication accessed on 4 April 2000 at http://www.globalforumhealth.org/docs/forum3doc36_2.htm).
65. *Mental health and primary health care*. Geneva, World Health Organization, 1997 (WHO Fact Sheet No. 129).
66. Morrow RH, Smith PG. *Field trials of health interventions in developing countries — a toolbox*. London, Macmillan, 1996.
67. Pal DK, Das T, Sengupta S. Comparison of key informant and survey methods for ascertainment of childhood epilepsy in West Bengal, India. *International Journal of Epidemiology*, 1998, **27**: 672–676.
68. *Epilepsy management at primary health level: protocol for a demonstration project in the People's Republic of China*. Geneva, World Health Organization, 2000 (unpublished document WHO/MSD/MBD/00.11).
69. Dekker PA. *Epilepsy — a manual for medical and clinical officers in Kenya*. Leiden, EPICADEC, 1998.
70. Cockerell OC et al. Mortality from epilepsy: results from a prospective population-based study. *Lancet*, 1994, **344**: 918–921.
71. Cockerell OC et al. Remission of epilepsy: results from the National General Practice Study of Epilepsy. *Lancet*, 1995, **346**: 140–144.