Epilepsy: the services
**Introduction**

- The respondents were asked about the availability of diagnostic equipment for the management of epilepsy, e.g. computerized axial tomography (CAT), magnetic resonance imaging (MRI), and electroencephalography (EEG). They were asked about the availability of long-term video/EEG monitoring, therapeutic drug monitoring, and neuropsychological services and also whether therapeutic drug monitoring and neuropsychological services were available free of charge or without special conditions when covered by insurance.

**Salient findings**

- CAT and MRI are available to health professionals in 85% and 68.6%, respectively, of the responding countries.
- In Africa, while CAT is available in 61.8% of the responding countries, MRI is available in only 20.6%. CAT is available in 70.5% of low-income countries, compared with MRI which is available in only 29.6%.
- EEG is available to the health professionals dealing with patients with epilepsy in 86.9% of the responding countries. Long-term video/EEG monitoring, however, is available in only 50% of the responding countries.
- EEG is available in 61.9% of the responding countries in the Western Pacific, 77.8% in South-East Asia, 82.4% in Africa, 92% in the Americas, 93.3% in the Eastern Mediterranean, and 100% in Europe.
- Long-term video/EEG monitoring is available in 21.7% of low-income countries compared with 77.1% of high-income countries.
- Therapeutic drug monitoring is available in 74.7% of the responding countries. In about two thirds of these countries it is available to people with epilepsy free of charge or without any special condition.

**Limitations**

- Because the sources of information in most countries were key people working in the area of epilepsy, the data pertain mainly to countries where individuals with an interest in providing epilepsy care exist. It is therefore possible that the figures might be overestimated.
- Some of the respondents mentioned that the equipment was present but not in working order and therefore not available for patient care.

**Conclusions**

- The diagnostic services are needed for appropriate management of epilepsy, especially at the referral level of care. The inequities observed across different income groups and regions need to be dealt with.
- Most new technologies are available in many countries, though they may be concentrated in a few centres or in major cities. The aim should be to improve the coverage to include the entire population.
- Sometimes the equipment constitutes a major component of the capital cost. In low-income countries where fewer resources are available, the high recurrent costs involved in maintaining the equipment may also limit its availability.
6.1 Computerised Axial Tomography (CAT) and Magnetic Resonance Imaging (MRI) in different income groups of countries

- Low: 29.6%
- Lower middle: 78.3%
- Higher middle: 88.5%
- High: 94.3%

- CAT
  - Low: 70.5%
  - Lower middle: 45.1%
  - Higher middle: 40%
  - High: 93.3%

- MRI
  - Low: 56.3%
  - Lower middle: 55.6%
  - Higher middle: 54.6%
  - High: 64.3%

6.2 Therapeutic drug monitoring in WHO regions and the world

- Africa: 82.4%
- Americas: 25.7%
- South-East Asia: 82.4%
- Eastern Mediterranean: 92%
- Europe: 77.8%
- Western Pacific: 33.3%
- World: 100%

- Free of charge: 95.8%
- Partially charged: 55.6%
- Fully charged: 93.3%

6.3 Electroencephalography (EEG) and Long term video/EEG monitoring in WHO regions and the world

- EEG
  - Africa: 80%
  - Americas: 68.9%
  - South-East Asia: 68.9%
  - Eastern Mediterranean: 80%
  - Europe: 80%
  - Western Pacific: 61.9%
  - World: 14.9%

- Video/EEG
  - Africa: 29.6%
  - Americas: 37%
  - South-East Asia: 37%
  - Eastern Mediterranean: 31.8%
  - Europe: 31.8%
  - Western Pacific: 18.6%
  - World: 150%

6.4 Neuropsychological services in different income groups

- Low: 188.6%
- Lower middle: 188.6%
- Higher middle: 80%
- High: 37%

- Free of charge: 6.4%
Introduction

• The respondents were asked to list the five main tasks of primary care workers involved in epilepsy care in the country. Ignoring the order of the individual responses, the proportion of countries that mentioned each task was calculated globally and for each of the regions.

Salient findings

• Follow-up and monitoring of treatment is reported among the five main tasks of primary health workers involved in epilepsy care by 74% of the responding countries. This task includes monitoring of AED compliance and adverse effects.

• Maintenance or prescription of AEDs is mentioned among the five main tasks by 54.8% of the responding countries.

• Information and education of the patients and caregivers regarding epilepsy is described among the five main tasks of primary health workers by 50.7% of the responding countries. A few respondents also mentioned counselling regarding driving, social issues, pregnancy, school education for children with epilepsy, medico–legal advice, and training in basic first-aid and seizure prevention among the five main tasks of primary health workers involved in epilepsy care.

• Case-finding is reported among the five main tasks of primary health workers by 43.8% of the responding countries.

• Referral of patients with epilepsy for confirmation of diagnosis, initiation of treatment, specialized investigations or specialist treatment for uncontrolled cases are also identified among the five main tasks of primary care workers by 46.6% of the responding countries.

• Psychosocial support and community rehabilitation (24% of the responding countries) and liaison with specialists and other services (13.7%) are also reported among the five main tasks of primary health workers involved in epilepsy care.

• Other tasks are also reported and include emergency treatment (10.3% of the respondents), initiation of treatment (9.6%) and maintenance of records (2.1%).

• Information and education of patients and caregivers regarding epilepsy is mentioned as one of the five main tasks by 69.1% of low-income countries compared with 37.5% of high-income countries.

Limitations

• The information is based on the experience and impression of a key person in a country working in the area of epilepsy and not on actual data from responding countries.

• The data report assessments by health professionals of the tasks performed by the primary care workers; it is possible that these may differ from the views of the primary care workers themselves.

• Information on the quality of services and their availability within each country was not obtained.

• Because the information was not obtained in a structured format, it might also underestimate some of the tasks performed by the primary care workers.

Conclusions

• Lack of access has been identified as a major barrier to adequate treatment in both high-income and low-income countries. Adequate training of the health workers providing first level of contact in case detection, initiation of treatment with AEDs (where local guidelines permit), follow-up and monitoring for compliance and adverse effects might be the most cost-effective way to decrease the treatment gap in the majority of countries.

• Primary health workers are the most appropriate choice for providing information and education to the patients, caregivers and the community as a whole about the disorder, the drugs and their side-effects, and the implications and social issues involved. This role needs to be encouraged.

• Health service reforms are ongoing in many countries, which provides the policy-makers and planners with an opportunity to include adequate epilepsy care among the tasks of primary health workers.

• Community-based rehabilitation needs to be advocated for better integration and improved psychosocial functioning of the patient with epilepsy.

• Better liaison and referral network services between primary and secondary care are required to ensure the best possible care for the patient with epilepsy.
Main tasks of primary care workers involved in epilepsy care reported by countries (%).

N=146

Follow-up and monitoring: 74%
Maintenance of drugs: 54.8%
Information and education: 46.6%
Referral: 24%
Case-finding: 14.8%
Liason: 13.7%
Support and rehabilitation: 10.3%
Emergency treatment: 9.6%
Initiation of treatment: 2.1%
Maintenance of records: 0.7%

Lower middle income:
- Follow-up and monitoring: 69.6%
- Maintenance of drugs: 43.5%
- Information and education: 41.3%
- Referral: 43.5%
- Case-finding: 52.2%

High income:
- Follow-up and monitoring: 75%
- Maintenance of drugs: 53.1%
- Information and education: 37.5%
- Referral: 56.3%
- Case-finding: 43.8%

Higher middle income:
- Follow-up and monitoring: 78.3%
- Maintenance of drugs: 60.9%
- Information and education: 43.5%
- Referral: 47.8%
- Case-finding: 43.5%
PROVISION OF CARE

Dr Patrick Kwan & Prof Martin J. Brodie

Introduction
The primary focus of care for patients with epilepsy is the prevention of further seizures which may lead to additional morbidity or even mortality (53). The goal of treatment should be the maintenance of a normal lifestyle, ideally by complete seizure control without or with minimal side-effects so that the patient’s functional capacity is restored to his or her maximal potential. If the seizures are provoked by external factors, for instance sleep deprivation or excessive alcohol, simple avoidance might be sufficient to prevent further attacks. For the majority of patients, however, AED therapy is the mainstay of treatment. Non-pharmacological strategies are primarily reserved for drug-resistant epilepsy. In addition to seizure control, patients with epilepsy have a range of psychosocial needs that may require attention. Despite the shared concerns of patients and doctors, the quality of care and therapeutic outcome may differ across countries because of variations in medical systems. The Commission of European Affairs of ILAE has defined standards for appropriate care (54), which have not yet been met by many European countries (55). The situation in many developing countries is likely to be even less satisfactory.

Pharmacological treatment
Modern pharmacotherapy of epilepsy was heralded by the serendipitous discovery of the anticonvulsant properties of phenobarbital in 1912 by Alfred Hauptmann. Despite the development of successive generations of AEDs, phenobarbital has retained a unique position in the therapeutic armamentarium and is still the most widely prescribed treatment worldwide. Its advantages include reliability of supply, affordable cost, broad spectrum of action and ease of use (56). The drug also has disadvantages such as sedation, behavioural side-effects, enzyme induction and possible teratogenesis.

Another significant milestone in AED development was the introduction of phenytoin, the first non-sedating AED, in the 1930s as a result of systematic screening of compounds using novel animal models. A number of other AEDs have become available in the ensuing years, including carbamazepine, ethosuximide, primidone, valproic acid and some benzodiazepines. These agents are generally regarded as “old” or “established” AEDs. After a hiatus of nearly 20 years, there has been accelerated development of newer AEDs, with 10 compounds having been licensed globally since the late 1980s. These are in chronological order, vigabatrin, zonisamide, oxcarbazepine, lamotrigin, felbamate, gabapentin, topiramate, tiagabine, levetiracetam and pregabaline. Although none of the modern AEDs has demonstrated superior efficacy to the established agents, they may be the preferred option for some patients as they are generally better tolerated and produce fewer drug inter-actions. Whether their substantially higher cost is justified in the majority of people with epilepsy is open to debate.

AEDs differ in many important aspects including their efficacy against different seizure types (i.e. absence, myoclonus, partial, tonic–clonic, and atonic), their side-effect profiles (i.e. neurotoxicity, idiosyncratic reactions, long-term complications, and teratogenicity), their potential for pharmacokinetic interactions (i.e. enzyme induction, and inhibition), and their ease of use (i.e. titration and daily dosing). An AED should be selected to “match” the characteristics of the patient, such as his or her epilepsy syndrome, age, gender, co-existing illnesses and concomitant medication (57). When monotherapy has failed, there are insufficient data to guide the physician on how best to combine AEDs. Combinations with low risk of pharmacokinetic interactions should be preferred, and there is some evidence that the success of duotherapy can be improved by paying attention to mechanisms of action and using lower dosages (58).

Patients newly diagnosed with epilepsy should be started on a single AED, which will be effective in controlling their seizures in approximately 60% (47). Treatment may be safely withdrawn in some patients who have entered remission, particularly in children (59). There is still no consensus about the duration of remission before AED withdrawal should start. In children a period of six months has been advocated and in adults a period of at least two years. When two successive AEDs given as monotherapy have failed, most authorities would recommend combination therapy. Outcome studies suggest that after failure of two or three treatment schedules, the chance of subsequent remission with further drug manipulation is small. Between 30% and 40% of patients will continue to have seizures despite “optimal” AED therapy (48). These individuals with refractory epilepsy should be assessed for suitability of non-pharmacological management strategies, such as surgery, vagus nerve stimulation (VNS), or ketogenic diet.

Non-pharmacological treatment
Epilepsy surgery is discussed separately in Section 14. Another form of non-pharmacological treatment for medically intractable epilepsy is VNS. The vagus nerve stimulator consists of a programmable signal generator implanted under the skin in the patient’s left upper chest. Powered by a battery, the system delivers intermittent electrical stimulation to the left vagus nerve in the neck via a connecting lead. VNS has demonstrated efficacy against partial onset and generalized seizures, although few patients have become seizure free (60). It is generally well tolerated, and implantation is not technically demanding.

The ketogenic diet is a high-fat, low-protein, and very low-carbohydrate diet used mostly in children with medically intractable epilepsy (61). It can be very effective in patients
who have failed numerous drug trials. The major problem in its use is adherence to the restrictive dietary regime. Close collaboration between the patient and family, paediatrician and dietician is essential for its successful implementation.

Psychosocial needs

Attending to the psychosocial, cognitive, educational and vocational aspects is an important part of caring for people with epilepsy. The implications of the diagnosis and the treatment rationale should be discussed with the patient and family to dispel any misconceptions and to ensure good adherence to medication. Support should be offered if lack of knowledge in society or stigma is an impediment for the use of the patient's full capacity and provokes job discrimination. Patients should be advised to refrain from activities that may precipitate the occurrence of seizures, e.g. sleep deprivation, excessive alcohol intake and illicit drug use. Counselling should be provided to women of childbearing potential about the effects of their epilepsy and its treatment on fertility, contraception and pregnancy. Clinicians should make their patients with epilepsy familiar with the laws regulating driving in their country.

Availability of treatment

There is wide disparity in the availability of treatment modalities in different parts of the world. The reasons for these inequalities are complex and multifactorial. They may include both "hardware" factors (e.g. availability of technologies and a reliable drug supply) and "software" factors (e.g. availability of expertise and access to health care), which are often dictated by economic constraints. The treatment gap in developing countries is discussed separately in Section 12. EEG and brain imaging, which are considered essential for accurate classification of seizure types and epilepsy syndromes, are not available to the majority of patients living in developing countries. Phenobarbital carries the lowest cost among the AEDs and can be reliably supplied to rural areas. Phenytoin, carbamazepine and valproic acid can also be accessed in most countries. The newer agents are mostly neither affordable nor available for the majority of patients. Because of the high level of expertise required in selecting suitable candidates, epilepsy surgery, VNS and ketogenic diet are also largely out of reach for many people in the developing world.

Delivery of care

Where resources are available, the care of epilepsy patients should be provided by a multidisciplinary team. The primary care physician is responsible for initial evaluation of all patients presenting with a suspected seizure and for subsequent follow-up. A specialist consultation is generally required to make the definitive diagnosis, to classify seizures and syndromes, and to formulate a management plan. An epilepsy nurse specialist may be the best person to offer counselling and health education. If the epilepsy is not controlled with the first two or three AED regimens, patients should be referred to a specialist centre for assessment of their suitability for alternative treatment modalities, such as epilepsy surgery (62).

Where medical manpower and sophisticated investigations are more limited, treatment delivery models tailored to local needs have been successfully implemented (63, 64). These programmes usually involve supervision by medically qualified personnel, health workers or paramedics and key informants or village authorities. The latter play a particularly important role in case identification and in patient education. The effectiveness of AEDs when used in this setting in a developing country is similar to that obtained in developed countries, even though many patients in developing countries may have a longer history of untreated epilepsy.

Conclusion

Epilepsy is a controllable disorder in the majority of affected individuals. Approximately 60–70% of patients will become seizure free with AED therapy. Treatment needs not be expensive. It has been estimated that the direct drug cost of treating a patient for a year with phenobarbital could be as low as US$ 2.60 (56). Recent expansion in the pharmacological armamentarium has been welcomed. Results from long-term outcome studies have aided the formulation of a more rational framework to identify drug-resistant epilepsy early so that other effective therapies, such as surgery, can be offered without unnecessary delay (65). Through more appropriate and timely utilization of these treatment modalities and better organization in the delivery of care, it is hoped that more people with epilepsy around the world can benefit from effective treatment and live safer and more fulfilling lives.
Introduction

◆ The respondents were questioned regarding the number of hospital beds for epilepsy care (for short-term use or residential long-term care) in the country.

Salient findings

◆ No inpatient facility for epilepsy care exists in 45.7% of the responding countries (N=92). A total of 19,265 hospital beds for epilepsy care are reported to be available in 50 countries. One third of these are reported for short-term epilepsy care while the rest are for residential long-term care.

◆ The median number of hospital beds for epilepsy care in these countries is 0.88 per 100,000 population (interquartile range 0.21–2.82). Of these, 53.1% have access to less than one hospital bed for epilepsy care per 100,000 population.

◆ The median number of hospital beds for epilepsy care per 100,000 population varies widely across regions: 0.05 in South-East Asia, 0.46 in the Western Pacific, 0.55 in Africa, 0.68 in the Americas, 0.83 in the Eastern Mediterranean, and 1.65 in Europe.

◆ The median number of hospital beds for epilepsy care per 100,000 population across different income groups of countries also varies: 0.18 for low-income countries compared with 1.46 for high-income countries. Almost half of the high-income countries also have less than one hospital bed for epilepsy care per 100,000 population.

◆ Many people with comorbid epilepsy are admitted to other special facilities, e.g. to cancer or stroke units. These facilities also provide inpatient care for people with epilepsy.

◆ There is also a significant proportion of people with multiple disabilities who are provided care under mental handicap services. These are not included in the above data.

Limitations

◆ In many countries beds are not earmarked for patients with epilepsy. Beds occupied by people with epilepsy are part of the pool for neurology, neuropsychiatry, internal medicine, geriatrics, paediatrics or general beds, so they may not have been reported.

◆ In many countries, patients with status epilepticus are managed on beds allocated to internal medicine, emergency services or intensive care units, so these may not have been reported.

◆ Many people with comorbid epilepsy are admitted to other special facilities, e.g. to cancer or stroke units. These facilities also provide inpatient care for people with epilepsy.

Conclusions

◆ Designated beds may be considered to be an indicator of the level of organization of epilepsy services in a country.

◆ In countries with well-developed epilepsy services at primary care level, development of epilepsy centres is advocated for providing comprehensive care. Improvement of inpatient facilities is one of the important components of these centres.

◆ Although hospitalization accounts for a small proportion of the total medical and public health impact of epilepsy, it represents a major direct cost for people with epilepsy. Some of the hospitalizations attributable to epilepsy are preventable with effective outpatient management focusing on proper diagnosis, treatment and patient compliance. Patients with refractory epilepsy, those experiencing difficulties in compliance, or those with adverse effects of antiepileptic medication need to be referred to epilepsy centres.

◆ Separate hospital beds for epilepsy management may not be desirable in many countries where the priority is still to provide appropriate epilepsy treatment through the primary care level. However, a special facility for providing referral services as a part of a general health-care service is necessary for the comprehensive management of epilepsy.
Median number of hospital beds for epilepsy care per 100 000 population in WHO regions and the world

N=50

0.18 0.49 1.46
Low Lower middle Higher middle High

Number of medical hospital beds for epilepsy care in WHO region

America
2 832 (N=12)

Europe
13 894 (N=17)

Africa
831 (N=6)

Eastern Mediterranean
665 (N=5)

South-East Asia
70 (N=2)

WHO 05.81

Western Pacific
968 (N=8)
Introduction

The respondents were asked to specify the five main services provided by epilepsy specialists in the country. Ignoring the order of the individual responses, the proportion of countries that mentioned each task was calculated globally and for each of the regions.

Salient findings

- Epilepsy specialists are reported to be available in 70.3% of the responding countries. The Western Pacific and Africa have epilepsy specialists in 43.5% and 57.1% of the responding countries, respectively, whereas 77.8% of countries in South-East Asia, 87% in the Americas, and 88.9% in Europe have epilepsy specialists.

- While epilepsy specialists provide care to people with epilepsy in 88.6% of high-income countries, they exist in only 55.6% of low-income countries.

- The main services provided by epilepsy specialists include patient care (diagnosis and documentation of cases of epilepsy and investigations such as EEG and video-monitoring) in 76.6% of the countries, treatment and follow-up services in 69.2%, raising awareness (education and counselling of people with epilepsy, their families and the general public) in 54.2%, and providing consultation services for referred patients in 29%.

- The other services provided by epilepsy specialists as reported by the respondents include rehabilitation and psychosocial support (29%), surgical therapy (24.3%), training and teaching of health professionals (22.4%), and performing and promoting research about basic and clinical aspects of epilepsy (19.6%).

- Of the responding countries, 45% and 26.3% in the Americas and Europe, respectively, mentioned providing surgical therapy among the main services of epilepsy specialists compared with 5.3% in Africa.

- Services provided by epilepsy specialists vary also among income groups of countries in relation to provision of surgical therapy. Of the low-income countries, 4% mention provision of surgery as a task of epilepsy specialists compared with 37.9% of high-income countries.

Limitations

- Because the sources of information were the national epilepsy organizations, the data pertain to countries where these exist. It is therefore possible that the above figures are overestimated.

- As no information was collected regarding the total number of epilepsy specialists in the country, affirmative responses may have been provided even if only a few such specialists exist. No information was obtained on the quality of services and their availability in each country.

- The data do not reflect the tools available to the specialists to carry out the above-mentioned services.

- No information was obtained regarding the basic field of training, e.g. neurology, neurosurgery or nursing.

- Because the information was not obtained in a structured format, the tasks performed by the epilepsy specialists might be underestimated.

Conclusions

- Epilepsy specialists from various disciplines provide comprehensive care to people with epilepsy, working as members of a multidisciplinary team.

- Epilepsy specialists also play an important role in awareness raising, advocacy, and education of professionals, people with epilepsy and the general public. These aspects are pertinent for a disorder such as epilepsy, where sociocultural issues are a major barrier to adequate treatment and rehabilitation.

- Efforts need to be made to develop specialization in epilepsy.
10.1 Presence of epilepsy specialists in the world
N=155

10.2 Countries with epilepsy specialists in WHO regions and the world
N=155

10.3 Countries with epilepsy specialists in different income groups of countries
N=152

10.4 Services provided by epilepsy specialists
Reported by countries (%)
N=107

- Diagnosis and investigation: 100%
- Treatment and follow-up: 100%
- Consultation: 100%
- Rehabilitation: 100%
- Surgical services: 100%
- Training of health professionals: 100%
- Research: 100%
- Advocacy: 100%