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Organization



**Global Campaign Against Epilepsy**

# *Atlas*

**EPILEPSY CARE  
IN THE WORLD  
2005**

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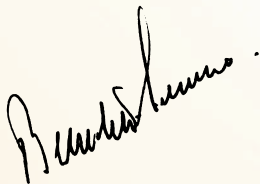
Epilepsy is one of the most common serious disorders of the brain, affecting about 50 million people worldwide. Epilepsy accounts for 1% of the global burden of disease; 80% of the burden of epilepsy is in the developing world, where in some areas 80–90% of people with epilepsy receive no treatment at all. It is imperative to recognize that epilepsy consists of more than seizures for the affected individual and immediate effects on his or her family. Epilepsy leads to multiple interacting medical, psychological, economic and social repercussions, all of which need to be considered in order to understand fully the impact of this condition. Fear, misunderstanding and the resulting social stigma and discrimination surrounding epilepsy often force people with this disorder “into the shadows”.

The World Health Organization (WHO) is responsible for providing technical information and advice to its Member States to help them to improve the health of their citizens. This task is facilitated by collaboration with various scientific and professional groups that have similar goals. To bring epilepsy “out of the shadows”, a Global Campaign Against Epilepsy was launched in 1997 “to improve acceptability, treatment, services and prevention of epilepsy worldwide”. The Campaign is conducted by WHO in partnership with the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). The aim of the Campaign is principally to reduce the treatment gap by providing better information about epilepsy and its consequences and to assist governments and those concerned with epilepsy to reduce the burden of the disorder. To gather information about the resources available for epilepsy care

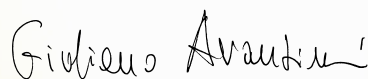
in countries, the *Atlas: Epilepsy Care in the World* was initiated. This Atlas represents a unique collaborative effort between WHO and the two leading nongovernmental organizations working in the field of epilepsy.

The results obtained from the study of country resources for epilepsy confirm that the available resources for epilepsy care in the world are insufficient when set against the large numbers of people needing such care and the known substantial burden associated with this disorder. In addition, there are large inequities across regions and income groups of countries, with low-income countries having extremely meagre resources. Since the prevalence of epilepsy is much higher and resources are much scarcer in low-income countries, the data reinforce the need for urgent, substantial and systematic action to enhance resources for epilepsy care in these countries.

It is hoped that the availability of essential information will lead to greater awareness among policy-makers of the gaps in resources for epilepsy care. The information is likely to assist health planners and policy-makers to identify areas that need urgent attention and to plan the upgrading of resources in those areas. The data will also serve as a baseline for monitoring the improvement in availability of resources for epilepsy care. We hope that personnel involved in caring for people with epilepsy, including health professionals and nongovernmental organizations, will use the Atlas data in their efforts to ensure more and better resources for epilepsy care.



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The *Atlas: Epilepsy Care in the World* is one of the most important projects within the framework of the ILAE/IBE/WHO Global Campaign Against Epilepsy (GCAE) "Out of the Shadows", representing a major collaborative effort involving WHO headquarters, regional and country offices and ILAE and IBE headquarters and their members.

The work was supervised and coordinated by Dr Leonid Prilipko and Dr Shekhar Saxena at WHO headquarters and Mrs Hanneke de Boer, Co-Chair, GCAE Secretariat. Dr Benedetto Saraceno provided vision and guidance to the project and Dr Giuliano Avanzini and Mr Philip Lee provided their continuous support to the Campaign. Dr Tarun Dua was responsible for completion of the data collection, data analyses and overall project management and for most of the writing of this report. Dr Harry Meinardi and Dr Gus Baker provided technical guidance and supervision. Dr Jerome Engel Jr, Dr Aleksandar Janca, Mr Philip Lee and Dr Harry Meinardi were involved in the development of the survey design and questionnaire. Ms Kathy Fontanilla was involved in the data management.

Collaborators from WHO regional offices include: Dr Custodia Mandlhate and Dr Therèse Agossou, African Regional Office; Dr Claudio Miranda and Dr Jose Miguel Caldas de Almeida, Regional Office for the Americas; Dr Vijay Chandra, South-East Asia Regional Office; Dr Wolfgang Rutz and Dr Matthijs Muijen, European Regional Office; Dr Ahmed Mohit and Dr R. Srinivasa Murthy, Eastern Mediterranean Regional Office; and Dr Helen Hermann and Dr Xiangdong Wang, Western Pacific Regional Office, all of whom made valuable contributions during the development of the project, the identification of key persons in the area of epilepsy in Member States, and the review of the results.

The information from various countries, areas or territories was provided by key persons working in the field of epilepsy identified by ILAE, IBE, WHO regional offices and the offices of WHO Representatives. Key collaborators who helped in the identification of key persons in the area of epilepsy in some of the countries include Dr Carlos Acevedo, Dr Amadou Gallo Diop, Dr Peter Halasz, Dr Shi Chuo Li and Dr Susan Spencer. The survey respondents

handled the many requests for clarification arising from the data. A list of their names is included at the end of the Atlas.

Various specialists contributed brief reviews of selected areas in relation to epilepsy, as follows. Dr Edward H. Reynolds: milestones in the history of epilepsy; Dr Nadir E. Bharucha: epidemiology; Dr Josemir W. Sander: aetiology and risk factors; Dr Patrick Kwan and Dr Martin J. Brodie: provision of care; Dr Amadou Gallo Diop: the treatment gap; Dr Jerome Engel Jr: epilepsy surgery; Dr Peter Wolf: education in epileptology; Dr Giuliano Avanzini: role of ILEA in fostering epilepsy care; Mr Philip Lee: role of IBE in providing epilepsy care; Mrs Kathryn Pahl and Mrs Hanneke de Boer: epilepsy and rights; Ms Dee Snape, Dr Ann Jacoby and Dr Gus A. Baker: stigma and social issues; Dr Dan Chisholm: the attributable and avertable burden of epilepsy; Mrs Hanneke de Boer, Dr Jerome Engel Jr and Dr Leonid Prilipko: Global Campaign Against Epilepsy.

An international group of leading experts in the field of epilepsy reviewed the project report and provided comments. They include: Dr Carlos Acevedo, Dr Hasan Aziz, Dr Charles Begley, Dr Sam Berkovic, Dr Nadir Bharucha, Dr Zenebe Gedlie Damtie, Dr Saleh M. Al Deeb, Dr Amadou Gallo Diop, Dr John Duncan, Dr Jerome Engel Jr, Dr Peter Halasz, Dr Shichuo Li, Dr Emilio Perucca, Dr Josemir W. Sander, Dr Masakazu Seino, Dr Nimal Senanayake and Dr Torbjörn Tomson.

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Mrs Caroline Morton helped in the data collection. Administrative support was provided by Ms Kathy Fontanilla and Ms Rosa Seminario.

The contribution of all of the above, along with input from many other unnamed people, has been vital to the success of this project.

Assistance in preparing the Atlas for publication was received from Tushita Bosonet (graphic design), Steve Ewart (maps) and Barbara Campanini (editing).

There is considerable evidence that the global burden of mental and neurological disorders is massive and is increasing. At the same time, little is known about the resources available to meet this burden: information is scarce in the vast majority of countries, while the information that is available is not comparable across different countries or over time. Accurate and up-to-date information is required on the available resources for these disorders and their distribution in various regions of the world.

In order to try and fill this knowledge gap, the World Health Organization (WHO) launched Project Atlas. The objectives of the project include collection, compilation and dissemination of relevant information about resources for mental and neurological conditions in countries. The first document in this series was published in 2001 as the Atlas of mental health resources in the world, followed by the Atlas of country resources for neurological disorders in 2004. Among other findings, epilepsy was confirmed as one of the major brain disorders worldwide. Epilepsy presents a global problem affecting all ages, social classes, groups and countries. It imposes enormous physical, psychological, social and economic burdens on individuals, families and countries. Many people with epilepsy suffer in silence, afraid to be found out. These problems are universal but cause the most serious impact in the developing world. This is most unfortunate since epilepsy provides the clearest example of a neurological disorder for which effective and cost-efficient treatment is available, and some 70% of people with epilepsy could lead normal lives if properly diagnosed and treated.

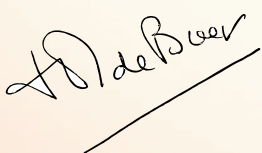
In order to map the resources available for epilepsy care, WHO decided to produce an Atlas on country resources for epilepsy, within the framework of the Global Campaign Against Epilepsy. The Global Campaign Against Epilepsy

– whose theme is “Out of the Shadows” – is a partnership of the International League Against Epilepsy (ILAE), with member organizations in more than 90 countries, the International Bureau for Epilepsy (IBE), with over 80 full members and 30 associate members, and WHO, a specialized agency of the United Nations with 192 Member States. ILAE member organizations consist of professionals concerned with medical and scientific aspects of epilepsy, while those of IBE are concerned with social aspects and the quality of life of people with epilepsy.

To gather information for this Atlas, a questionnaire was developed by a number of experts, covering the profile of epilepsy resources available in countries. The work started in 2002 and data have been collected from 160 countries, spanning all WHO regions and covering 97.5% of the world population, making this a global exercise. We are not aware of any other exercise in the field of epilepsy that can compare with the present one for its coverage and comprehensive nature.

The data confirm what professionals in the field of epilepsy have known for a long time, that epilepsy care is grossly inadequate compared with the needs in most countries: “when it comes to epilepsy care, most countries are developing countries”. The value of the Atlas is that it replaces impressions and opinions by facts and figures. In following uniform definitions and units, it allows for comparisons to be made across countries and regions.

We hope that the realities uncovered by the Atlas will motivate governments and health-care providers to improve epilepsy care. The picture is clear and the goal is within reach: to bring epilepsy out of the shadows.



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Epilepsy is one of the most common serious disorders of the brain, affecting about 50 million people worldwide. Epilepsy accounts for 1% of the global burden of disease; 80% of the burden of epilepsy is in the developing world, where in some areas 80–90% of people with epilepsy receive no treatment at all. Not much information exists regarding the resources available within countries to tackle the huge medical, social and economic burden caused by epilepsy. In order to fill this gap, information regarding country resources for epilepsy services and care was collected under the Global Campaign Against Epilepsy (GCAE) “Out of the Shadows”. The study represents a major collaborative effort involving World Health Organization (WHO) headquarters, regional and country offices, the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). This work was undertaken under WHO’s Project Atlas, ongoing since 2000.

The *Atlas: Epilepsy Care in the World* (the Epilepsy Atlas) provides an illustrative presentation of data and information on the current status of epilepsy services and care available from 160 countries, areas or territories covering 97.5% of the world population. The information is primarily gathered from key persons in the area of epilepsy care in each country identified by ILAE/IBE and, in some cases, by WHO regional offices. It is one of the most comprehensive compilations of available resources for epilepsy ever attempted. Limitations are to be kept in mind, however, when interpreting the data and their analyses. The key persons were among the most knowledgeable persons in their countries, but the possibility remains of the data being incomplete and in certain areas even inaccurate. The draft report was reviewed by leading experts in the field of epilepsy and regional advisers of the six WHO regions, and their comments were incorporated. The Epilepsy Atlas also includes brief reviews of selected topics summarizing the medical, lifestyle, social and economic issues surrounding people with epilepsy.

The analyses of the reported aetiology of epilepsy show that trauma, central nervous system infections, antenatal and perinatal risk factors, cerebrovascular disorders, and idiopathic aetiology are among the most frequently reported globally, as well as in all WHO regions. The information regarding the aetiology of epilepsy has implications for making decisions about the development of locally relevant strategies for prevention and management, research goals, and education of primary health-care workers and community physicians. The top four most frequently reported causes of epilepsy are in fact preventable. Concerted multidisciplinary efforts concentrating on the risk factors (e.g. enforcement of strict traffic regulations, and improvement in perinatal care) or providing specific protection (e.g. vaccination) for these preventable causes can help to decrease substantially the burden attributable to epilepsy.

For appropriate management of people with epilepsy, diagnostic services constitute an important resource. Computer-

ized axial tomography (CAT), magnetic resonance imaging (MRI), electroencephalography (EEG) and long-term video/EEG monitoring are available to health professionals in 85%, 69%, 87% and 50% of the responding countries, respectively. Therapeutic drug monitoring and neuropsychological services are available in 75% and 64% of the responding countries, respectively. These figures do not indicate, however, how many people who need the services can, in fact, make use of them, nor how appropriately the services are used. There is inequity in availability of diagnostic services across different income groups: e.g. neuropsychological services are available in 37% of low-income countries compared with 89% of high-income countries. Most new technologies are available in many countries, but they are often concentrated in only a few centres or in major cities. The aim should be to improve their coverage in order to serve the entire population.

The most cost-effective way to decrease the treatment gap in the majority of countries would be to deliver the epilepsy services through primary health care. The main tasks of the personnel in primary care settings involved in epilepsy care as reported by countries include follow-up and monitoring of treatment, maintenance and/or prescription of antiepileptic drugs, information and education of the patients and caregivers, referral of patients with epilepsy for specialist treatment, and case-finding. Interestingly, information and education of patients and caregivers regarding epilepsy was mentioned as one of the five main tasks by 69% of the low-income countries compared with 38% of the high-income countries.

Separate hospital beds for epilepsy management may not be desirable in many countries where the priority is still to provide appropriate epilepsy treatment at the primary care level. However, a special facility for providing referral services as a part of a general health service is necessary for the comprehensive management of epilepsy. Referral services are also an important indicator of the level of organization of epilepsy services in a country. No inpatient facility for epilepsy care exists in 46% of the responding countries. A total of 19 265 hospital beds for epilepsy care are reported to be available in 50 countries. Of the total number of beds, one third is reported to be for short-term epilepsy care while the rest are for residential long-term care.

Data regarding the inclusion of first-line antiepileptic drugs in the country’s list of essential drugs show that phenobarbital is included in 95% of the responding countries, carbamazepine in 93%, phenytoin in 86%, and valproic acid in 87%. A government policy regarding their availability only by prescription (either from a general practitioner or a specialist) exists in more than 90% of the countries. The median cost of the daily defined dose (DDD) of these in international dollars varies. While worldwide the median cost of phenobarbital is 0.14 international dollars, it is threefold for phenytoin, elevenfold for carbamazepine and 16 times more for valproic acid. In international dollars the median cost of treatment for epilepsy is three and half times higher for carbamazepine, phenytoin



and valproic acid and two times higher for phenobarbital in low-income countries compared with high-income countries. The inequity in the cost of first-line antiepileptic drugs across regions, countries and income categories needs to be specifically confronted.

The presence of sub-specialized epilepsy services indicates the level of organization and development of epilepsy care in a country. Sub-specialized services are important, because many people with epilepsy require highly specialized skills for appropriate diagnosis and management. Such services also provide the basis for conducting research and training. The respondents reported availability of special education in 62% of the responding countries, social rehabilitation in 57%, epilepsy surgery in 41%, and sheltered work in 26%. There is large variation in their availability across different income groups of countries: e.g. epilepsy surgery is available in only 13% of low-income countries compared with 66% of high-income countries.

Specialist medical professionals are important members of the team providing comprehensive care, especially at tertiary level, for people with epilepsy. They are also essential for training and providing support and supervision to primary health-care providers in epilepsy care. The respondents were asked about the number of specialist medical professionals such as neurologists, neuropaediatricians, psychiatrists and neurosurgeons spending 50% or more of their time in providing epilepsy care. This assessment is used as a marker of their predominant involvement in providing epilepsy care. A total of 32 668 neurologists, neuropaediatricians, psychiatrists and neurosurgeons are reported to be involved predominantly in providing epilepsy care in the responding countries (108, 87, 80 and 75 countries reported neurologists, neuropaediatricians, psychiatrists and neurosurgeons, respectively). The median numbers per 100 000 population of neurologists, neuropaediatricians, psychiatrists and neurosurgeons in the countries that report their presence are 0.18, 0.08, 0.10 and 0.04, respectively. The percentage of specialist medical professionals involved predominantly in epilepsy care varies across regions and income groups of countries: e.g. 100% of the total neurologists are involved predominantly in providing epilepsy care in low-income countries compared with 7% in high-income countries. More psychiatrists are involved predominantly in epilepsy care in low-income countries compared with high-income countries (median per 100 000 population: 0.09 and 0.03, respectively). One of the possible reasons for this could be the presence of the practice where psychiatrists rather than neurologists take care of people with epilepsy.

Professionals allied to medicine, such as neurological nurses, psychologists and social workers, are important members of the multidisciplinary team providing comprehensive care to people with epilepsy. They play an important role in the diagnosis, treatment, and rehabilitation of people with epilepsy. A total number of 19 732 such professionals involved

in epilepsy care exist in the responding countries (52, 67 and 62 countries reported neurological nurses, psychologists and social workers, respectively). The median numbers per 100 000 population of neurological nurses, psychologists and social workers in the countries that report their presence are 0.11, 0.05 and 0.07, respectively. Low-income countries have a median number of 0.04 per 100 000 population of social workers involved predominantly in epilepsy care, whereas higher-middle and high-income countries have 0.19 and 0.07 per 100 000 population, respectively. The percentage of professionals allied to medicine involved predominantly in epilepsy care is low: e.g. only 5% of the total numbers of psychologists are involved predominantly in providing epilepsy care.

Epilepsy specialists are professionals in the health sector devoted predominantly to providing epilepsy care. They 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. Epilepsy specialists are reported to be available in 70% of the responding countries. While they provide care to people with epilepsy in 89% of high-income countries, they exist in only 56% of low-income countries. The main services provided by epilepsy specialists include patient care by diagnosing and documenting cases of epilepsy and carrying out investigations such as EEG and video/EEG monitoring (in 77% of the countries), providing treatment and follow-up services (69%), providing consultation services for referred patients (29%), and education services and counselling to people with epilepsy and the general public, thus raising awareness (54%).

Specialist training in epileptology is needed on multiple levels to reach all those concerned with epilepsy management. Training facilities in epileptology are, however, available in only 16% of the responding countries. No facility for training in epileptology is reported by countries in the South-East Asia Region, whereas such facilities exist in 3% of the countries in Africa, 7% in the Eastern Mediterranean, 17% in the Western Pacific, 21% in the Americas and 32% in Europe. Educational materials, including standard guidelines for diagnosis and care of people with epilepsy, ought to be produced and distributed in resource-poor countries where training facilities cannot be established because of the high costs involved. Opportunities for the training of professionals involved in epilepsy care from low-income countries should also be encouraged.

The presence of professional organizations of epilepsy specialists is an important aspect of the provision of the highest quality of care and well-being for people with epilepsy or other related seizure disorders. A professional organization of epilepsy specialists exists in 61% of the responding countries; such an organization does not exist in 64% of the low-income countries or in 23% of the high-income countries. The median number of professionals per 100 000

population who are members of an organization of epilepsy specialists is 0.17 in Africa compared with 2.15 in Europe. The professional organizations of epilepsy specialists are mainly involved in organizing professional meetings and conferences on epilepsy, publishing guidelines and recommendations on epilepsy, advocacy on epilepsy-related issues, and advising governments. A large number of these organizations work under the umbrella of ILAE, leading to a collaborative effort in various activities related to patient care, education, training and research.

The lay associations have a significant role in handling the non-medical aspects of epilepsy including education, employment, insurance, driving and awareness raising; these activities are crucial in providing epilepsy care. Many of the patient associations are members of IBE. Of the responding countries, 60% have at least one patient or lay association working in the field of epilepsy. No patient or lay epilepsy association exists in 60% of the responding countries in the Eastern Mediterranean, 53% in Africa, 44% in South-East Asia, 48% in the Western Pacific, 32% in the Americas, and 18% in Europe.

Adequate financing of epilepsy services is essential to providing the needed care. However, only 6% of the responding countries have a separate budget for epilepsy services within their health budgets. Out-of-pocket payment, tax-based funding and social insurance are the primary methods of financing epilepsy care, each method being used in about one third of the responding countries. Private insurance and private foundations constitute 2% and 1%, respectively, as the primary method of financing. Out-of-pocket expenses are the primary source of financing epilepsy care in Africa, South-East Asia and the Eastern Mediterranean, social insurance in Europe and the Americas, and tax-based funding in the Western Pacific. Out-of-pocket expenditure is the primary method of financing epilepsy care in 73% of low-income countries compared with 4% of high-income countries. Epilepsy services are scarce in low-income countries and on top of that patients have to pay, resulting in further inequity in the utilization of services. Efforts need to be made to introduce some form of public financing into the health infrastructure of countries to cover epilepsy services.

Disability benefits of some form for people with epilepsy are available in 47% of the responding countries. Disability benefits are available in only 15% of the low-income countries compared with 82% of high-income countries. The types of disability benefits available include monetary benefits, rehabilitation and health benefits, benefits at the workplace and other benefits including housing, transport, education and special discounts. Efforts need to be made to advocate better provision of benefits for functionally disabled people with epilepsy, especially in resource-poor countries where they are most needed.

An organized health reporting system is essential in assessing the situation so as to enable the health planners to decide

how to use various resources. Epilepsy is included in the annual health reporting system of 40% of the responding countries. Epidemiological data facilitate the gathering of information regarding the disease burden and trends and help to identify the high priority issues. This information is highly useful for planning health services and monitoring trends over time. A data collection system for epilepsy exists in 40% of the responding countries. Efforts need to be made to increase the number of countries collecting epilepsy data.

Many constraints and difficulties hinder the provision of adequate epilepsy care in countries. Qualitative data were also collected about the major problems encountered by health professionals and people with epilepsy. Lack of drug supply due either to logistics or to economy, poor community knowledge and awareness, cultural beliefs, stigma, lack of government resources, poor economy and lack of infrastructure are identified as major problems by both health professionals and people with epilepsy. Factors related to health services including capital and human resources are identified more commonly as major problems by health professionals than by people with epilepsy. Lack of social and rehabilitation support and the social burden of the disorder, however, are identified more commonly by people with epilepsy (79%) than by health professionals (24%). The social issues identified by respondents include employment, driving, marriage, social isolation, and education opportunities. The treatment gap for epilepsy thus has to be understood in terms of the economic, social, political and cultural frameworks within which it exists. All of these aspects need to be tackled to decrease the treatment gap. There were differences reported in the problems encountered among various regions or income categories. This may suggest the relative importance of a particular issue rather than its absolute importance: e.g. in low-income countries, availability of epilepsy surgery is considered desirable but not a primary asset that must be available. Also, the data represent the issues of highest priority that need immediate improvement.

On the whole, the Epilepsy Atlas data show that the available resources for epilepsy care in the world are insufficient when set against the large numbers of people needing such care and the known significant burden associated with this disorder. In addition, there are large inequities across regions and income groups of countries, with low-income countries having extremely meagre resources. Because the prevalence of epilepsy is much higher and resources are much lower in low-income countries, the Epilepsy Atlas reinforces the need for urgent, substantial and systematic action to enhance resources within these countries for epilepsy care.



The word *epilepsy* derives from the Greek *epilambanein*, meaning *to be seized, to be overwhelmed by surprise* (1). Epilepsy is one of the most common serious disorders of the brain, affecting at least 50 million people worldwide. It knows no geographical, racial or social boundaries. Epilepsy accounts for 1% of the global burden of disease, determined by the number of productive life years lost as a result of disability or premature death. Among primary disorders of the brain, this burden ranks with depression and other affective disorders, Alzheimer's disease and other dementias, and substance abuse. Among all medical conditions, it ranks with breast cancer in women and lung cancer in men. Eighty per cent of the burden of epilepsy is in the developing world, where 80–90% of people with epilepsy receive no treatment at all (2). It is also necessary to recognize that epilepsy consists of more than seizures for the affected individual and effects on his or her family. Epilepsy leads to multiple interacting medical, psychological, economic and social repercussions, all of which need to be considered.

Fear, misunderstanding and the resulting social stigma and discrimination surrounding epilepsy often force people with this disorder "into the shadows". The social effects may vary from country to country and culture to culture, but it is clear that all over the world the social consequences of epilepsy are often more difficult to overcome than the seizures themselves. Significant problems are often experienced by people with epilepsy in the areas of personal relationships and, sometimes, legislation. These problems may in turn undermine the treatment of epilepsy.

To bring epilepsy "out of the shadows", a Global Campaign Against Epilepsy was launched in 1997 "to improve acceptability, treatment, services and prevention of epilepsy worldwide". The Campaign is conducted by the World Health Organization (WHO) in partnership with the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). The aim of the Campaign is principally to reduce the treatment gap by providing better information about epilepsy and its consequences and to assist governments and those concerned with epilepsy to reduce the burden of the disorder (3).

Major advances in the understanding and treatment of epilepsy have occurred in the last century, and research has been carried out on the epidemiological, diagnostic and social aspects of the disorder. Not much information exists, however, regarding the resources available within the countries to tackle the huge medical, social and economic burden caused by epilepsy. The information that exists cannot be compared across countries because varying definitions and units of measurement are used. Lack of information about existing resources is a major impediment for the policy-makers at local, national and international level for planning appropriate services for epilepsy care. In order to

improve the availability of resources in the countries, accurate information about existing resources is crucial.

In order to fill the information gap about the resources available for care of patients with mental and neurological disorders, WHO launched Project Atlas in 2000 aimed at collecting, compiling and disseminating information and data on the existing resources and services. The first document in the series was published in 2001 as the Atlas of mental health resources in the world (4), followed by the Atlas of country resources for neurological disorders in 2004 (5). Because epilepsy care is one of the priority areas of WHO, to bridge the information gap in this area, it was decided to expand Project Atlas into the area of epilepsy and to conduct a survey of country resources available for epilepsy care. The main objectives of this large international study were to obtain expert opinion about:

- ◆ aetiology of epilepsy and problems encountered by people with epilepsy and health professionals involved in epilepsy care;
- ◆ availability of epilepsy treatments and services including antiepileptic drugs;
- ◆ number and types of health professionals involved in the delivery of epilepsy care;
- ◆ characteristics of training in epileptology;
- ◆ budget and financing for epilepsy care, including various types of health insurance and disability benefits;
- ◆ presence and characteristics of information and epidemiological data collection systems for epilepsy;
- ◆ availability, role and involvement of professional, patient and lay associations for epilepsy.

The Epilepsy Atlas has been an important activity of the Global Campaign Against Epilepsy. The study represents a major collaborative effort involving WHO headquarters, regional and country offices, ILAE and IBE. The Epilepsy Atlas provides an illustrative presentation of data and information on the current status of epilepsy services and care available in different parts of the world. It is hoped that the Epilepsy Atlas data will stimulate global and national epilepsy programmes. It will be a useful reference guide for health professionals, planners and policy-makers at national as well as international levels, helping them in planning, developing and providing better care and services for people with epilepsy throughout the world.



All the information and data contained in the Epilepsy Atlas have been collected in a large international survey which was carried out in the period 2002–2004 and included 160 countries, areas or territories.

## Data collection

The Epilepsy Atlas is based on the information and data collected by WHO in collaboration with ILAE and IBE within the framework of the Global Campaign Against Epilepsy. At WHO, the work was led by headquarters in close collaboration with the regional offices. The first step in the development of the Epilepsy Atlas was to identify specific areas where information related to resources and services for epilepsy care was lacking. In order to obtain this information, a questionnaire was drafted in English in consultation with a group of WHO and ILAE/IBE consultants. A glossary of terms used in the questionnaire was also prepared in order to ensure that the questions were understood in the same way by different respondents. Subsequently, the draft questionnaire and glossary were reviewed by selected experts. The questionnaire was piloted in one high-income and one low-income country and necessary changes were made. The questionnaire and the glossary were then translated into some of the other official languages of WHO – Arabic, French, Russian and Spanish.

The questionnaire and glossary were sent to the official delegates of all the Chapters of ILAE/IBE. In addition, WHO regional offices were also asked to identify a key person working in the field of epilepsy in those countries where the ILAE/IBE liaison person was not available or not responsive. The key persons were requested to complete the questionnaire based on all possible sources of information available to them. All respondents were asked to follow closely the glossary definitions, in order to maintain uniformity and comparability of received information. The Epilepsy Atlas project team responded to questions and requests for clarification. Repeat requests were sent to the key persons in cases where there was delay in procuring the completed questionnaire. In the case of incomplete or internally inconsistent information, the respondents were contacted to provide further information or clarification; where appropriate, documents were requested to support completed questionnaires.

Received data were entered into an electronic database system using suitable codes and analysed using Stata (special edition) version 8 software. Values for continuous variables were grouped into categories based on distribution. Frequency distributions and measures of central tendency (mean, medians and standard deviations) were calculated as appropriate. Countries were grouped into the six WHO regions (Africa, the Americas, South-East Asia, Europe, East-

ern Mediterranean, and Western Pacific) and four World Bank income categories according to 2003 gross national income (GNI) per capita according to the World Bank list of economies, April 2005 (6). The GNI groups were as follows: low-income (US\$ 765 or less), lower middle-income (US\$ 766–3035), upper middle-income (US\$ 3036–9385) and high-income (US\$ 9386 or more). The results of the analysis are presented in the Epilepsy Atlas.

## Representativeness of data collected

Completed questionnaires were received from various WHO Member States, areas or territories: 155 Member States (out of a total of 192), one Associate Member (Tokelau) and four territories, which are henceforth referred to as countries for the sake of convenience. From the Member States, data were available from 38 countries in the African Region (82.6%), 25 countries in the Region of the Americas (71.4%), 9 countries in the South-East Asia Region (81.8%), 45 countries in the European Region (86.5%), 15 countries in the Eastern Mediterranean Region (71.4%) and 23 countries in the Western Pacific Region (85.2%). In terms of population covered, the data pertain to 97.5% of the world population; 94.4% of the population in Africa, 97.2% in the Americas, 98.5% in South-East Asia, 97.6% in Europe, 89.8% in the Eastern Mediterranean and 99.9% in the Western Pacific.

## Limitations

- ◆ The most important limitation of the data set is that only one key person in each country was the source of all information. Although the respondent was an ILAE/IBE Chapter official and was able to consult other local people working in the area of epilepsy and numerous sources of information, the received data should still be considered as the best estimates by the respondents. In spite of this limitation, the Epilepsy Atlas is the most comprehensive compilation of resources for epilepsy in the world ever attempted.
- ◆ Because the sources of information in most countries were the key persons working in the field of epilepsy, the data set mainly covers countries where there are experts or others with an interest in epilepsy.
- ◆ Certain questions, especially in relation to resources for epilepsy care, were framed in such a way that responses could be “yes” or “no”. Although this facilitated a rapid gathering of information, it failed to take account of differences in coverage and quality. Respondents may have replied positively to the question of availability of epilepsy services in the country even if only a very limited number of such facilities were available in a few large cities. Also,

the response does not provide information about distribution across rural or urban settings or across different regions within the country.

- ◆ While attempts have been made to obtain all the required information from all countries, in some countries it was not available. Hence, the denominator for various themes is different and this has been indicated with each theme. The most common reason for missing data was the non-availability of the information in the country.
- ◆ The data regarding number of people with epilepsy represent an estimate and have not been collected and calculated using stringent epidemiological research methods as for prevalence studies.
- ◆ It is possible that definitions for various terms vary from country to country. As a result, countries may have had difficulties in interpreting the definitions provided in the glossary. The definitions regarding various human resources, for example, may need to be amended and expanded in future.
- ◆ While all possible measures have been taken to compile, code and interpret the information given by countries using uniform definitions and criteria, it is possible that some errors may have occurred during data handling.

## Data organization and presentation

The information in the Epilepsy Atlas is presented in four broad sections. The data included are organized in 17 themes and are presented as graphics, world maps and written text. Bar and pie charts are provided to illustrate frequencies, medians and means as appropriate. Because the distribution of most of the data is skewed, the median has been used to depict the central tendency of the various variables. The terms used in the process of collecting the data are contained in the Glossary (page 84). It was not possible to present all the findings from the analyses. The results are presented as global, regional and by income categories within each theme. Limitations specific to each theme are to be kept in mind when interpreting the data and their analyses. Selected implications of the findings for further development of resources for epilepsy care are highlighted with each theme. The Epilepsy Atlas also includes brief reviews of selected topics summarizing the medical, lifestyle, social and economic issues surrounding people with epilepsy.







# Epilepsy: the disorder



**Prof Edward H. Reynolds**

## Introduction

Epilepsy is a common medical and social disorder or group of disorders with unique characteristics. Epilepsy is usually defined as a tendency to recurrent seizures. The word “epilepsy” is derived from Latin and Greek words for “seizure” or “to seize upon”. This implies that epilepsy is an ancient disorder; indeed, in all civilizations it can be traced as far back as medical records exist. In fact, epilepsy is a disorder that can occur in all mammalian species, probably more frequently as brains have become more complex. Epilepsy is also remarkably uniformly distributed around the world. There are no racial, geographical or social class boundaries. It occurs in both sexes, at all ages, especially in childhood, adolescence and increasingly in ageing populations (3).

The periodic clinical features of seizures are often dramatic and alarming, and frequently elicit fear and misunderstanding. This in turn has led to profound social consequences for sufferers, which has greatly added to the burden of this disease. In ancient times, epileptic attacks were thought to be the result of invasion and possession of the body by supernatural forces, usually malign or evil influences, requiring exorcism, incantations or other religious or social approaches. Today, seizures are viewed as electromagnetic discharges in the brain in predisposed individuals, attributable in part to putative genetic factors, underlying neurological disorders, and largely unknown neurochemical mechanisms. A wide range of different seizure types and epilepsy syndromes have been identified. Patients are now treated with pharmacotherapy, occasionally with neurosurgical techniques, as well as with psychological and social support. How have we arrived at this transformation in our understanding of epilepsy? What have been the milestones along the way?

## Ancient descriptions and concepts

The earliest detailed account of epilepsy is in the British Museum, London. It is part of a Babylonian text on medicine, *Sakikku* [All diseases], which was written over 3000 years ago, i.e. before 1000 BC. I have had the privilege of working with a Babylonian scholar, James Kinnier Wilson, on the translation of this text (Figure 1.1) (7). The Babylonians were keen observers of clinical phenomena and provide remarkable descriptions of many of the seizure types (*miqtu*) that we recognize today, including what we would call tonic clonic seizures, absences, drop attacks, simple and complex partial seizures and even focal motor (Jacksonian) or gelastic attacks. They also understood some aspects of prognosis, including death in status as well as post-ictal phenomena. The Babylonians had no concept of pathology, however, and each seizure type was associated with invasion of the body by a particular named evil spirit. Thus treatment was not medical but spiritual.

This supernatural view has dominated thinking about epilepsy until quite recently and even now remains a deeply rooted negative social influence in some parts of the world. It was, however, unsuccessfully challenged by the School of Hippocrates in 5th-century BC Greece, which first suggested that the brain was the seat of this disorder, as it was the mediator also of the intellect, behaviour and the emotions. In a famous text Hippocrates stated: “I do not believe that the Sacred Disease is any more divine than any other disease but, on the contrary, has specific characteristics and a definite cause. Nevertheless because it is completely different from other diseases it has been regarded as a divine visitation by those who, being only human, view it with ignorance and astonishment. ... The brain is the seat of this disease, as it is of other very violent diseases” (8). Interestingly, Hippocrates also had some notion that epilepsy could become chronic and intractable if not treated early and effectively, although it is not clear exactly what treatments he had in mind: “Moreover it can be cured no less than other diseases so long as it has not become inveterate and too powerful for the drugs which are given. When the malady becomes chronic, it becomes incurable.”

Unfortunately the Hippocratic concept of a treatable brain disorder had little influence on the prevailing supernatural view, as is well described in the scholarly history of epilepsy from the Greeks to the late 19th century by Temkin (9).

## Epilepsy as a brain disorder

It was not until the 17th and 18th centuries that the Hippocratic concept of epilepsy as a brain disorder began to take root in Europe – illustrated, for example, by an “Essay of the pathology of the brain and nervous stock: in which convulsive diseases are treated of” by Thomas Willis (10). During these two centuries epilepsy was one of several key areas of debate in the gradual identification and separation of “nervous disorders” from “mental disorders”, which led to the beginnings of modern neurology in the 19th century. A major issue was what to include within the concept of epilepsy, i.e. all periodic “convulsive diseases” or only those with a rather restricted kind of motor convulsion with or without loss of consciousness. Thus many treatises on convulsive diseases appeared which included hysteria, tetanus, tremors, rigors and other paroxysmal movement disorders. The latter were gradually separated off from epilepsy in the 19th century, as illustrated in the distinguished Lumleian Lectures on convulsive diseases by Robert Bentley Todd in 1849 (11) and Jackson in 1890 (12).

With the development of neuropathology as a new discipline in the 19th century there also began a great debate, which is still with us to some extent, as to the distinction between pure primary idiopathic epilepsy, in which the brain is macroscopically normal, from secondary symptomatic epilepsy, associated with many different brain pathologies.

Also in the 19th century, with the development of the concept of functional localization in the brain (13) and the discovery, for example, of the motor cortex (14), the concept of “epileptiform” or “partial” seizures arose as models for the study of “generalized” seizures (15, 16). By meticulously studying the clinical features of unilateral epileptiform motor seizures, Jackson was able to conclude, as was later confirmed experimentally, that the motor cortex was concerned with movements rather than individual muscles (16). Paroxysmal episodes of an intellectual, emotional or behavioural kind, including hysteria or “hystero-epilepsy” (17), were more difficult to classify and localize; it was not until the discovery of human electroencephalography (EEG) in the 20th century (18) that the concepts of temporal lobe or frontal epilepsy were gradually clarified, and psychological concepts of hysteria evolved.

### Electrical basis of epilepsy

As the concept of a brain disorder gradually took hold between the 17th and 19th centuries it was widely believed that epilepsy must have a vascular basis attributable to either acute anaemia or acute congestion of the brain. This view was challenged by Todd who was the first to develop an electrical theory of brain function and of epilepsy in his Lumleian Lectures of 1849 (11). Todd was an anatomist, physiologist and pathologist as well as an outstanding physician with an interest in disorders of the nervous system. He was aware of the great new discoveries in electromagnetism through his contact with his contemporary in London, Michael Faraday, the greatest electrical scientist of all time. Influenced by Faraday, Todd conceived of “nervous force” as a polar force, analogous to electricity but mediated by unknown molecular or nutritional mechanisms. He therefore preferred the term “nervous polarity”. Applying Faraday’s concept of “disruptive discharge” he viewed seizures as the result of electrical discharges in the brain, which he confirmed experimentally in the rabbit using Faraday’s recently discovered magnetolectric rotation machine.

It is often taught that Jackson was the first to develop an electrical theory of epilepsy with his famous statement that “Epilepsy is the name for occasional, sudden, excessive, rapid and local discharges of grey matter” (16). It is difficult to understand why, in his Lumleian Lectures of 1890 (12), Jackson did not acknowledge Todd’s lectures on the same subject 41 years earlier (11). However, it is apparent that the Jackson theory was not an electrical one. As Gowers makes clear (17), Jackson’s concept of discharge was a vague one of a discharge of energy, as for example in a bent pin or spring. Jackson supposed the “liberation of energy during rapid decomposition (katabolism) of some matter in, or part of, those cells”.

As a philosopher physician it is doubtful if Jackson had any significant grasp of electromagnetism in an era before the

discovery of the human EEG. In fact, it was only about this time that Caton first discovered the EEG in rabbits, cats and monkeys (18). But it was not until 52 years later, in 1929, that Berger reported the discovery of the human EEG (19). This led rapidly to the confirmation that seizures were the result of electrical discharges in the brain, for example by Lennox at the 1935 Neurological Congress in London where he also finally laid to rest the still widely believed vascular theories of epilepsy (20).

In 1952 Hodgkin & Huxley (21) made the Nobel Prize-winning discoveries of the ionic basis of Todd’s nervous polarity/force. Interestingly, it was Faraday’s mentor at the Royal Institution in London, Sir Humphry Davy, who discovered sodium, potassium, chlorine, calcium and magnesium among other elements (22).

### The modern era

It is premature to assess recent developments in historical terms, but in the second half of the 20th century remarkable progress was made in diagnostic facilities and possibilities through structural and functional neuroimaging, including CAT and MRI, as well as in video-telemetry and magnetoencephalography.

The modern era of pharmacotherapy probably began with bromides (1856), phenobarbital (1912) – still the most widely used drug in the world – and phenytoin (1938). In recent decades there has been a proliferation of new drugs in the developed world, for example nine in the United Kingdom in the last 15 years. To what extent newer drugs are more or less effective, selective or toxic than older drugs is still a matter of debate and evaluation, as is the role of polytherapy in the event of failure of carefully monitored monotherapy. The mechanisms of action of the drugs are largely unknown and it is uncertain whether the drugs merely suppress seizures or influence longer-term prognosis through “arresting” epilepsy (17) or other antiepileptic mechanisms.

The functional localization detected by studying focal or partial seizures played a key role in developing neurosurgery in the late 19th century, as did the development of the EEG in the first half of the 20th century. The modern interest in neurosurgery for epilepsy itself, especially intractable seizures associated with focal cortical lesions, including temporal lobe epilepsy, was pioneered by Horsley, Penfield and Falconer, among others (23).

The modern era is also marked by an expansion of interest in basic mechanisms underlying seizures and epilepsies, stimulated by developments in genetics, molecular biology, neurophysiology, functional imaging and numerous neurochemical techniques for exploring the concepts of excitation, inhibition, modulation, neurotransmission and synchronization. Every advance seems to add to the enor-



mous complexity of the nervous system and the probability that multiple elusive genetic–molecular–metabolic mechanisms contribute to the wide range of epilepsies.

### Public health and social developments

Despite scientific advances in the 19th century, epilepsy remained a profound social problem compounded by deeply rooted historical concepts of a supernatural or sacred disorder. Widespread ignorance, fear, misunderstanding and stigma contributed to severe legal and social penalties.

In Budapest in 1909 a group of European physicians founded the International League Against Epilepsy (ILAE) (24). From the beginning, ILAE was concerned with both the scientific and social aspects of epilepsy and with education, through international collaboration, congresses and its journal *Epilepsia*. Unfortunately the outbreak of the First World War led to the demise of ILAE for 20 years from 1915 to 1935, when it was reborn and reconstituted at the Second International Neurological Congress in London (20, 24). Apart from a brief interruption during the Second World War, the League has grown steadily into a truly international organization.

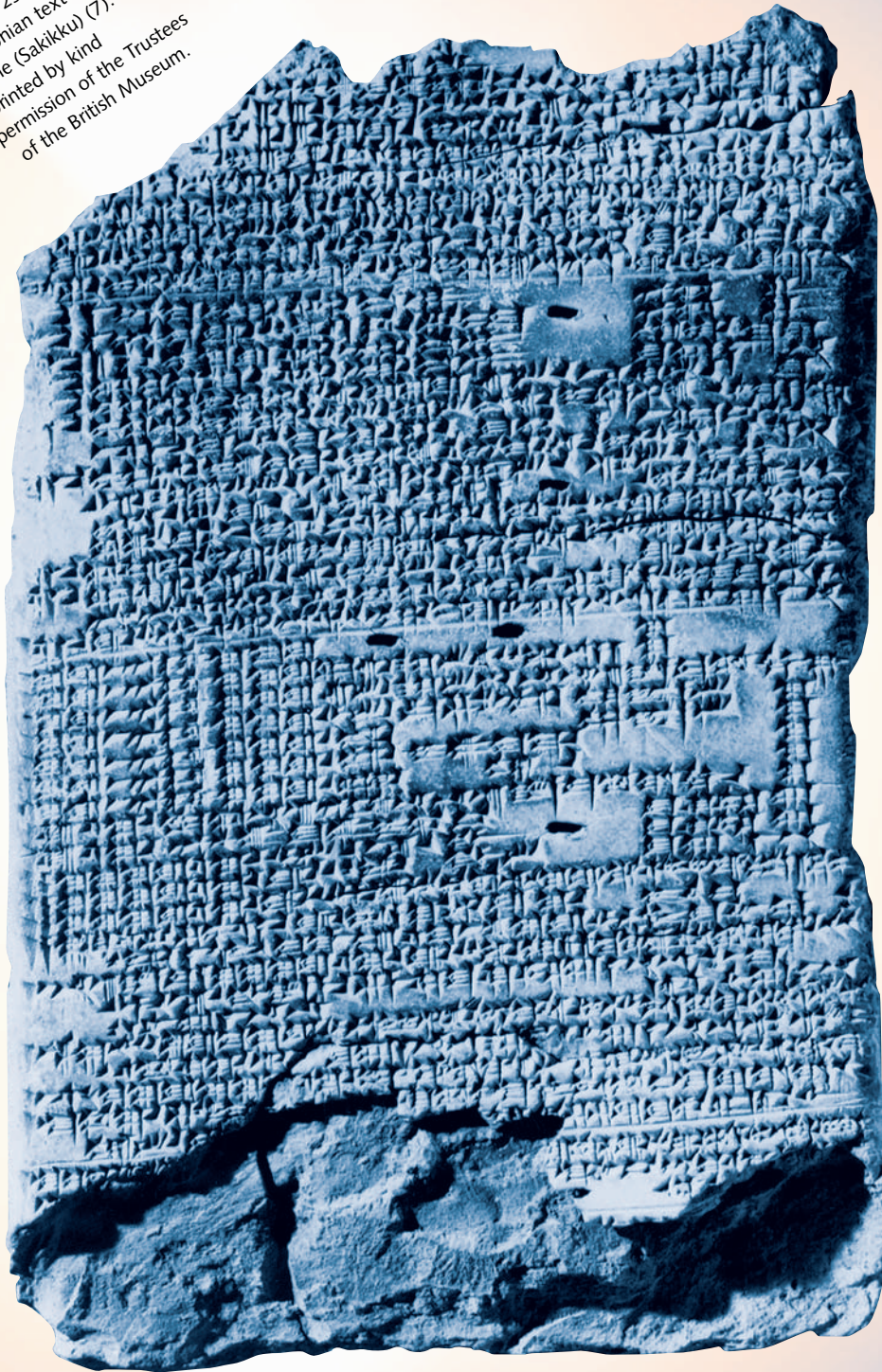
By 1966 it was felt that the social dimension of epilepsy required an organization of its own, involving patients and public, and the International Bureau for Epilepsy (IBE) was founded. By the end of the 20th century ILAE had over 90 Chapters and IBE over 80 full members and 30 associate members, covering every continent. Regional structures for both organizations are now evolving. In the last 25 years ILAE has played a key role in defining and classifying

seizures and epilepsy syndromes through its International Commission on Terminology and Classification (25, 26).

After some initial tensions in the late 1970s and early 1980s, including a merger then separation, ILAE and IBE have worked very well together with interlocking executive committees. They are both nongovernmental organizations affiliated to WHO. During my presidency of ILAE (1993–1997) I proposed a major new initiative to address the public health aspects of epilepsy, including social aspects, involving a partnership between the League (professional), the Bureau (patients/public) and WHO (political). The ILAE/IBE/WHO Global Campaign Against Epilepsy was launched from Geneva and Dublin in the summer of 1997. Its objectives include raising political and public awareness of epilepsy, reducing stigma and misunderstanding, improving education, and especially the delivery of services, treatment and care to millions of people with epilepsy, mainly in developing countries, where studies have shown that between 60% and 90% of patients have no access to modern treatment, the so-called “treatment gap”, despite the availability of relatively cheap medication (27).

Following the first phase of political and public awareness raising (1997–2001), the then Director-General of WHO, Dr Gro Harlem Brundtland, launched the second phase of the Campaign from Geneva and raised its status to the highest level within WHO, the first neurological disorder to be accorded this priority (3). Demonstration Projects are now under way in several developing countries including in Africa and China, and a third phase of the Campaign is being planned.

- 1.1** The oldest detailed account of epilepsy  
Source: Tablet 25 or 26 in a Babylonian text on medicine (Sakikku) (7).  
Reprinted by kind permission of the Trustees of the British Museum.





## Introduction

- ◆ Knowledge about the number of people with epilepsy is essential for the identification of needs and the planning of appropriate services.

## Salient findings

- ◆ A total of about 43 704 000 people with epilepsy are reported from 108 countries covering 85.4% of the world population.
- ◆ The mean number of people with epilepsy per 1000 population is 8.93 (SD 8.14, median 7.59) from 105 responding countries.
- ◆ The mean number of people with epilepsy per 1000 population varies across region. While it is 12.59 and 11.29 in the Americas and Africa, respectively, it is 9.97 in South-East Asia, 9.4 in the Eastern Mediterranean, 8.23 in Europe, and 3.66 in the Western Pacific.
- ◆ The mean number of people with epilepsy per 1000 population ranges from 7.99 in the high-income countries to 9.50 in the low-income countries.

## Limitations

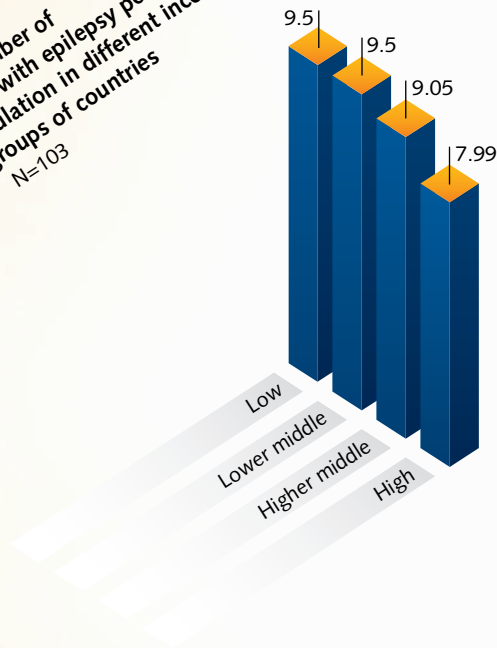
- ◆ The data regarding the number of people with epilepsy were not collected using stringent research methods as for epidemiological studies; such methods are costly and are not easy to carry out.
- ◆ The sources of information vary across responding countries, limiting the interpretation of the data set. For example, some respondents provided figures based on generic prevalence or findings from one particular area of the country or on the number of people eligible for antiepileptic drugs. One of the reasons for low prevalence reported from the Western Pacific could be the lower prevalence rates reported from Pacific Islands; it also puts a bias on the global outcome, as the Western Pacific comprises 27% of the population in all WHO regions.
- ◆ Information regarding the number of people with active epilepsy was not obtained.
- ◆ Information regarding the number of people with epilepsy among special groups, e.g. children, was not obtained.

## Conclusions

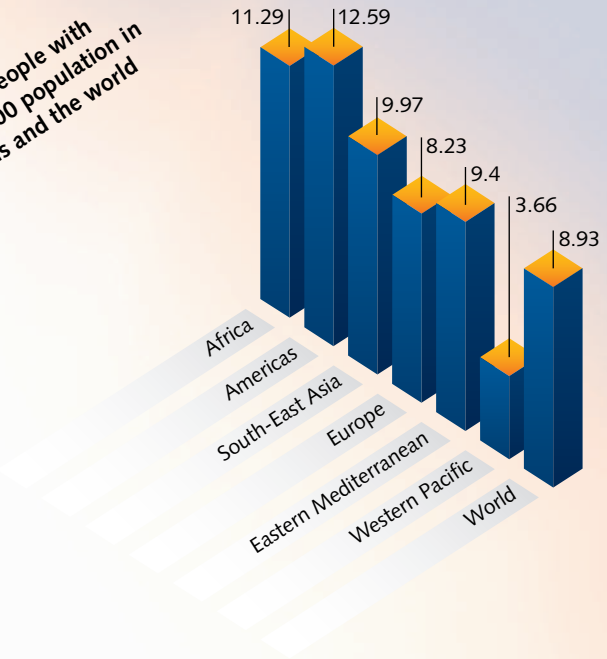
- ◆ The number of people with epilepsy is high in most regions of the world, thus constituting epilepsy as a major public health concern.
- ◆ There is a need to carry out multinational epidemiological studies using standardized definitions and case ascertainment methods.
- ◆ Studies of the burden of epilepsy should raise the awareness of authorities about the impact of epilepsy on the country.



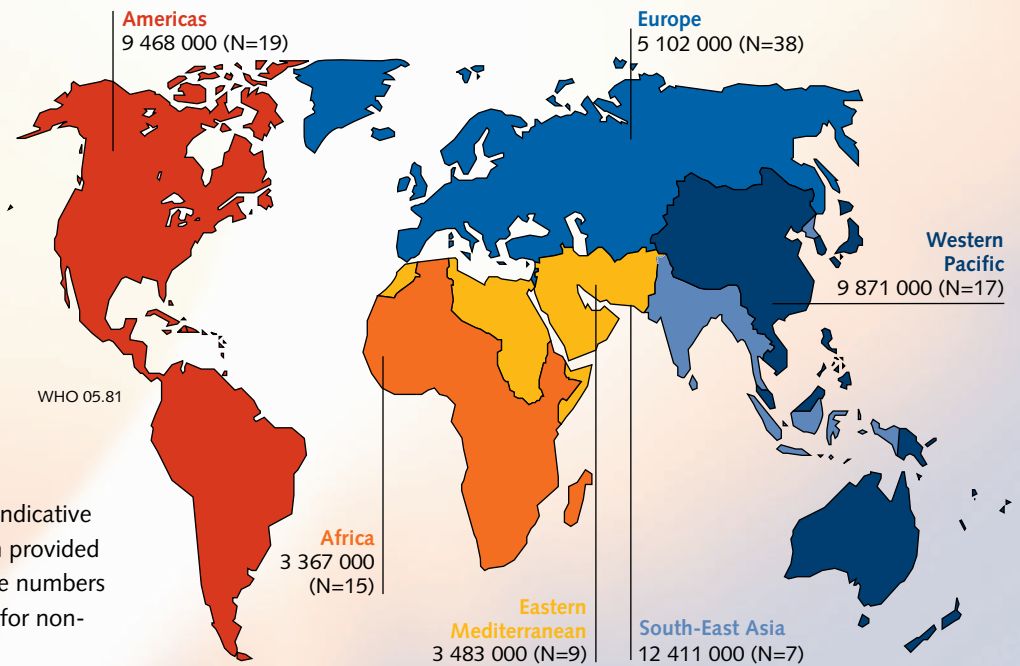
**2.2** Mean number of people with epilepsy per 1000 population in different income groups of countries  
N=103



**2.1** Mean number of people with epilepsy per 1000 population in WHO regions and the world  
N=105



**2.3** Number of people with epilepsy in WHO regions  
N=105\*



\* These numbers are only indicative based on the information provided by Atlas respondents. The numbers have not been corrected for non-responding countries.

**Prof Nadir E. Bharucha**

## What is neuroepidemiology?

Neuroepidemiology is the study of the distribution and determinants of neurological diseases in human populations (28). While the clinician is concerned with disease in the individual patient, the epidemiologist is concerned with the occurrence of disease within a community. Epidemiological information benefits health policy-makers, public health officials, medical practitioners and patients, the pharmaceutical industry and other epidemiologists (29).

## Diagnosis

Accuracy of medical diagnosis is fundamental. Diagnosis is clinical and should be confirmed by a professional with expertise in epilepsy. EEG may help diagnosis, but is certainly needed to classify seizure type and give a meaningful prognosis. Most epidemiological studies to date have lacked investigatory facilities in the field, especially in developing countries.

Studying epilepsy is beset with difficulties. Accurate diagnosis and case ascertainment remain major problems, because epilepsy is only a symptom of many disparate causative entities. Confident diagnosis or exclusion in all cases of seizures is difficult because seizure types vary, unusual behaviour and blank spells may not be recognized as seizures, there may be no accompanying neurological signs and if an eyewitness account is lacking, the diagnosis may not be made at all. Other conditions are readily confused with epileptic seizures. The most frequently occurring non-epileptic events requiring distinction and exclusion are pseudo-seizures and syncope (30).

## Definition of seizures and epilepsies

To ensure comparability of epidemiological studies, ILAE's guidelines for epidemiological studies on epilepsy (31) should be followed. The term epilepsy should be used only for recurrent, unprovoked seizures.

Seizures are categorized as partial or generalized. A partial seizure is presumed to start in a part of the brain and may or may not spread. The cause must always be sought, and epilepsies may be classified according to aetiology and type of seizure, as follows:

- ◆ Aetiology: remote symptomatic of known aetiology; cryptogenic probably symptomatic but unknown aetiology; idiopathic presumed genetic.
- ◆ Type of seizure: if partial, the epilepsy is localization-related, and if generalized, the epilepsy is either generalized or localization-related (generalized seizures can occur in both generalized and localization-related epilepsies).

Acute symptomatic seizures are those occurring in close temporal association with an acute systemic, metabolic, or toxic insult or in association with an acute central nervous system insult (34). Acute symptomatic seizures, though

sometimes life-threatening and very common, are not considered epilepsy. They do, however increase the risk of future epilepsy. Febrile seizures are a type of acute symptomatic seizure and the commonest seizure disorder in children.

Progressive symptomatic seizures are unprovoked seizures owing to progressive central nervous system disorders (34). The prognosis is worse. The last group is the undetermined and unclassifiable epilepsies. Epidemiological studies often wrongly omit this group altogether.

Failure to separate active from inactive epilepsy causes differences in rates. A person with active epilepsy has had at least one epileptic seizure within the previous five years, regardless of antiepileptic drug (AED) treatment. In general, patients with inactive epilepsy do not need continuing treatment.

## Incidence and prevalence

The incidence (the number of new cases per year) of epilepsy is 24–53 per 100 000 population in developed countries (32). There are few incidence studies in developing countries, none of which is prospective: they show rates from 49.3 to 190 per 100 000 population (33). Higher incidence rates in developing countries, thought to be attributable to parasitosis particularly neurocysticercosis, HIV, trauma, perinatal morbidity and consanguinity, are difficult to interpret because of methodological issues, particularly the lack of age adjustment, which is important because epilepsy has a bimodal peak with age. Incidence rates worldwide are greater in men than women. In developed countries, incidence among the elderly is rising and among children it is falling. This is relevant to developing countries as longevity rises and risk of cerebrovascular disease increases. Conversely, better obstetric care and infection control can diminish incidence in children.

The prevalence (the total number of cases at a particular point in time) of active epilepsy in a large number of studies has been shown to be fairly uniform at 4–10 per 1000 population (34). Higher prevalences in sub-Saharan Africa and Central and South America have been reported, possibly due to methodological differences, consanguinity or environmental factors and particularly so in rural areas (35). It is difficult to tease out racial and socioeconomic factors. Prevalence data are primarily used by health planners and for generating aetiological hypotheses.

## Aetiology

Population-based prevalence and incidence surveys present percentage frequencies of presumed aetiologies of epilepsy. In most, no cause is found. Precise diagnosis remains difficult – even in the study in Rochester, MN, two thirds of cases were classified as idiopathic or cryptogenic (36). Aetiology of epilepsy is discussed in Section 5.



## Seizure type and epilepsy syndrome

Generalized seizures are common in field studies, especially in developing countries, often because partial seizures are missed. In developed countries, over half the incidence cases are partial. Partial and generalized seizures vary with age, partial seizures being more common in the very young and in elderly people. Generalized tonic-clonic seizures occur uniformly throughout the life-course; absence seizures occur maximally between 5 and 10 years of age; and myoclonic seizures in the under-five-year-olds and around 15 years. Idiopathic epilepsy is usually seen in the young, and remote symptomatic epilepsy at the extremes. In developing countries, however, symptomatic epilepsy caused by infections should be considered at any age.

Diagnosis by syndrome is important for prognosis and treatment. For example, a cryptogenic/symptomatic localization syndrome, the commonest paediatric syndrome (37), is likely to be caused by a brain lesion which may be amenable to surgery if seizures are medically uncontrollable. Childhood absence epilepsy, the commonest idiopathic generalized epilepsy, whose prognosis is poor if untreated and excellent if treated, may be missed altogether in population screening.

## Genetic studies

Genetic studies have identified rare epilepsy syndromes attributable to single gene mutations and simple Mendelian inheritance (38). Most idiopathic epilepsy syndromes have complex inheritance, probably because of interacting genetic and environmental factors. The category of cryptogenic epilepsies is diminishing as results of genetic and neuroimaging studies become available. There is scope for developing and developed countries to collaborate in properly designed incidence and genetic studies of different epilepsy syndromes. Genetic epidemiological studies will give information on individual prognosis and risk to other family members. When pathophysiological mechanisms are clearer, tailoring the drug to the gene will also become possible.

## Prognosis

One in three people with a single unprovoked seizure will have a second seizure over the next five years (39). Treatment should be considered only to prevent recurrence, not to prevent epilepsy. Untreated, after a second seizure, 75% will have another seizure within the next one or two years (40). Whether “seizures beget seizures” is unclear. Numerous predictors for recurrence, control, remission and intractability have been developed at the onset and during treatment. Most important are diagnosis by syndrome and response to the first appropriately prescribed and taken AED. Persistence of seizures after two AEDs requires pre-surgical evaluation, as chances of remission are less than 5% with a third AED and 50–80% following successful surgery (41).

## Mortality

In developed countries, mortality measured by the standardized mortality ratio (SMR) is 2–3 times that of the general population. Deaths may be attributable either to the cause of epilepsy, when death will occur soon after onset, or to the epilepsy itself, as in chronic epilepsy, or it may be unrelated. Comparison between studies is difficult because of different study designs and different populations studied. Symptomatic epilepsy has a higher mortality ratio than idiopathic epilepsy. The important epilepsy-related deaths are sudden unexpected, unexplained death in epilepsy (SUDEP) (2–18% of all deaths in epilepsy), death in status epilepticus (12.5%) and suicide (0–2%) (42). In status epilepticus, the mortality depends on the cause and is higher in elderly symptomatic patients. Risk of suicide is greatest when epilepsy starts in adolescents with a history of associated psychiatric disturbance. Both developing and developed countries need prospective incidence cohort studies with long-term follow-up.

## Morbidity

Some psychiatric and physical conditions are more common in people with epilepsy (43). Cerebrovascular disease and brain tumours may be causally related to epilepsy. Head injury and psychiatric conditions may be caused by or result from epilepsy. AED teratogenic morbidity needs further study. Alert health providers must be aware of all these issues, in order to improve the quality of life of special groups such as women and children.

## Interventional epidemiological studies

Up to 94% of patients with epilepsy in developing countries do not receive appropriate treatment and 80% of available AEDs are utilized by 20% of the world's sufferers. Phenobarbital is an AED that is effective, tolerable, cheap and easy to use, all essential considerations in developing countries (44). Surgery for refractory epilepsy could be cost beneficial. Cost-benefit and risk-benefit ratios of new AEDs should be assessed on a large scale in developed countries; such information would be of value for developing countries after appropriately designed clinical trials.

## Conclusion

In developing countries with large rural populations, a few urban and semi-urban neurologists, substantial burden of disease and scantily allocated health-care resources, epidemiology provides information necessary for all involved in promoting health to optimize care in epilepsy. Neuroepidemiological studies provide more than indices of burden: they show the way forward.

## Acknowledgement

Dr Roberta H. Raven for her help in preparing this manuscript.

## Introduction

- ◆ The respondents were asked to provide the five most frequently encountered causes of epilepsy. Ignoring the order of the individual responses, the proportion of

countries that mentioned each aetiology was calculated globally and for each of the regions.

## Salient findings

- ◆ Globally, trauma was the most frequently reported aetiology of epilepsy by 92% of the responding countries.
- ◆ Central nervous system infections (including abscesses, encephalitis with all aetiologies, and bacterial meningitis but excluding parasitic infestations), antenatal and perinatal risk factors and cerebrovascular disorders were among the most frequently reported aetiology of epilepsy by 60.4%, 57.7% and 55% of the responding countries, respectively.
- ◆ Idiopathic epilepsy (including the genetic causes) was mentioned as one of the five most common aetiologies of epilepsy by 54.4% of the responding countries.
- ◆ Trauma, central nervous system infections and idiopathic epilepsy were mentioned among the five most frequently reported aetiologies of epilepsy by the responding countries across different income groups of countries.
- ◆ Among the five most common aetiologies, tumours were mentioned by 40.9% of the responding countries, congenital defects (27.5%), parasitic infestations (22.1%), exogenous chemicals including alcohol and drugs (13.4%), cryptogenic (9.4%), degenerative disorders (8.7%), febrile convulsions (7.4%), hippocampal sclerosis (7.4%) and cerebral palsy (2.7%).
- ◆ Cerebrovascular disorders were also among the five most frequently reported aetiologies of epilepsy by the responding countries in all income categories, except low-income countries where parasitic infestations were an important aetiology of epilepsy as mentioned by 44.2% of countries.
- ◆ Perinatal causes were reported among the five most important aetiologies of epilepsy by all income categories except high-income countries.

## Limitations

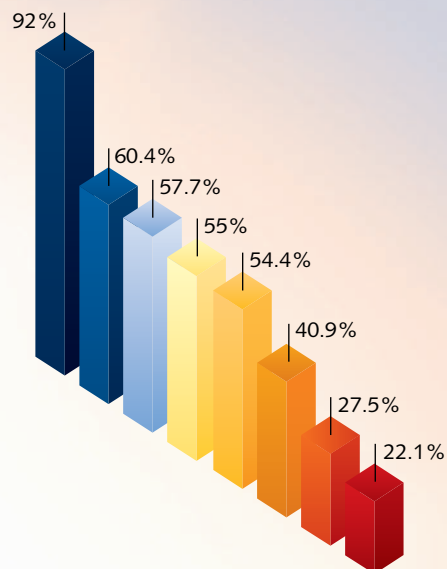
- ◆ Aetiologies of epilepsy as reported by respondents are a rough estimate; data were not collected and calculated using stringent epidemiological research methods. The information is based on the experience and impression of a key person in a country working in the area of epilepsy and not necessarily on actual data from responding countries.
- ◆ In most cases a specific cause can only be determined using basic investigations including neuroradiological and electrophysiological services. There could be methodological differences among various countries because many low-income countries have poor accessibility to even basic investigations.
- ◆ In almost 30-60% of cases of epilepsy, the aetiology cannot be identified even with the most sophisticated methods. However, the cause being unknown was mentioned by only 8.4% of countries. One possible reason could be the way in which the question was framed. Another could be the use of term "idiopathic", which according to some refers to a genetic syndrome with strictly defined clinical and EEG findings while others may use it for any case in which aetiology has not been established.
- ◆ Some of the entities mentioned, such as cerebral palsy, are manifestations of cerebral damage where epilepsy coexists rather than being the cause of epilepsy.

## Conclusions

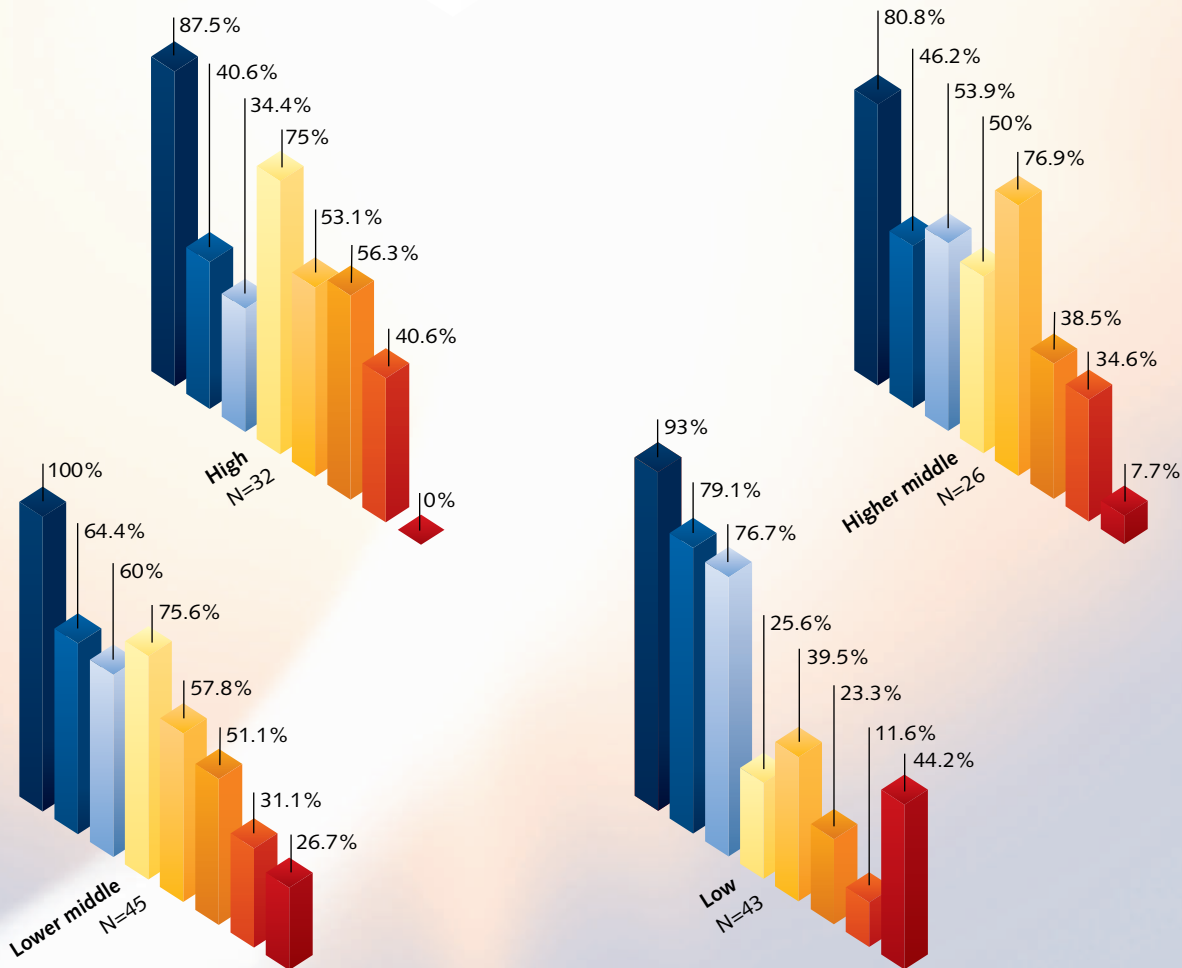
- ◆ Identifying the correct aetiology is essential in order to establish appropriate treatment and offer a prognosis to the patient and family.
- ◆ The information regarding the causes of epilepsy also has implications for making decisions about the development of locally relevant strategies for prevention and management, research goals, and education of primary health-care workers and community physicians.
- ◆ The inequity in availability of diagnostic resources (including human resources) required for assessing the aetiology of epilepsy needs to be dealt with.
- ◆ The top four most frequently reported aetiologies of epilepsy (trauma, central nervous system infections, cerebrovascular disorders and perinatal risk factors) are preventable. Concerted multidisciplinary efforts focusing on the risk factors (e.g. enforcement of strict traffic regulations to prevent trauma) or providing specific protection (e.g. immunization against communicable diseases) for these preventable causes can help to decrease substantially the burden attributable to epilepsy.



**4.1** Most frequently reported aetiology of epilepsy  
Reported by countries (%)  
N=149



**4.2** Most frequently reported aetiology of epilepsy in different income groups of countries  
Reported by countries (%)



**Prof Josemir W. Sander**

Epilepsy is the propensity for an individual to have recurrent unprovoked epileptic seizures. These seizures are produced by abnormal discharges of neurons and may be a manifestation of many different conditions, which modify neuronal function or cause pathological changes in the brain. Many environmental, genetic, pathological and physiological factors may be involved in the development of seizures and epilepsy. The presence of a family history of epilepsy is known to enhance most risk factors for epilepsy (45). The susceptibility to epilepsy may, therefore, be partly genetically determined and this may vary according to the stage of brain maturation.

Epilepsy is associated with a variety of static or progressive pathological changes, either congenital or acquired (46). In addition, a number of inherited conditions may express themselves solely through epileptic seizures. It may therefore be more appropriate to describe epilepsy as a symptom complex rather than as a medical condition in its own right.

Aetiologically, the epilepsies are classified into four groups: idiopathic, symptomatic, cryptogenic and progressive (26, 31). The idiopathic epilepsies are thought to be genetically determined and are usually associated with particular clinical characteristic and specific electroencephalography (EEG) findings (26). Symptomatic epilepsies are acquired conditions and are usually associated with a structural abnormality of the brain. Epilepsy is classified as cryptogenic when no clear abnormality or putative risk factor is identified for what is presumed to be a symptomatic or acquired epileptic condition (26, 31). The term progressive epilepsy is used when epilepsy is associated with an evolving neurological condition (31).

The probable aetiology or risk factor for epilepsy depends on the age of the patient and the type of seizure (47–52). The most common acquired causes in young infants are perinatal hypoxia and trauma, metabolic disturbances, congenital malformations of the brain, and infection. In young children and adolescents, idiopathic epilepsies account for the majority of cases, although trauma and infection play a role. Febrile seizures, which are usually short convulsive attacks occurring during the early phase of a febrile disease, are common in children under the age of five years and need to be distinguished from seizures triggered by central nervous system infections causing fever, such as meningitis and encephalitis. Unless febrile seizures are prolonged, recurrent or occurring on a background of neurological handicap, the prognosis is excellent, and it is unlikely that the child will develop chronic epilepsy.

The causes of adult onset epilepsy are very varied (47, 52). Both idiopathic epilepsy and epilepsy attributable to birth trauma may begin in early adulthood. Other important causes of seizures in adulthood are head injury, alcohol abuse, brain tumours and cerebrovascular disease. In devel-

oping countries, parasitic disorders such as cysticercosis and malaria may be important causal agents for epilepsy.

### Idiopathic and genetically determined epilepsies

The idiopathic (or primary) generalized epilepsies are the most common of the genetically determined epilepsies. The precise mode of inheritance for most of these conditions is currently unknown. Other inherited conditions in which seizures are the sole clinical manifestation include the idiopathic partial epilepsies (e.g. benign rolandic epilepsy). In addition to these conditions with seizures as the main clinical expression, there are many rare inherited disorders that present as neurological or systemic illnesses including seizures. The most common of these disorders are tuberous sclerosis and neurofibromatosis. Trisomy 21 (Down's syndrome) may be accompanied by seizures, particularly in later life.

### Symptomatic epilepsies

Common causes of symptomatic epilepsies include head trauma, birth trauma, cerebrovascular disorders, cerebral anoxia, brain infections, cortical malformations and brain tumours. In resource-poor countries, parasitic infestations such as malaria, neurocysticercosis and paragonimiasis are important risk factors. Most epilepsies starting in adult life are symptomatic and investigations to detect any underlying aetiology are mandatory.

Head trauma is an important cause of symptomatic epilepsy and may account for up to 10% of all cases of epilepsy. The likelihood of developing epilepsy after head trauma depends on the severity of the injury and the presence of complicating factors, including prolonged loss of consciousness, post-traumatic amnesia, intracranial bleeding, missile penetration, or depressed skull fracture. It is unusual for epilepsy to develop unless one of these factors is present. Seizures occurring immediately after the injury do not usually presage the development of chronic epilepsy.

Thromboembolic events and cerebral haemorrhage are important causes of symptomatic epilepsy starting in later life, where they are responsible for up to 50% cases. It is estimated that approximately 15% of people with strokes will eventually develop epileptic seizures. Vascular malformations and cerebral aneurysms may also cause symptomatic epilepsy, whether or not haemorrhage has occurred.

Any intracranial infection, whether viral, bacterial or fungal, can cause seizures. The severity of the epileptic disorder usually depends on the nature of the infection and the extent of the damage. Meningitis, the most common intracranial infection, is common in young children but also affects older age groups. Epilepsy is an unusual complica-



tion of acute bacterial meningitis, occurring mainly in people given inadequate or late treatment.

Intracranial tuberculosis can cause cortical and meningeal tuberculomas that may present with seizures, sometimes developing years after the primary infection. Fungal infections of the central nervous system are a rare cause of epilepsy; the most common, cryptococcosis and blastomycosis, are often associated with immune deficiencies. Survivors of viral encephalitis, especially resulting from herpes, may develop epilepsy that is intractable to medical treatment. Intrauterine and perinatal infections caused by toxoplasmosis, rubella and syphilis may cause extensive cortical damage, and severe partial epilepsy may result if the child survives.

Brain abscesses are rare and often fatal. Epilepsy develops in about three quarters of survivors and is usually very severe and intractable.

Epilepsy may occur in the course of a number of parasitic disorders, including neurocysticercosis, falciparum malaria, schistosomiasis, and paragonimiasis. Such infections may be responsible for the higher incidence of epilepsy in some parts of the tropical world; those most frequently associated with epilepsy are neurocysticercosis and falciparum malaria. Neurocysticercosis is the most common acquired cause of epilepsy in resource-poor countries. This occurs when a human becomes the intermediate host for *Taenia solium* through the ingestion of eggs contained in human faeces. Cysts containing an embryo may emerge in any area of the cerebrum, ventricles or subarachnoid space of the infested patient, leading to a variety of neurological signs including epilepsy. Cerebral malaria, which is the most important complication of falciparum malaria, may first present as status epilepticus. It carries a high mortality and morbidity; survivors often have neurological disabilities and partial seizures that respond poorly to treatment.

An allergic reaction to vaccine components very occasionally leads to an acute encephalopathy that may result in chronic epilepsy. It is extremely rare, however, and is becoming even more uncommon as more purified and less antigenic vaccines are used. As the incidence of epilepsy is at its highest in early childhood, the age at which most vaccinations are carried out, some children will develop seizures in temporal association with vaccination by coincidence. Other children experience a febrile reaction to some vaccinations and may have a febrile seizure as a result, without long-term sequelae.

Errors in neuronal migration during embryogenesis may result in cortical malformations. These malformations were until recently considered to be rare; however, with the development of high-resolution neuroimaging they are being recognized with increasing frequency. The aetiology for these cortical malformations is unknown at this stage,

but potential causes may include intrauterine infection, maternal illness or exposure to toxins at crucial phases of brain formation.

Hippocampal sclerosis is the most common lesion identified in pathological specimens of patients with temporal lobe epilepsy who have undergone temporal lobectomy. It consists of atrophic changes with a variable degree of cell loss and gliosis involving part or the whole of the hippocampus. It is usually unilateral and can be identified by brain imaging. Temporal lobe epilepsy with hippocampal sclerosis is strongly associated with a history of prolonged febrile convulsions in childhood. Resection of the atrophic area, when possible, is associated with a good surgical outcome, with complete seizure control in over 70% of cases.

### Cryptogenic epilepsies

Currently up to 40% of patients have no identifiable cause for their seizures. This proportion is rapidly decreasing as advances in neuroimaging, particularly magnetic resonance imaging (MRI), are made. The term cryptogenic epilepsy is sometimes used interchangeably with idiopathic epilepsy. This should be avoided, and the term idiopathic epilepsy reserved for those inherited conditions in which seizures occur as the only manifestation of the disorder.

### Progressive epilepsies

The progressive myoclonic epilepsies are a group of disorders characterized by the development of myoclonic and other seizures in association with other clinical inherited degenerative brain disorders and inborn errors of metabolism. These include adrenoleukodystrophy, Alpers' disease and Tay-Sachs disease. Phenylketonuria, porphyria and neuronal ceroid-lipofuscinosis may also cause seizures.

Epilepsy may sometimes complicate degenerative brain conditions such as Alzheimer's disease, Huntington's chorea, striatonigral degeneration and Creutzfeldt-Jakob disease; as many as 20% of patients with Alzheimer's disease may develop seizures.

Involvement of the central nervous system eventually occurs in the majority of people developing AIDS. It may take the form of opportunistic infection or neoplastic lesions. An encephalopathy that seems to be caused by HIV itself has also been recognized.

Intracranial tumours, either primary or metastatic, may result in epilepsy. Tumours are responsible for about a fifth of seizures starting between the ages of 30 and 50 years, and about 10% of seizures starting after the age of 50 years.







# 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.
- ◆ Therapeutic drug monitoring is available in 45.1% of the responding countries in Africa, 54.6% in the Western Pacific, 55.6% in South-East Asia, 85.7% in the Eastern Mediterranean, 93.3% in Europe, and 95.8% in the Americas. Furthermore, it is available free of charge or without any special condition for people with epilepsy in three-quarter of countries in Europe where such facilities exist, compared with one-third in the Eastern Mediterranean.
- ◆ Neuropsychological services are available in 64.3% of the responding countries. In more than half of these countries, they are available to people with epilepsy free of charge or without any special condition.
- ◆ Neuropsychological services are available in 37% of low-income countries and are available free of charge in about one third of them. Such facilities are present in 88.6% of high-income countries and are available free of charge in two thirds of them.

## 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.
- ◆ Respondents may have replied positively to the question of availability of diagnostic facilities in the country even if only a very limited number of such facilities are available in a few large cities. No information was obtained on the type, quality and estimated numbers of such facilities.
- ◆ In some countries there are priority rules for access to CAT or MRI.

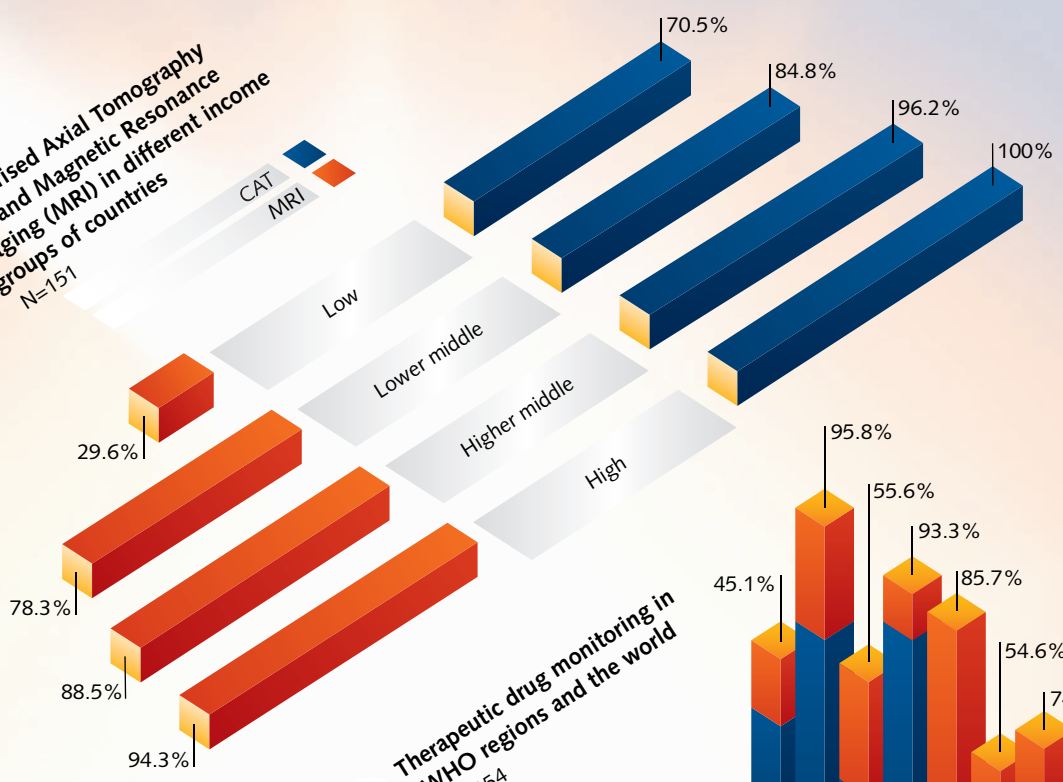
## Conclusions

- ◆ 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.



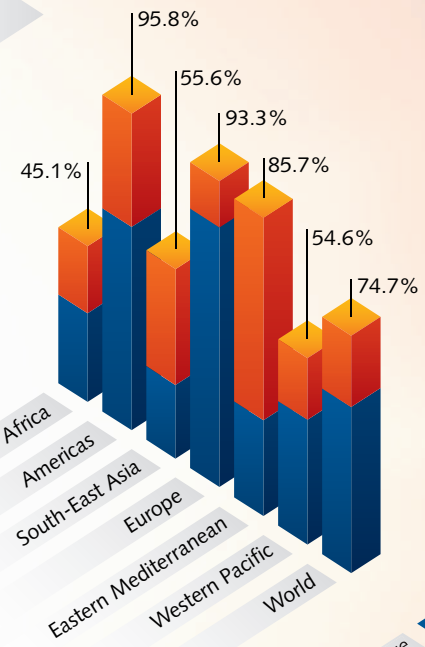
6.1

Computerised Axial Tomography (CAT) and Magnetic Resonance Imaging (MRI) in different income groups of countries  
N=151



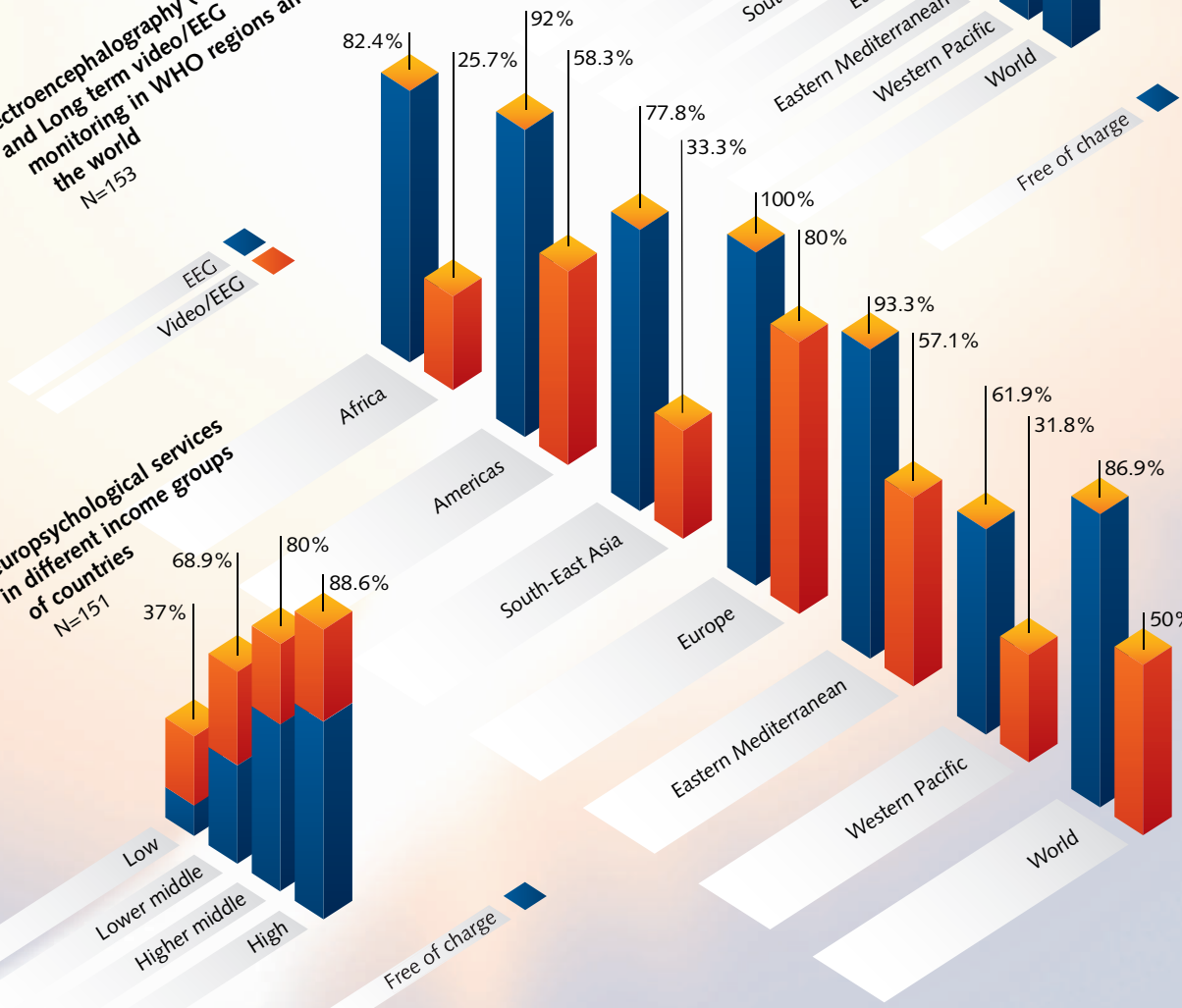
6.2

Therapeutic drug monitoring in WHO regions and the world  
N=154



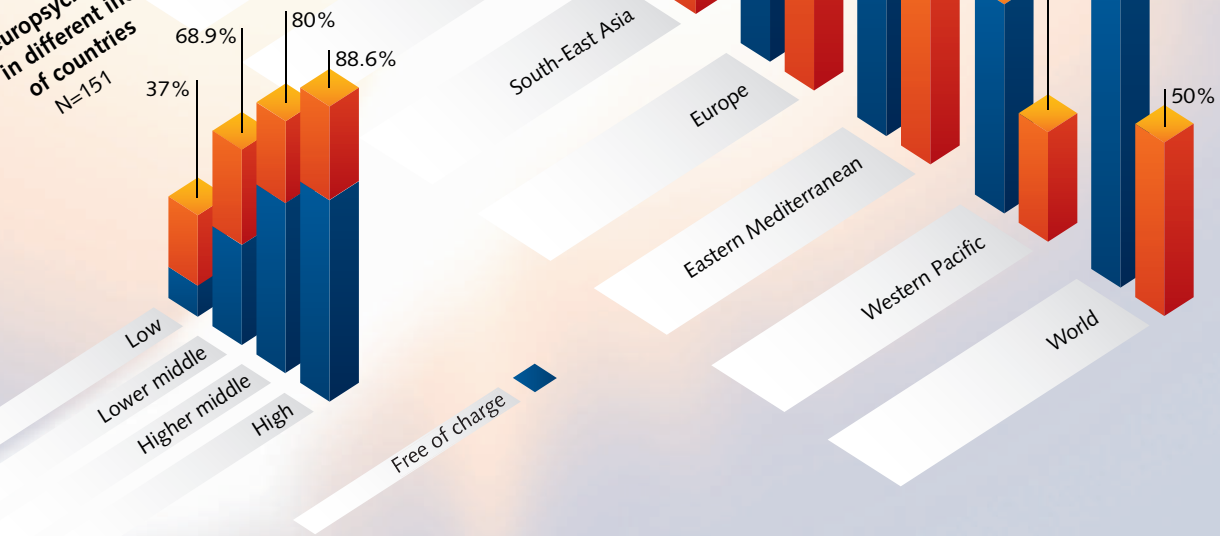
6.3

Electroencephalography (EEG) and Long term video/EEG monitoring in WHO regions and the world  
N=153



6.4

Neuropsychological services in different income groups of countries  
N=151



## 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

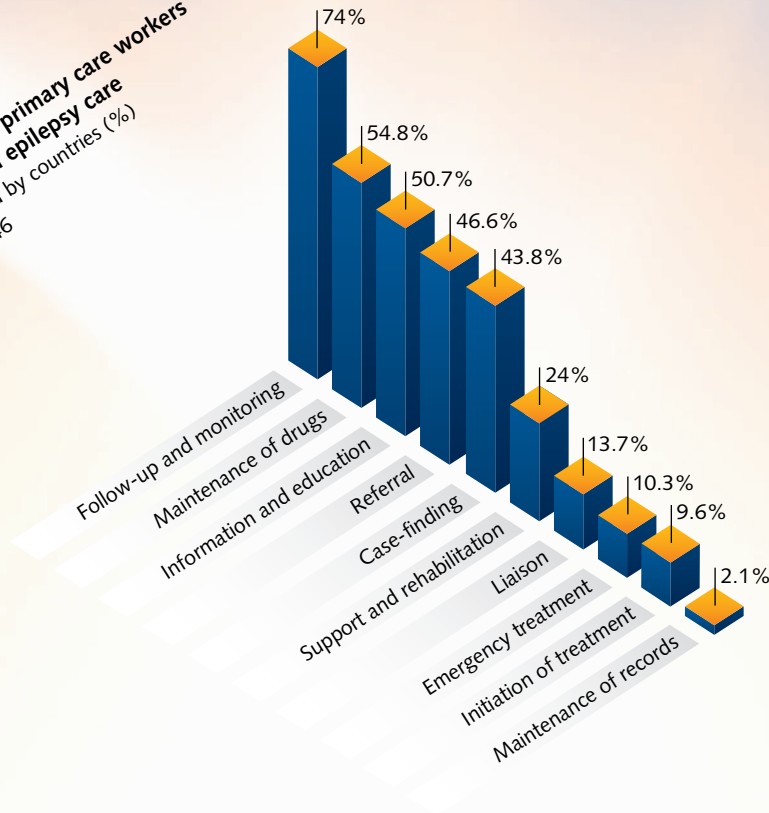
- ◆ The information is based on the experience and impression of a key person in a country working in the area of epilepsy and not on actual data from responding countries.
- ◆ The data report assessments by health professionals of the tasks performed by the primary care workers; it is possible that 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

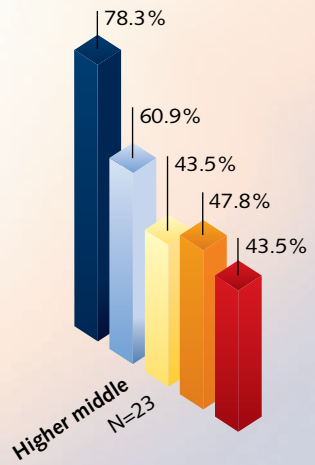
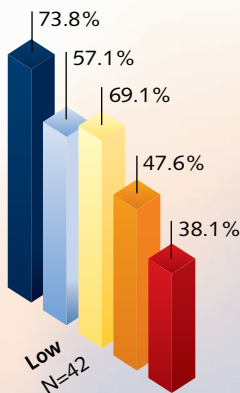
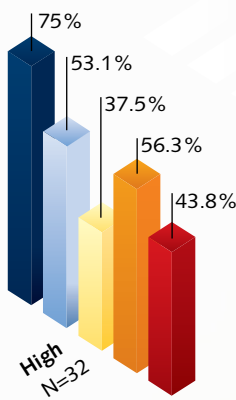
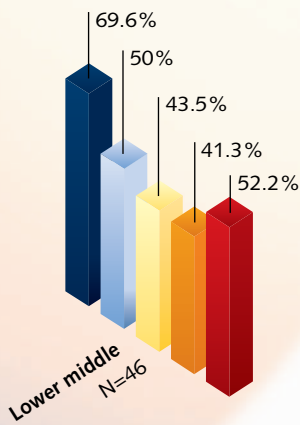
- ◆ Lack of access has been identified as a major barrier to adequate treatment in both high-income and low-income countries. Adequate training of the health workers providing first level of contact in case detection, initiation of treatment with AEDs (where local guidelines permit), follow-up and monitoring 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.



**7.1** Main tasks of primary care workers involved in epilepsy care  
Reported by countries (%)  
N=146



**7.2** Main tasks of primary care workers involved in epilepsy care in different income groups of countries  
Reported by countries (%)



## 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, lamotrigine, felbamate, gabapentin, topiramate, tiagabine, levetiracetam and pregabalin. 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% (41). 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 pharmaceutical 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.

## Limitations

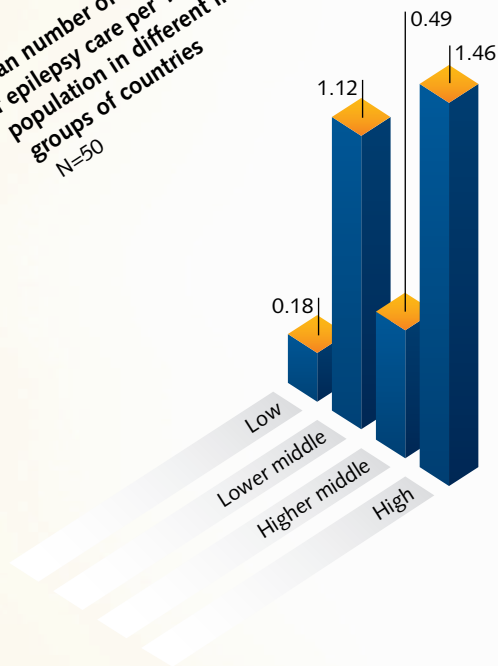
- ◆ In many countries beds are not earmarked for patients with epilepsy. Beds occupied by people with epilepsy are part of the pool for neurology, neuropsychiatry, internal medicine, geriatrics, paediatrics or general beds, so they may not have been reported.
- ◆ In many countries, patients with status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

## Conclusions

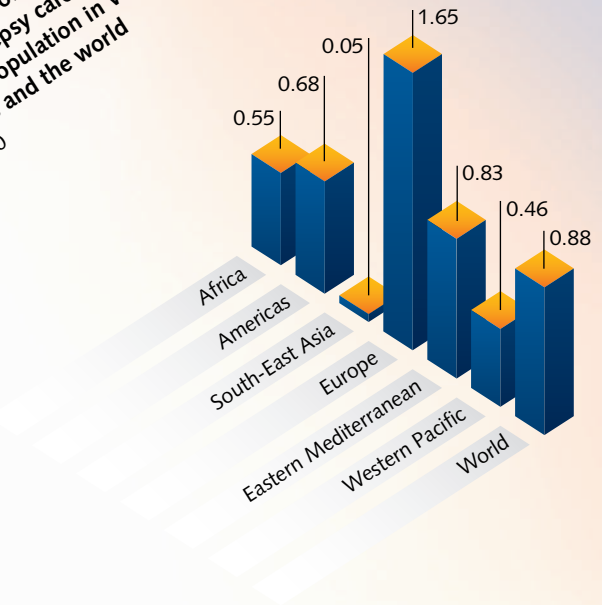
- ◆ Designated beds may be considered to be an indicator of the level of organization of epilepsy services in a country.
- ◆ In countries with well-developed epilepsy services at primary care level, development of epilepsy centres is advocated for providing comprehensive care. Improvement of inpatient 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.



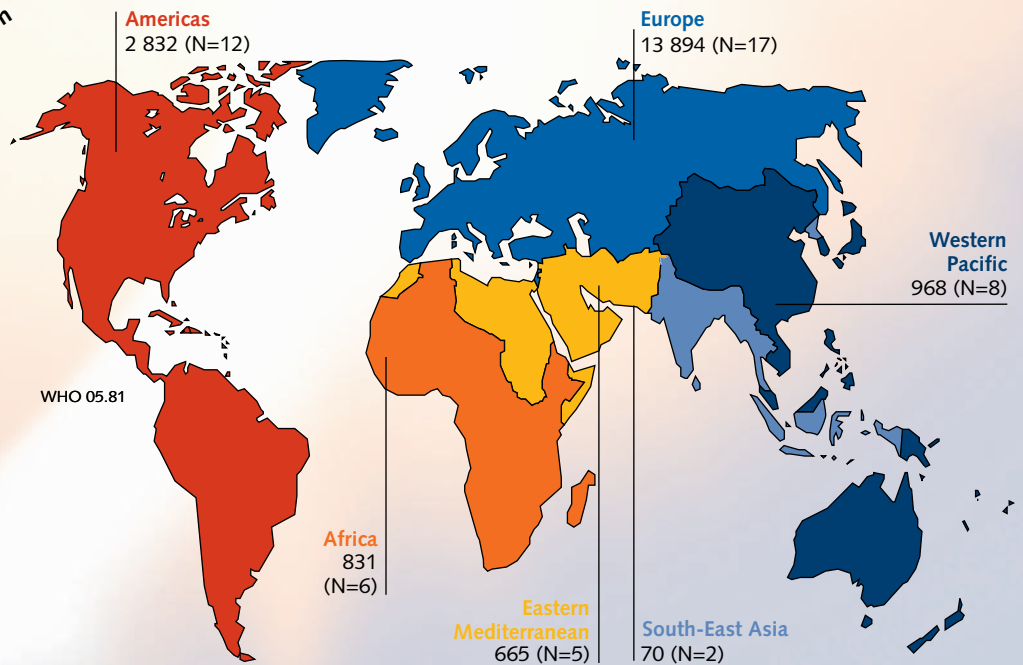
**9.2** Median number of hospital beds for epilepsy care per 100 000 population in different income groups of countries  
N=50



**9.1** Median number of hospital beds for epilepsy care per 100 000 population in WHO regions and the world  
N=50



**9.3** Number of medical hospital beds for epilepsy care in WHO region



## 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.

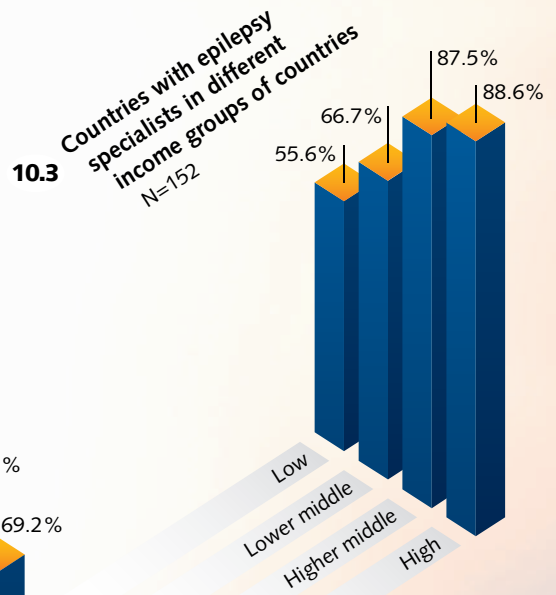
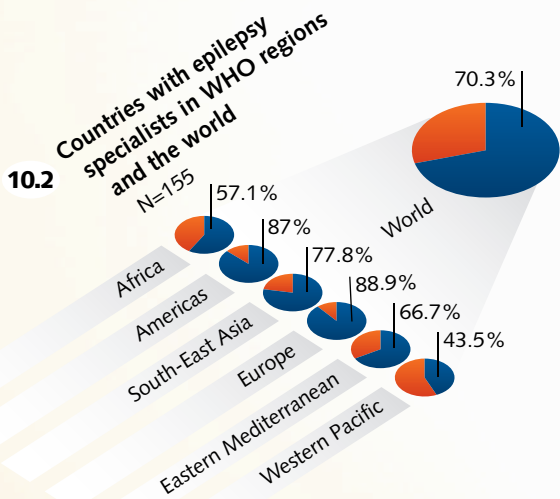
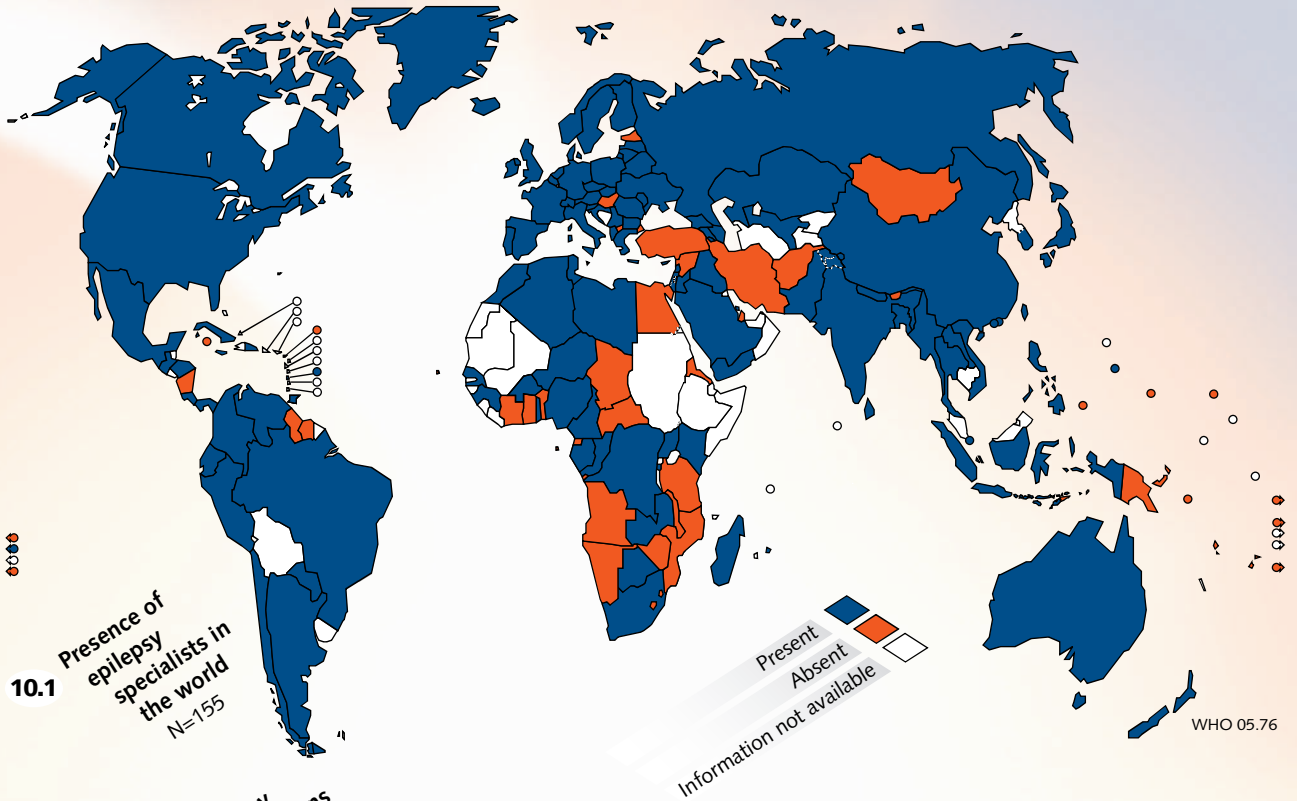
## Limitations

- ◆ 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.

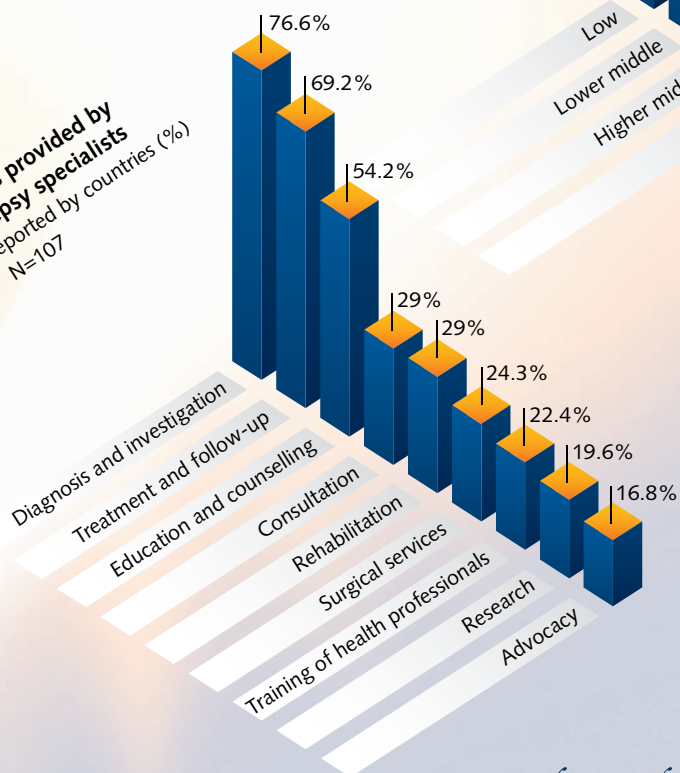
## Conclusions

- ◆ 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.





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



## Introduction

◆ The data are presented for the four commonly used AEDs: phenobarbital, phenytoin, carbamazepine and valproic acid. The respondents were asked about their inclusion in essential lists of drugs, government policy

on licensing, and the costs of the commonly used strength of the AEDs in local currency. For purposes of comparison, the costs are presented in international dollars as at 2000.

## Salient findings

◆ Inclusion of the first-line AEDs in the country's list of essential drugs varies. Phenobarbital is included in 95.4%, carbamazepine in 93.1%, phenytoin in 86.1% and valproic acid in 86.7% of the responding countries.

◆ In low-income countries, inclusion in the list of essential drugs varies for first-line AEDs. Phenobarbital is included in 96%, carbamazepine in 82.6%, phenytoin in 68.2% and valproic acid in 62.5% of the responding countries.

◆ Phenobarbital is included in the list of essential drugs in more than 90% of the responding countries in all the regions except South-East Asia, where it is included in 80% of the responding countries. In contrast, valproic acid is included by two thirds of the responding countries in Africa and South-East Asia.

◆ A government policy regarding availability of the first-line AEDs only by prescription (from either a general practitioner or a specialist) exists in more than 90% of the countries.

◆ The median cost of the daily defined dose (DDD) of the first-line AEDs in international dollars varies. While the median cost of phenobarbital is 0.14 international dollars, it is three times more for phenytoin, 11 times for carbamazepine and 16 times for valproic acid.

◆ The median cost in international dollars for the first-line AEDs is variable across WHO regions. The cost of carbamazepine and valproic acid in Europe and the Western Pacific is almost half that of other regions. The cost of phenobarbital is 2.7 times higher in South-East Asia than in Europe. The median cost of phenytoin in international dollars is five times more in the Americas than in the Western Pacific.

◆ In international dollars the median cost of treatment of epilepsy is three and half times higher for carbamazepine, phenytoin and valproic acid and two times higher for phenobarbital in low-income countries than in high-income countries.

## Limitations

◆ The data are available from only half the responding countries. However, the data represent 75% of the world's population.

◆ It is possible that a drug might be included in the country's essential drug list but that it is not available at all times and in the appropriate dosage in publicly provided services.

◆ Sometimes an essential drug list exists but it does not guide the purchasing and management of public sector drug supplies.

◆ The dose used for some of the people with epilepsy and children is lower than the DDD in many instances. The above-mentioned costs are therefore overestimated.

## Conclusions

◆ Presence of AEDs in the essential drug list can enhance their availability and public provision. This is an important measure to narrow the treatment gap for epilepsy.

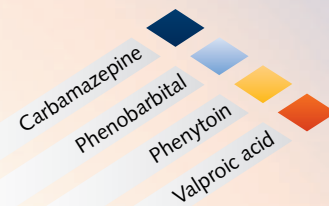
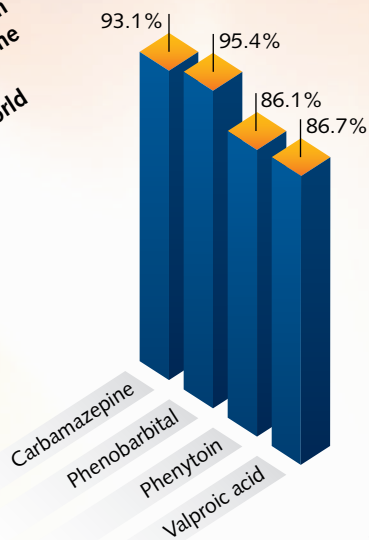
◆ In some high-income countries, drug formularies rather than essential drug lists exist, which are detailed lists of drugs that are approved or recommended for health providers and supply systems. Factors such as safety, effectiveness and cost-effectiveness are assessed before drugs are included in the formularies. This is important, especially for the newer AEDs.

◆ Inequity in the cost of first-line AEDs across regions, countries and income categories needs to be specifically tackled.

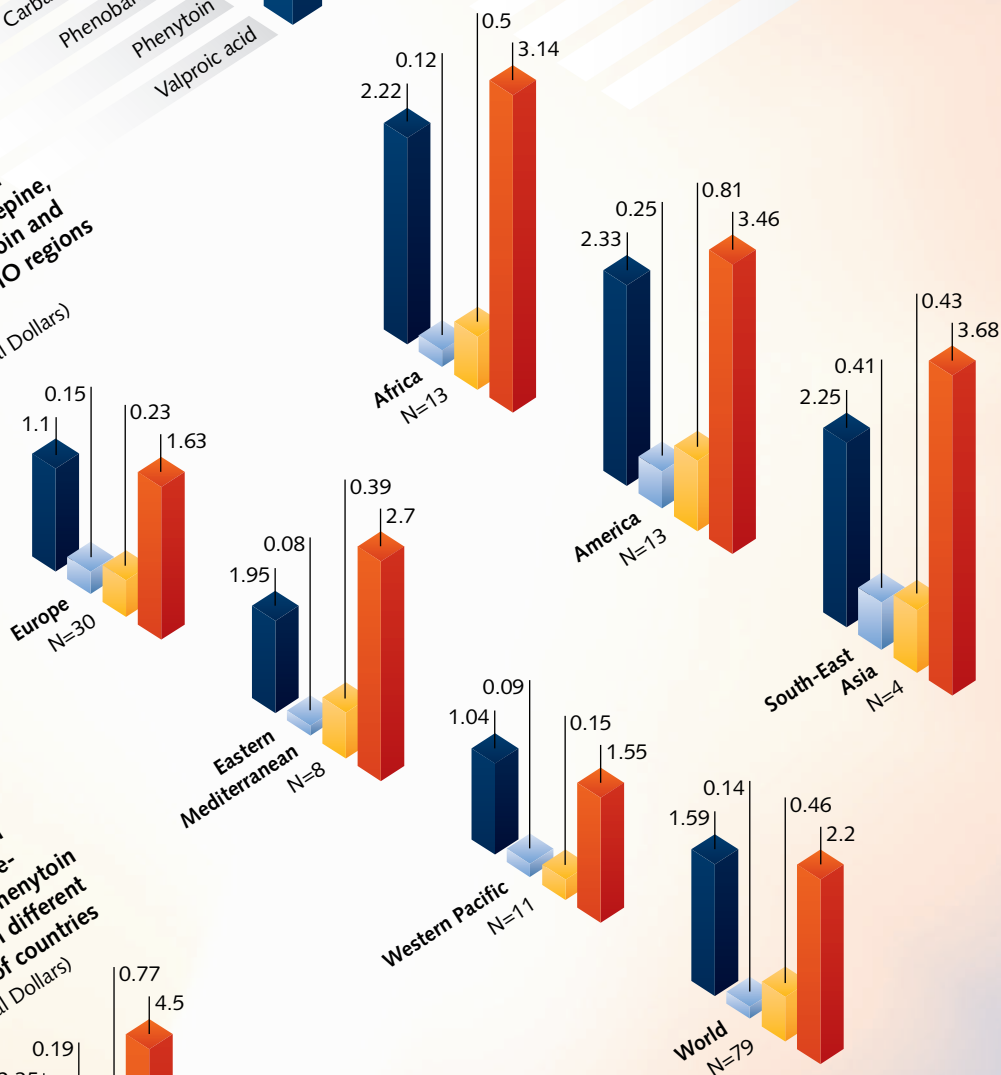
◆ Procedures must be adopted to decrease the pharmaceutical expenditure as it is a major component of the direct cost of epilepsy. This could be done by improving selection, open and transparent purchasing procedures and competitive purchasing.



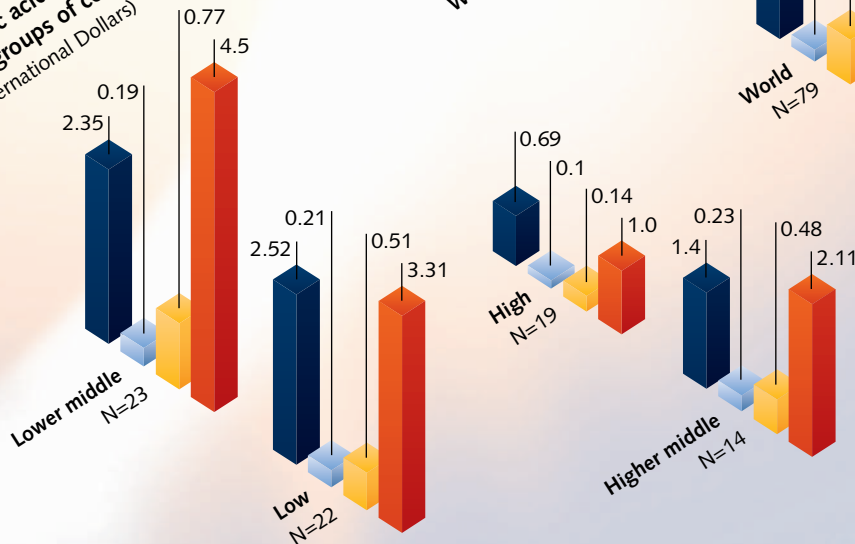
**11.1** Carbamazepine, Phenobarbital, Phenytoin and Valproic acid in the list of essential drugs in the world  
N=86



**11.2** Median cost of daily defined dose (DDD) of Carbamazepine, Phenobarbital, Phenytoin and Valproic acid in WHO regions and the world  
(in International Dollars)



**11.3** Median cost of daily defined dose (DDD) of Carbamazepine, Phenobarbital, Phenytoin and Valproic acid in different income groups of countries  
(in International Dollars)



### Prof Amadou Gallo Diop

A consensual definition of the so-called “treatment gap” was adopted by international experts gathered together by the ILAE: “The difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given point in time, expressed as a percentage” (2). It is estimated that 80% of the global health burden represented by epilepsy is borne by the developing world, where 80% of people with epilepsy reside and do not receive modern treatment, or are not even identified (66). Poor infrastructure, insufficient availability of drugs and scarcity of trained medical personnel are relevant factors in this situation (67). Some potential causes could be the level of health-care development, cultural beliefs, economy, distance from health-care facilities and supply of AEDs, and a lack of prioritization in national health policies.

Epilepsy is one of the major brain disorders worldwide. The condition is characterized by repeated seizures or “fits” which take many forms, ranging from a very short lapse of attention to severe and frequent convulsions. Epilepsy is responsible for an enormous amount of suffering affecting about 50 million people around the world (68), yet in the developing countries the large majority of people with epilepsy remain excluded from receiving care and are consequently maintained in the shadow of the treatment gap.

Both cultural and structural factors underpin the treatment gap. In many developing countries, epilepsy is perceived as a manifestation of supernatural forces, caused by ancestral spirits or attributed to possession by evil spirits (69, 70). The levels of literacy and knowledge influence cultural beliefs and treatment choices. Usually the family and the patient first consult the traditional healers and follow their recommendations for a long period of time (71, 72). The mean duration before seeking modern medical care can be several years and depends on the area of residence (urban or rural), the impact of cultural belief and the financial means; for example, reports from some countries reveal that this period can last 6–14 years (72).

People with epilepsy are often stigmatized, which discourages them from seeking the diagnoses and care they need and deserve (73). Another burden is the discrimination experienced by people who have seizures, who are able to work but are unemployed or underemployed. In some societies the fear of “contamination” by the breath, blood, sperm and genital secretion of people with epilepsy, and who are not treated, leads to unacceptable responses such as rushing away from a person experiencing a seizure without offering any help (70). Death, drowning, burning and other injuries may result from such situations. Children with epilepsy, victims of the treatment gap, often face discrimination and isolation at school, resulting in low self-esteem and underachievement. Surveys conducted in schools revealed a high rate of social withdrawal among children with epilepsy.

As far as structural factors are concerned, in several countries health insurance is poorly developed and the population consequently has to pay for health care. In such countries general economy, health and education expenditures are low while malnutrition and morbidity are dramatically high. Many aspects of health care have become unaffordable for the patient because of health system reforms conducted in the majority of the countries: one of the reasons invoked by the population for not seeking medical treatment is financial.

Epilepsy is a clear-cut example of a neurological disorder for which several pharmacological and alternative treatments are available. Recent studies in both the developing and the developed world revealed that, if properly treated, up to 70% of people with this condition could live productive and fulfilling lives, free from seizures (68). The AEDs most often prescribed in the developing world are phenobarbital and phenytoin. These two drugs are the cheapest and are prescribed in 65–85% of treated epileptic patients (68). They are available in most health establishments but are not accessible to the large majority of people with epilepsy (74, 75).

Another form of treatment gap is related to non-medical therapy for severe epilepsy in developed and developing countries. When people with epilepsy continue to have frequent seizures despite multiple drug therapy, epilepsy surgery may be indicated (76). In some parts of the world, epilepsy centres are performing surgery routinely, with minimal resources and good results in those selected from the 25% of people with epilepsy who do not benefit from drug therapy and who are candidates for such operations. Surgery could represent a significant improvement in the quality of life for some of the 20–30% of people with epilepsy who continue to have seizures while taking appropriate medication. Another alternative, especially in children with drug-resistant epilepsy, is the use of a ketogenic (very high fat content) diet. Although it is expensive and difficult to tolerate, reduction in the frequency of seizures has been consistently reported. There are no reports on the use of this method in Africa. An alternative to surgery is vagus nerve stimulation; as this involves implantation of an expensive device, its present applicability is limited to the developed world.

### Bridging the treatment gap

In order to solve progressively the huge challenge of reducing the treatment gap, professionals from various sectors managing every aspect of the lives of people with epilepsy will need to take action in a multidisciplinary approach, coordinating health, education, social and professional activities and psychology. These trained health and social workers must cooperate with patients and families, communicators, community leaders and opinion leaders, with the support of governments, national and international institu-



tions and nongovernmental organizations, bilateral and multilateral agencies and pharmaceutical companies. This need is summed up in ILAE/IBE/WHO Global Campaign Against Epilepsy publications (68, 77). The main actions recommended to bridge the epilepsy treatment gap are:

- ◆ fostering political commitment;
- ◆ improving access to care for epilepsy;
- ◆ arranging educational and training programmes on epilepsy for medical practitioners, nurses and midwives, social workers, and schoolteachers;
- ◆ developing adapted guidelines for epilepsy management;
- ◆ considering the cultural environment in any epilepsy health plan;
- ◆ facilitating collaboration with traditional healers and community leaders;
- ◆ ensuring the integration of epilepsy prevention in public health interventions;
- ◆ providing appropriate support and care.

In conclusion, the main problems are the lack of knowledge about epilepsy and the limited human and material resources in the majority of countries. In other words, the treatment gaps are widest where there is a lack of available, accessible and affordable health care – and part of good care is awareness raising and eradicating stigma. People with epilepsy in the developing world can wait years from the moment of their first seizure before they consult modern medical services and benefit from the progress achieved. The opportunity offered by the international collaborative initiative set up by the Campaign should progressively transform the situation and eliminate any possibility of a person with epilepsy not receiving treatment.

## Introduction

- ◆ The respondents were asked about the availability of various services such as epilepsy surgery, social rehabilitation, special education, sheltered work and special equipment.

They were asked whether these services were available free of charge or without special conditions when covered by insurance.

## Salient findings

- ◆ Epilepsy surgery is available in 40.9% of the responding countries.
- ◆ Epilepsy surgery is not available in 88.6% of the responding countries in Africa, 68.2% in the Western Pacific, 66.7% in South-East Asia, 50% in the Americas and the Eastern Mediterranean, and 33.3% in Europe.
- ◆ Epilepsy surgery is not available in 87% of low-income countries. The facility for epilepsy surgery is also absent in 34.3% of high-income countries.
- ◆ Facilities for social rehabilitation are available in 56.5% of the responding countries. In about half of them, social rehabilitation is available to people with epilepsy free of charge or without any special condition.
- ◆ No social rehabilitation services are available in 68.2% of the responding countries in the Western Pacific, 66.7% in South-East Asia, 57.1% in the Eastern Mediterranean, 37.8% in Europe, 37.1% in Africa, and 25% in the Americas.
- ◆ Some special equipment is available free of charge or without any special condition in 19.3% of the responding countries.
- ◆ Facilities for special education are available in 62.3% of the responding countries. In two thirds of them it is available to people with epilepsy free of charge or without any special condition.
- ◆ Special education facilities are available in 45.7% of low-income countries and in one third of them they are available free of charge. Such facilities are present in 77.1% of high-income countries and are available free of charge in three quarters of them.
- ◆ Facilities for sheltered work are available in 25.5% of the responding countries. In two thirds of them, sheltered work is available to people with epilepsy free of charge or without any special condition.
- ◆ Sheltered work facilities are available in 50% of the responding countries in the Americas, 42.2% in Europe, 9.1% in the Western Pacific, 8.6% in Africa, and 7.1% in the Eastern Mediterranean. They are not present in any of the responding countries in South-East Asia.
- ◆ Sheltered work facilities are not available in 93.5% of low-income countries. They are also absent in 37.1% of high-income countries.

## Limitations

- ◆ Respondents may have replied positively to the question of availability of sub-specialized services for epilepsy in the country even if only a very limited number of such facilities are available in a few large cities.
- ◆ Because the sources of information in most countries were key persons 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 above figures are overestimated.

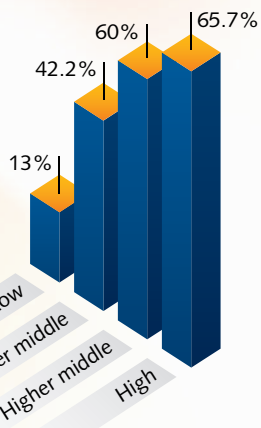
- ◆ Some respondents may have replied in the affirmative even if the sub-specialized services are part of the general services. It is also not clear what percentage of these services is available and utilized by people with epilepsy.

## Conclusions

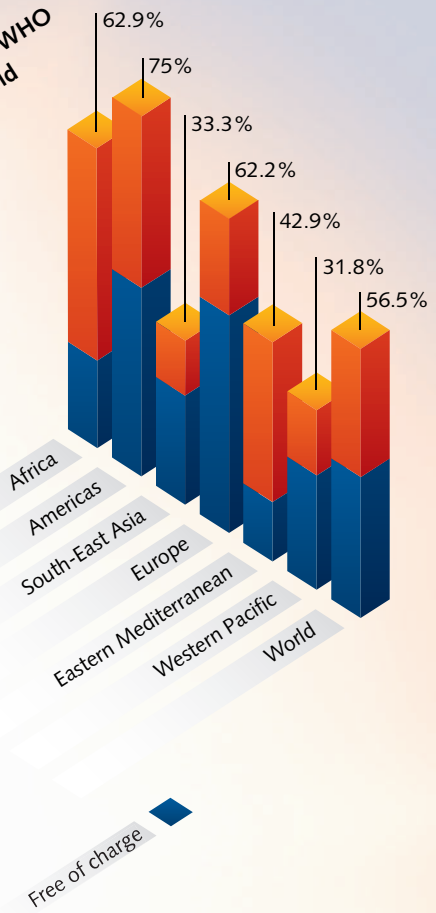
- ◆ Epilepsy surgery is an important treatment option for patients with intractable epilepsy and may reduce the need for long-term drug treatment.
- ◆ Severe social problems may occur in people with poorly controlled seizures, e.g. fewer social contacts, friends and leisure activities. Special social rehabilitation units aim to facilitate independent lifestyles and to reduce psychosocial disabilities.
- ◆ Special equipment is important for the rehabilitation of a subcategory of people with epilepsy to allow them a better quality of life and improved general social functioning.
- ◆ It is important to include as many children with epilepsy in mainstream schools as possible. Specialist units need to be established within countries to cope with the special educational needs of children with associated learning difficulties.
- ◆ Sheltered workshops allow the development of vocational competence, train for competitive employment and provide appropriate job placement.
- ◆ The inequity in the availability of sub-specialized services across regions and income groups of countries needs to be dealt with. The availability of these services needs to be improved even in high-income countries.



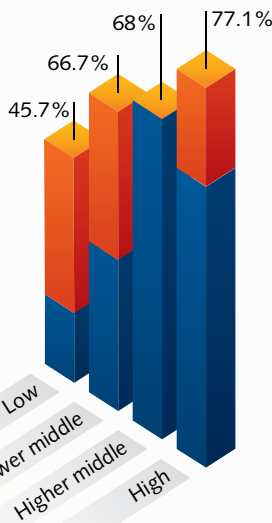
**13.1** Epilepsy surgery in different income groups of countries  
N=151



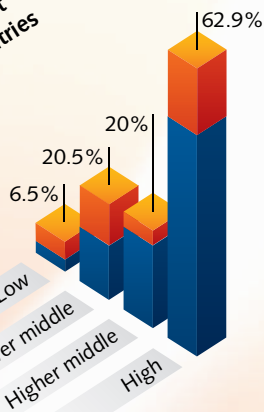
**13.2** Social rehabilitation in WHO regions and the world  
N=154



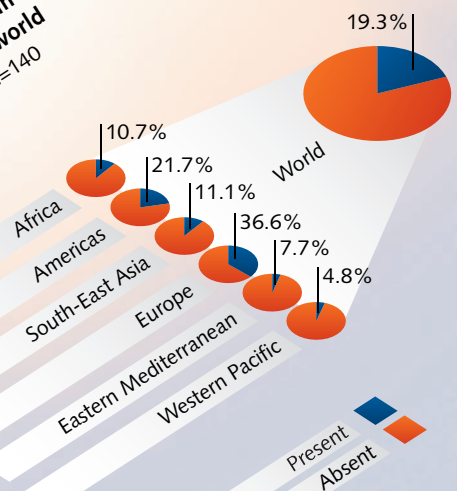
**13.3** Special education in different income groups of countries  
N=151



**13.4** Sheltered work in different income groups of countries  
N=150



**13.5** Special equipment free of charge in WHO regions and the world  
N=140



### Prof Jerome Engel Jr

Healers have entered the intracranial space for thousands of years to treat various illnesses. Ancient neurosurgical therapies, however, were based on beliefs of supernatural causes of disease and a need to release evil spirits. The modern approach to surgical treatment for epilepsy began in the late 19th century with the advent of scientifically based concepts of natural causes of epilepsy and the technical development of brain surgery (78). Initially, epilepsy surgery was based on identification of a visible, resectable lesion in the cerebral cortex, usually caused by head trauma resulting in an obvious skull fracture or scalp wound. Surgeons were also guided to the location of the epileptogenic brain area by the initial behavioural features of the epileptic seizures (79). By the early 20th century, potentially epileptogenic disturbances in the brain could be visualized by neuro-radiological techniques such as pneumoencephalography and cerebral angiography. The discovery of electroencephalography (EEG) in the mid-20th century, however, made it possible to localize an epileptogenic region for surgery based entirely on focal epileptiform EEG abnormalities, permitting effective surgery even in the absence of visible structural pathology (80, 81). Surgery, particularly for temporal lobe epilepsy, thus became an important alternative treatment for epilepsy in the industrialized world.

The application of epilepsy surgery again advanced significantly towards the end of the 20th century as a result of greatly improved neuroimaging, specifically magnetic resonance imaging (MRI), positron emission tomography (PET), and single photon emission computed tomography (SPECT), which further improved the ability to identify resectable epileptogenic brain lesions that were not apparent with previous diagnostic tools (82, 83). For the first time, hippocampal sclerosis, perhaps the most common cause of human epilepsy, could be reliably identified noninvasively, and the visualization of a variety of malformations of cortical development greatly enhanced opportunities for surgical treatment of catastrophic epilepsies of infancy and early childhood.

Today, as a result of continuing improvement in presurgical diagnostic technology, as well as microsurgical techniques, epilepsy surgery is a safe and effective alternative treatment for a wide variety of epileptic conditions that are not adequately treated by AEDs. Because surgical treatment is presently the only therapy that can actually cure epilepsy, and because complete elimination of epileptic seizures can prevent or reverse the severe psychological and social consequences of epilepsy, as well as developmental delay in some childhood epilepsy conditions, its timely application offers the potential to rescue people with epilepsy from a lifetime of disability.

Despite the introduction of many new AEDs over the past two decades, 30–40% of people with epilepsy who have access to such medications have seizures that cannot be

completely controlled by pharmacotherapy. It is estimated that one quarter to one half of people with medically refractory seizures are potential candidates for surgical therapy, or about 10% of the entire population of people with epilepsy. There is, therefore, a great need to facilitate the identification of potential surgical candidates, and to expand facilities for performing surgical therapy. A major impediment to timely and effective surgical intervention, however, has been the prevalent misconception that epilepsy surgery should be a last resort, considered only after treatment with all available AEDs has failed. There are now so many different AEDs available in the industrialized world that it would literally take a lifetime to try them all in every conceivable combination. In countries where many pharmacotherapeutic alternatives exist, it is necessary to develop guidelines to determine when to stop additional drug trials and consider surgical intervention.

The concept of surgically remediable epilepsy syndromes has been a major advance in this regard (84). Surgically remediable epilepsy syndromes are well-defined conditions with known pathophysiologies and natural histories. For these conditions, failure of two or three appropriate AEDs at adequate doses predicts subsequent pharmacoresistance with a high degree of confidence, whereas the likelihood of a seizure-free outcome with surgery, by definition, is 70–80%. Surgically remediable syndromes can be easily diagnosed noninvasively in most patients, and early surgical intervention is not only associated with seizure freedom in these patients but can prevent the development of irreversible psychological and social disabilities. The prototype of a surgically remediable epilepsy syndrome is mesial temporal lobe epilepsy. Patients with focal epilepsy due to discretely localized brain lesions also have surgically remediable epilepsy syndromes, as do infants and young children with catastrophic epilepsies attributable to diffuse brain disturbances limited to one hemisphere.

Surgically remediable syndromes can be easily identified by history, including an accurate description of the clinical seizures, routine EEG, and neuroimaging, preferably MRI. Presurgical evaluation usually requires inpatient video/EEG monitoring in order to capture and characterize habitual seizures and localize their site of origin in the brain. For some surgically remediable epilepsies, such as temporal lobe epilepsy, neuropsychological evaluation is important, often including an intracarotid amobarbital procedure to confirm that the contralateral hemisphere can support memory following mesial temporal lobe resection. Where sufficient resources exist, additional diagnostic techniques, such as intracranial video/EEG monitoring with intracerebral depth or subdural electrodes, PET, SPECT, functional MRI and magnetoencephalography (MEG) can also be used to help determine the area of brain to be resected. These diagnostic approaches, however, are usually only necessary when



patients present with difficult diagnostic problems, and not for those with the typical surgically remediable epilepsies. A psychiatric assessment is also recommended as part of the presurgical evaluation, to predict potential postoperative behavioural problems and help to deal with them. Patients operated on early in the course of their disorder are usually easily rehabilitated, but those who have had epilepsy for long periods of time may have difficulty adjusting to their seizure-free state.

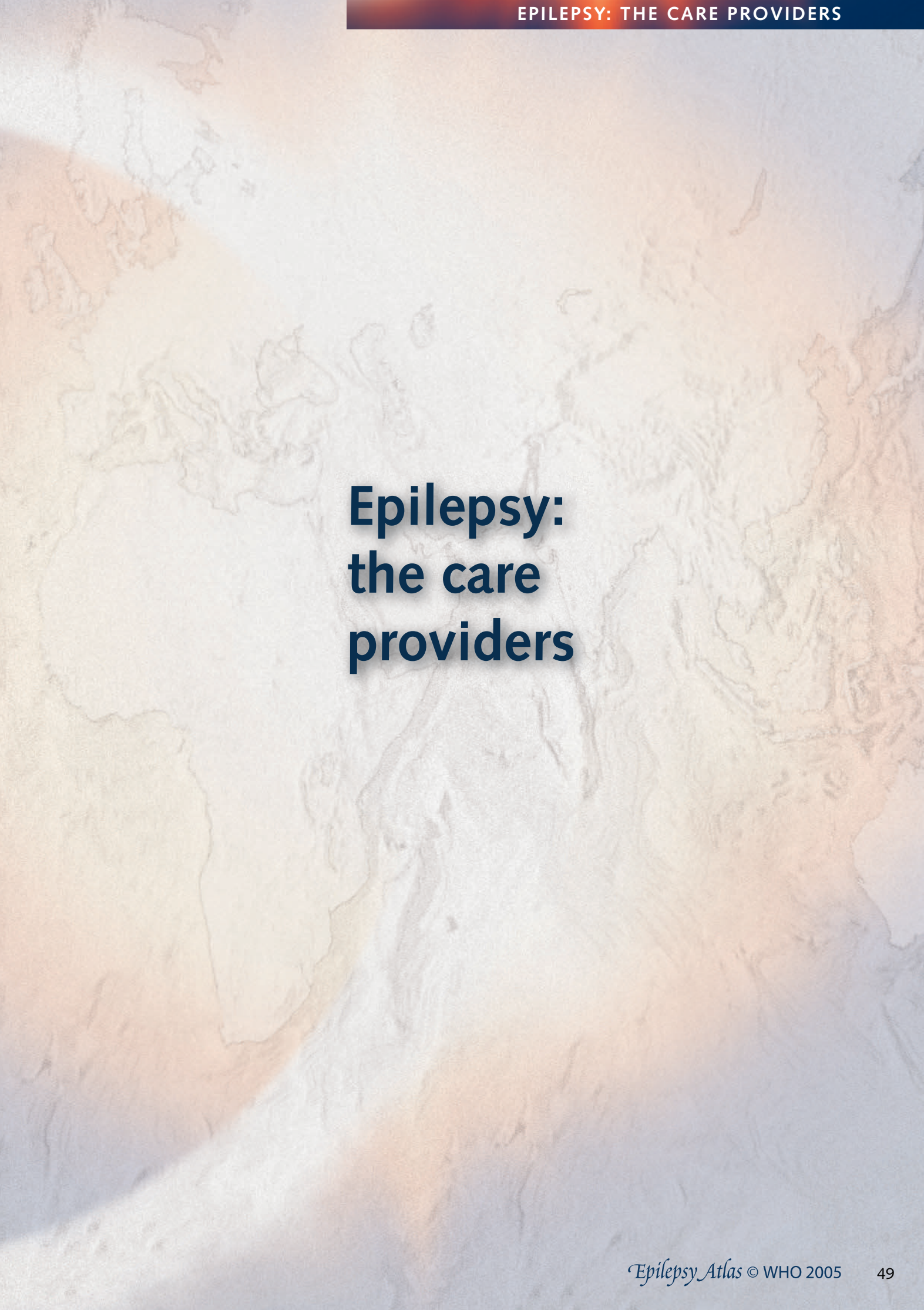
Temporal lobe epilepsy is usually treated with an anterior mesial temporal resection, and localized cortical lesions are treated with limited resections, which may require additional functional mapping to ensure that essential cortex is not damaged in the process. Published reports indicate that 60–90% of patients receiving these treatments can expect to become free of disabling seizures (85, 86). Complications, including infections, and unexpected neurological deficits occur in approximately 6% of patients, but half of these are transient. Surgical mortality is negligible. Infants and young children with catastrophic epilepsy are treated with hemispherectomy, hemispherotomy, or multilobar resections, and 60–80% become free of disabling seizures (87). Because these children usually already have hemiparesis with a useless hand, the surgery does not introduce additional neurological deficits. In fact, contralateral motor function can improve slightly, and developmental delay is often reversed. Surgical mortality, however, is somewhat higher than with the more focal resections. Many other types of epilepsy that are not the typical surgically remediable syndromes can also be treated surgically, but they require a more extensive presurgical evaluation; prognosis for a seizure-free outcome may range from 30% to 60%, and surgical complications are more likely. The risk–benefit ratio for surgery in these conditions is

considerably greater, therefore, than for the surgically remediable epilepsy syndromes, and these are not cost-effective procedures for countries with limited resources.

Whereas the treatment gap for epilepsy is of considerable concern in the developing world, there is a marked treatment gap with respect to epilepsy surgery even in industrialized countries, where perhaps only 5% of potential surgical candidates are ever referred to an epilepsy surgery centre. This is largely attributed to misinformation about the risks and benefits of surgery, particularly with respect to recent advances in diagnostic and surgical approaches that have greatly improved safety and efficacy. Until recently, epilepsy surgery was not available in countries with limited resources, but epilepsy surgery programmes are now prominent in Brazil, China, India and Turkey and are being developed in many other countries with limited resources where it is recognized as a more cost-effective treatment for surgically remediable syndromes than continued pharmacotherapy (88, 89). The success of epilepsy surgery programmes in countries with limited resources depends more on a well-trained clinical team, including a neurologist, neurosurgeon, clinical neurophysiologist, neuropsychologist, neuroradiologist and psychiatrist, than on high-level diagnostic and surgical technology. By investing in the appropriate clinical expertise, countries with limited resources can operate on patients with surgically remediable epilepsy syndromes and achieve results identical to those in the industrialized world, with only video/EEG and MRI. Because of the relatively high prevalence of surgically remediable epilepsy syndromes, particularly mesial temporal lobe epilepsy, investment in such epilepsy surgery centres, even in the poorest regions of the world, could greatly reduce the economic and human burden of epilepsy.







# Epilepsy: the care providers

## Introduction

- ◆ The respondents were asked about the number of specialist medical professionals such as neurologists, neuropaediatricians, psychiatrists and neurosurgeons involved

for 50% or more of their time in providing epilepsy care. This figure is used as a marker of their predominant involvement in epilepsy care.

## Salient findings

- ◆ A total number of 32 668 neurologists, neuropaediatricians, psychiatrists and neurosurgeons are reported to be involved predominantly in providing epilepsy care in the responding countries.
- ◆ Neurologists are involved predominantly in providing epilepsy care in 85% of the responding countries. A total of 14 094 neurologists involved predominantly in epilepsy care are reported to be available in 108 countries. In these countries, the median number per 100 000 population is 0.18 (interquartile range 0.05–0.46)
- ◆ The median number of neurologists per 100 000 population involved predominantly in epilepsy care varies widely across regions: 0.01 in South-East Asia, 0.06 in Africa and the Eastern Mediterranean, 0.08 in the Western Pacific, 0.30 in the Americas, and 0.33 in Europe.
- ◆ Neuropaediatricians are involved predominantly in providing epilepsy care in 77% of the responding countries. A total of 5 283 neuropaediatricians involved predominantly in epilepsy care are reported to be available in 87 countries. The median number per 100 000 population is 0.08 (interquartile range 0.03–0.23).
- ◆ The median number of neuropaediatricians involved predominantly in epilepsy care per 100 000 population varies from zero in South-East Asia to 0.14 in Europe.
- ◆ Psychiatrists are involved predominantly in providing epilepsy care in 69.6% of the responding countries. A total

of 11 869 psychiatrists involved predominantly in epilepsy care are reported to be available in 80 countries. The median number per 100 000 population is 0.10 (interquartile range 0.03–0.28).

- ◆ The median number of psychiatrists involved predominantly in epilepsy care per 100 000 population is 0.08 in Africa, while it is 0.20 in the Eastern Mediterranean.
- ◆ More psychiatrists are involved predominantly in epilepsy care in low-income countries compared with high-income countries (median number per 100 000 population: 0.09 and 0.03, respectively).
- ◆ Neurosurgeons are involved predominantly in providing epilepsy care in 68.8% of the responding countries. A total of 1422 neurosurgeons involved predominantly in epilepsy care are reported to be available in 75 countries. The median number per 100 000 population is 0.04 (interquartile range 0.01–0.09).
- ◆ The percentage of medical professionals involved in epilepsy care varies across income groups of countries. For example, 100% of total number of neurologists are involved predominantly in providing epilepsy care in low-income countries compared with 7% in high-income countries (The data for the total number of neurologists refers to the Atlas of country resources for neurological disorders (5)).

## Limitations

- ◆ It is difficult to quantify the number of medical professionals involved predominantly in epilepsy care. The figures are based on best estimates by the respondents.
- ◆ Information about the distribution of the medical professionals in countries is not available but, as reported by some respondents, the majority are likely to be concentrated in urban areas, thus leading to more inequity than is apparent from the above figures.

- ◆ The number of medical professionals is greater in higher middle-income countries than in high-income countries. This could be attributable to different definitions of the specialists, or there could be reporting errors.
- ◆ The number of psychiatrists involved in epilepsy care is lower in high-income countries compared with low-income countries. One possible reason for this could be the presence or absence of neurology specialists in these countries.

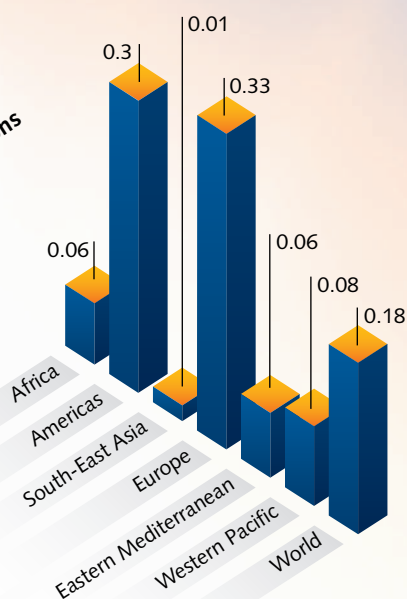
## Conclusions

- ◆ Specialist medical professionals are important members of the team providing comprehensive care for people with epilepsy, especially at tertiary level. They are also essential for training and providing support and supervision to primary health-care providers in epilepsy care.

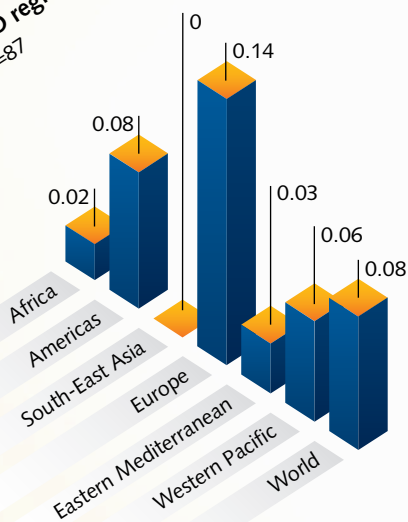
- ◆ The inequity in the number of specialist medical professionals observed across countries in different income groups and geographical areas needs to be specifically dealt with.



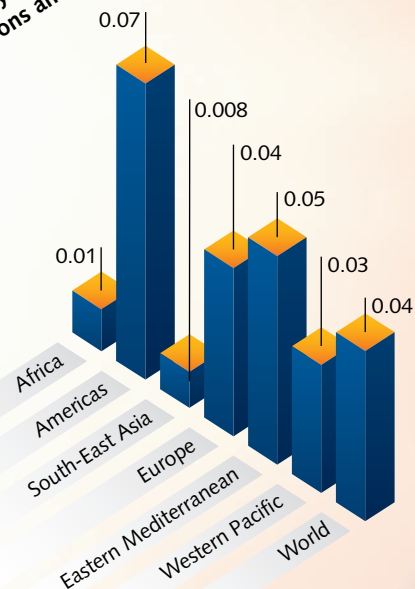
**15.1** Median number of neurologists per 100 000 population involved predominantly in epilepsy care in WHO regions and the world  
N=108



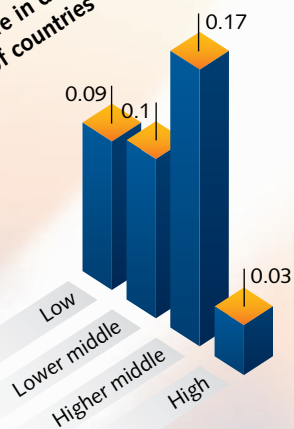
**15.2** Median number of neuropaediatricians per 100 000 population involved predominantly in epilepsy care in WHO regions and the world  
N=87



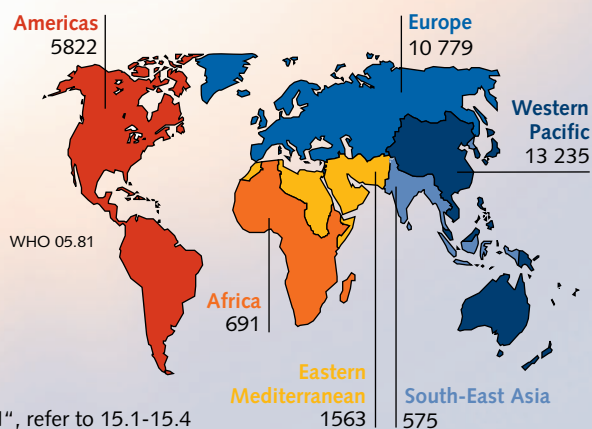
**15.3** Median number of neurosurgeons per 100 000 population involved predominantly in epilepsy care in WHO regions and the world  
N=75



**15.4** Median number of psychiatrists per 100 000 population involved predominantly in epilepsy care in different income groups of countries  
N=80



**15.5** Number of medical professionals providing epilepsy care in WHO regions\*



\* For "N", refer to 15.1-15.4

## Introduction

- ◆ The respondents were asked about the number of professionals allied to medicine such as neurological nurses, psychologists and social workers involved for 50% or

more of their time in providing epilepsy care. This figure is used as a marker of their predominant involvement in epilepsy care.

## Salient findings

- ◆ A total number of 19 732 neurological nurses, psychologists and social workers are reported to be involved predominantly in providing epilepsy care in the responding countries.
- ◆ Neurological nurses are involved predominantly in providing epilepsy care in 56.5% of the responding countries (N=92). A total of 2036 neurological nurses involved predominantly in epilepsy care are reported to be available in 52 countries. In these countries, the median number per 100 000 population is 0.11 (interquartile range 0.06–0.36).
- ◆ While the median number of neurological nurses per 100 000 population in Europe is 0.19, it is 0.03 in South-East Asia.
- ◆ The median number of neurological nurses per 100 000 population involved predominantly in epilepsy care is 0.07 for low-income countries; it is 0.17 and 0.11, respectively, for higher middle-income and high-income countries.
- ◆ Psychologists are involved predominantly in providing epilepsy care in 63.2% of the responding countries (N=106). A total of 10 342 psychologists involved predominantly in epilepsy care are reported to be available in 67 countries, in which the median number per 100 000 population is 0.05 (interquartile range 0.02–0.12).
- ◆ Social workers are involved predominantly in providing epilepsy care in 62% of the responding countries (N=100). A total of 7354 social workers involved predominantly in epilepsy care are reported to be available in 62 countries. The median number per 100 000 population is 0.07. This number varies widely across regions: it is 0.004 in South-East Asia, 0.03 in the Eastern Mediterranean, 0.07 in Africa, 0.09 in the Americas and Europe, and 0.27 in the Western Pacific.
- ◆ The percentage of professionals allied to medicine involved predominantly in epilepsy care is low, e.g. only 5% of the total numbers of psychologists are involved predominantly in providing epilepsy care (the data for the total number of psychologists refers to the Atlas of mental health resources in the world (4)).

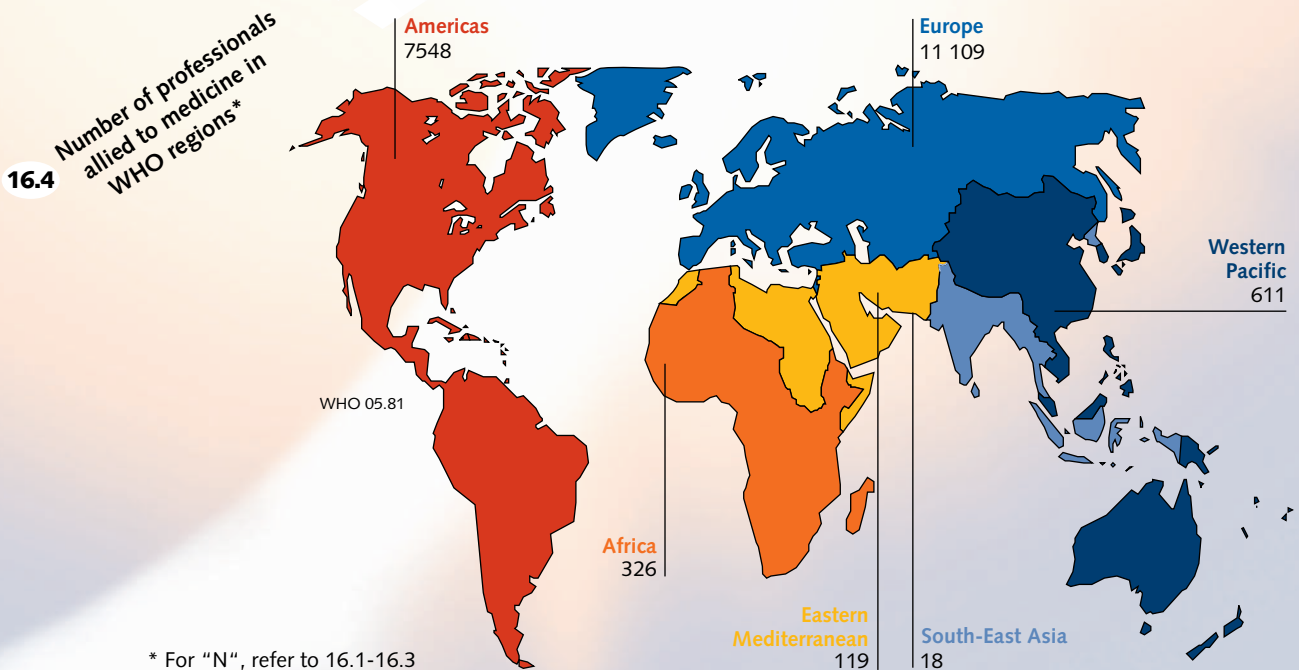
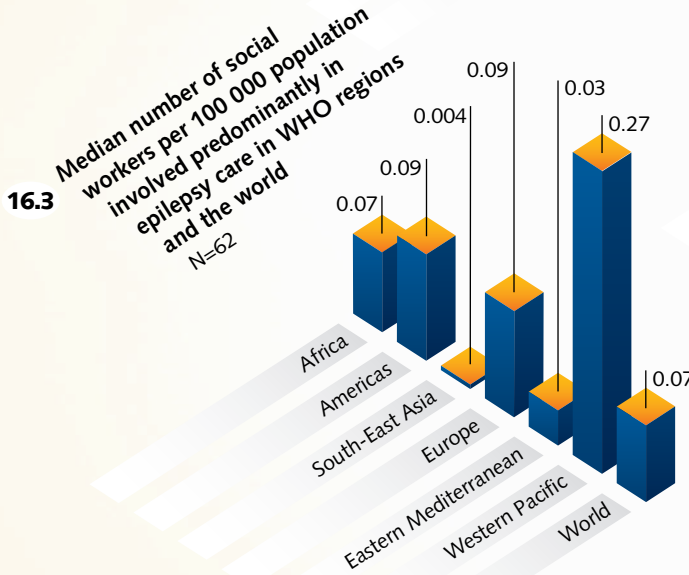
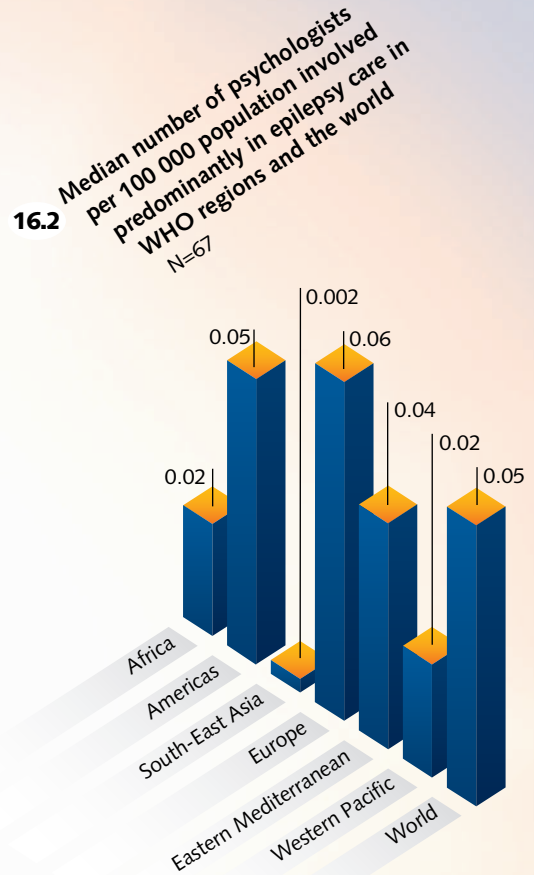
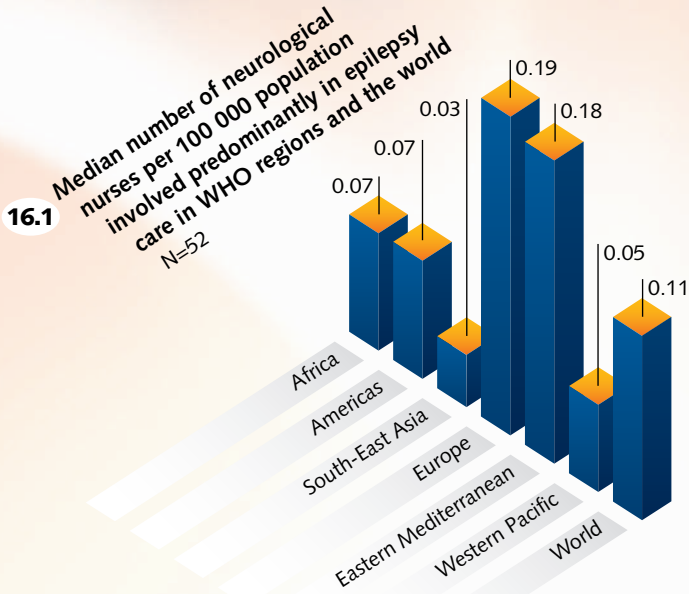
## Limitations

- ◆ Some countries were unable to provide data regarding various professionals allied to medicine as they do not have a separate register.
- ◆ Information about the distribution within countries of professionals allied to medicine is not available but, like all other specialist human resources, the majority are likely to be concentrated in urban areas.
- ◆ The number of professionals allied to medicine is greater in higher middle-income countries than in high-income countries. This could be attributable to different definitions of the specialists, or there could be reporting errors.
- ◆ In significant number of countries where no formal training programme exists for neurological nursing, many nurses are informally trained in aspects of neurological care. This is not reflected in the data.
- ◆ It is possible that the job description of social workers differs among the countries, making comparison of numbers difficult.

## Conclusions

- ◆ For many chronic disorders such as epilepsy, nurses can be important providers of primary care and liaison services at community level. Emphasis is needed to give them appropriate training and facilities for providing care to people with epilepsy.
- ◆ In spite of the limitations of the data set, it is clear that the number of social workers working in the field of epilepsy is grossly inadequate. Efforts need to be made to improve the situation.
- ◆ Psychologists are important members of the multidisciplinary team providing comprehensive care to people with epilepsy. They have an important role in the diagnosis, treatment, presurgical evaluation and rehabilitation of people with epilepsy.





\* For "N", refer to 16.1-16.3

## Introduction

- ◆ This theme refers to specialist training in the diagnosis, prevention, care, rehabilitation and research in epilepsy for medical graduates and professionals allied to medicine.

## Salient findings

- ◆ Training facilities in epileptology are available in only 15.8% of the responding countries.
- ◆ No facility for training in epileptology exists in countries in South-East Asia, whereas such facilities exist in only 2.6% of the countries in Africa, 6.7% in the Eastern Mediterranean, 17.4% in the Western Pacific, 20.8% in the Americas, and 31.8% in Europe.
- ◆ While only 2.1% of the low-income countries have a training programme in epileptology, 28% and 23.5% of the higher middle-income and high-income countries, respectively, offer training in epileptology.
- ◆ The median duration of training in epileptology is 12 months (interquartile range 5–12). A median number of 10 (interquartile range 5–20) students obtain a specialist degree in epileptology every year in the responding countries.

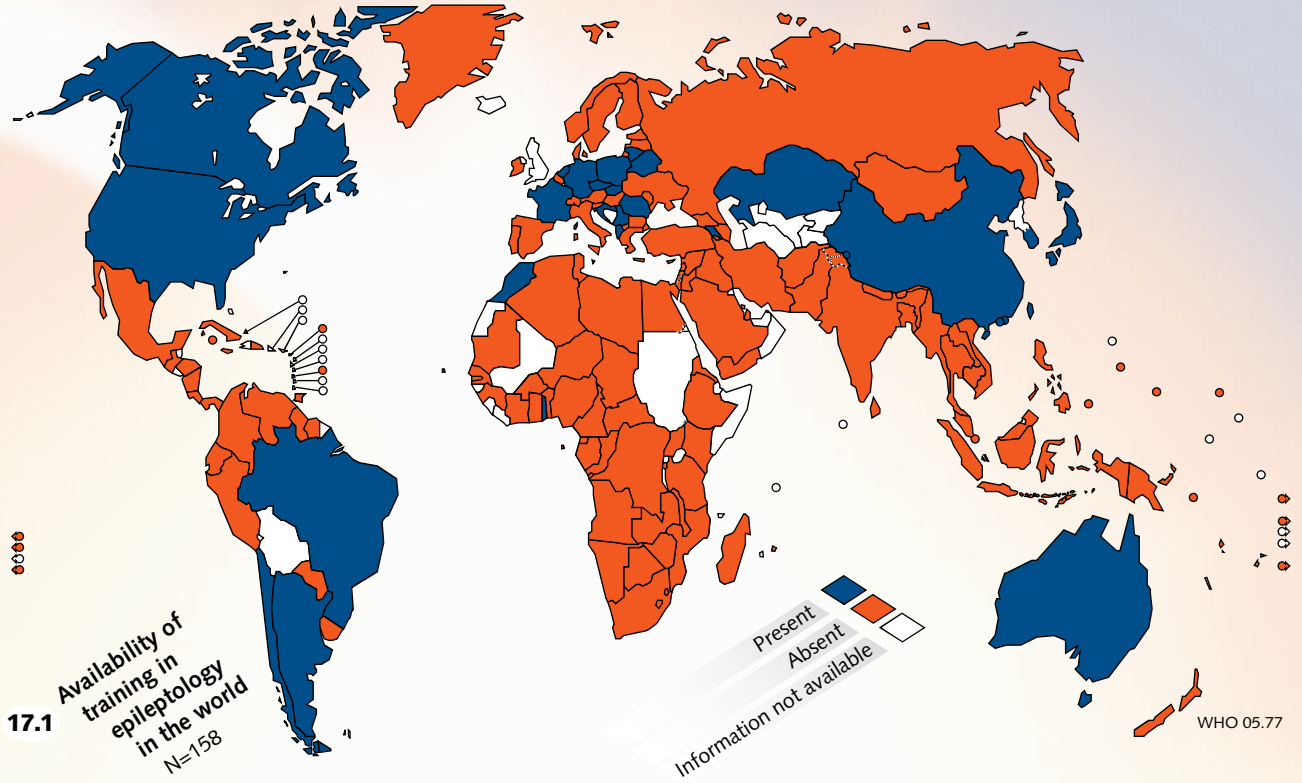
## Limitations

- ◆ Information was not obtained regarding the prerequisite qualification required to train in epileptology.
- ◆ As mentioned by some respondents, informal training in epileptology is carried out without licensing. The data do not include this information; e.g. in several countries that do not provide a formal diploma or degree in epileptology academic chairs have been instituted, usually in the department of neurology and often in combination with the chair for electroencephalography and clinical neurophysiology.
- ◆ Data regarding the structure of training or the training curriculum are not available.

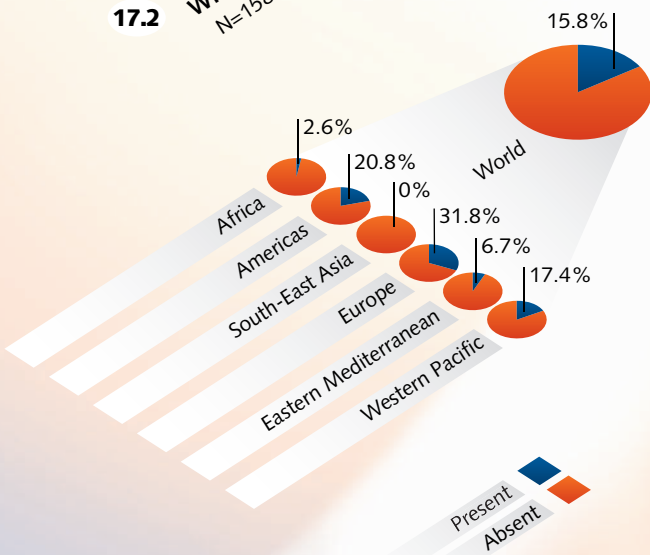
## Conclusions

- ◆ Education in the field of epileptology plays a key role in reducing the burden of epilepsy and facilitating the rehabilitation of people with epilepsy.
- ◆ Specialist training in epileptology is needed on multiple levels to reach all those concerned in epilepsy management.
- ◆ There is a need to establish eligibility criteria for entry to training programmes, accreditation of training centres and criteria for epileptologists based on local needs. The epilepsy organizations are playing a significant role in organizing epilepsy education.
- ◆ Educational materials, including standard guidelines for diagnosis and care of people with epilepsy, ought to be produced and distributed in resource-poor countries where training facilities cannot be established because of the high costs involved. Opportunities for the training of professionals involved in epilepsy care from low-income countries should also be encouraged.

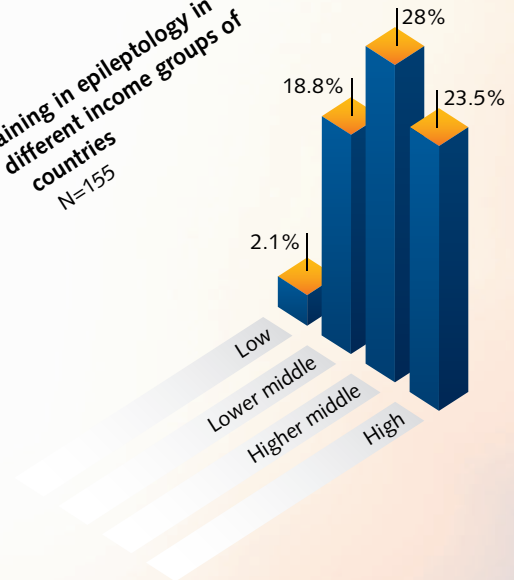




**17.2 Training in epileptology in WHO regions and the world**  
N=158



**17.3 Training in epileptology in different income groups of countries**  
N=155



### Prof Peter Wolf

Good training and continuous education of the professionals involved in epilepsy treatment are the key to any improvements in the care of people with epilepsy. Epilepsy care needs to be comprehensive, including medical, social and psychological aspects, and multiple professions are therefore involved. Dependent on the complexity of the individual case, care is provided at the primary, secondary and tertiary levels of health care. ILAE gives professional education the highest priority. Traditionally, epileptological training is obtained on-site in well-known epilepsy centres, and updates of knowledge are offered in courses and other meetings organized by ILAE Chapters, epilepsy centres, pharmaceutical companies and others. Since the early 1990s, a master course in epilepsy is offered for a fee by King's College, London, United Kingdom, and the French ILAE Chapter has organized a diploma course in epileptology in cooperation with several universities (diplôme inter-universitaire).

Organized, structured educational activity on a larger scale started in ILAE in 1996, with the establishment of a regional academy in the European Region – the European Epilepsy Academy (EUREPA) – which has since been given global responsibility. The Academy set out by establishing a modular curriculum for the education and certification of epilepsy specialists to ensure the availability of a three-level system of care in all European countries. Many epilepsy centres and other institutions that provide on-site training in epileptology joined the Academy. Existing educational courses and meetings in the various countries were included in the curriculum on the basis of indicators of quality, and with systematic evaluations. These courses which receive EUREPA acknowledgement were supplemented with new courses in previously neglected fields. Educational seminars of EUREPA became a regular part of the international and regional epilepsy congresses of ILAE and IBE and other major meetings, including the annual meetings of several national ILAE Chapters.

Train-the-trainer courses established a multinational and multilingual group of certified EUREPA trainers who take responsibility for these educational activities at the national and regional levels. It turned out that the Academy courses were attended by doctors working at the secondary health-care level even more than by aspiring epilepsy specialists, so the trainers adjusted the focus of their teaching accordingly to neurologists, paediatricians and psychiatrists.

In addition, EUREPA's system of medical education is now being supplemented by a similar programme for other health professionals involved in epilepsy care – professions allied to medicine such as neurological nurses, psychologists, social workers and EEG technicians. This extension is being developed as a joint endeavour of ILAE and IBE.

The globalization of ILAE's educational activity is taking place in various ways. Other regional commissions in cooperation with EUREPA are organizing similar academies in their regions. The most advanced of these is the Asian and Oceanian Epilepsy Academy (ASEPA), whose activities include epilepsy meetings for the primary and secondary sector in the least developed countries of the region, educational sessions at the biennial regional epilepsy congresses, and an offer of scholarships for training selected individuals in epilepsy centres. An Eastern Mediterranean Epilepsy Academy is also under development.

Advanced courses and summer schools are offered to groups of postgraduate students for 1–2 weeks with a distinguished faculty of international epileptologists. Since 2002, ILAE has been organizing annual summer courses in Venice, Italy, at the International University on San Servolo. Students from all over the world are selected on the basis of their qualifications, experience, affiliation and publications, with grants to candidates from less affluent countries. The courses are partially research-oriented (e.g. Bridging basic with clinical epileptology) and partly theme-centred (e.g. Paediatric epileptology). In September 2005, a new summer school on clinical pharmacology of antiepileptic drugs was organized for the first time, in Eilat, Israel, on behalf of the ILAE Commission on European Affairs, also with grants to allow the participation of non-Europeans.

More needed to be done, however, to reach out to regions where distances are larger than in Europe, travel is expensive, and fewer possibilities exist to receive on-site education in centres or to attend quality courses. In 2004, EUREPA therefore started a programme of distance education with a pilot module about genetics in epilepsy. This e-learning programme uses the Internet with a special learning platform. The advantages are:

- ◆ participation on an equal basis is possible for anyone with a computer and Internet access in any part of the world;
- ◆ a tutorial system gives every participant individual access to interaction with an expert in the specific field;
- ◆ apart from an initial meeting, no displacements are necessary;
- ◆ costs are much lower than for meetings or on-site education; for students who cannot pay even the modest course fee, grants are made available.

There are also some disadvantages:

- ◆ the course has a tight time schedule which may cause problems for students who have many professional or personal commitments;



- ◆ a ratio of 20 students to one tutor seems to be the reasonable maximum, which means that either many tutors are needed or only a few students can participate;
- ◆ the students have different levels of epileptological knowledge when they enter the course;
- ◆ computers with Internet access are often not available in some of the countries most in need;
- ◆ a relatively high standard of fluency is required in the language in which the course takes place (at present tuition is available only in English).

Because there is a high interest in these distance learning courses, ILAE will need to recruit many tutors in several languages from its membership. This seems to be possible, however, because the need for education is widely understood. Other modules need to be developed so that distance training in as many aspects of epileptology as possible can be provided. For some fields more sophisticated technologies will be required, to enable the exchange of EEG and imaging data or of videos.

The linguistic aspect of education that becomes evident with respect to e-learning has in fact been recognized by EUREPA from the outset. On the principle that a high standard education in epilepsy should be available to everybody in his or her own language, the certified EUREPA trainers already cover more than 35 languages. More specifically, as Africa

remains a region where epileptology is difficult to develop, EUREPA and members of the French ILAE Chapter took an initiative for French-speaking Africa of establishing a francophone section of EUREPA in 2002. Special sessions took place during annual meetings of the French League, and a series of train-the-trainer courses in French for participants from North and West Africa was started in autumn 2004. These activities are already beginning to make a visible difference in Africa.

At its last strategic planning meeting, ILAE decided to pursue, intensify and broaden these initiatives, and to make education the first priority for the coming years. Special attention will be paid to regions that until now have been only marginally involved in ILAE's educational programmes. For some regions, this will require the education of the primary health-care sector including professions allied to medicine. Additional language Academy sections are planned, the next being a Portuguese-speaking section as a joint effort of the Portuguese and Brazilian ILAE Chapters and EUREPA. The modular system of provision of education, comprising the three components of on-site training in centres, summer schools and advanced courses, and e-learning will be further developed and streamlined. It is ILAE's ambition to establish an exemplary global educational system, and in this way take epilepsy care worldwide a large step further.

## Introduction

- ◆ Professional organizations refer to the organizations of physicians and other health professionals in the field of patient care, research or education in epilepsy and whose

principal concern is with the problems of epilepsy; such organizations are usually nongovernmental.

## Salient findings

- ◆ A professional organization of epilepsy specialists exists in 60.6% of the responding countries.
- ◆ Of the responding countries, 69.6% and 63.2% in the Western Pacific and Africa, respectively, do not have a professional organization of epilepsy specialists, compared with 44.4% in South-East Asia, 26.7% in the Eastern Mediterranean, 24% in the Americas, and 8.9% in Europe.
- ◆ A median number of 75 (interquartile range 30–213) professionals are members of the organization in the responding countries. The median number of professionals who are members of organizations per 100 000 population is 0.75 (0.25–2.08).
- ◆ The median number of professionals per 100 000 population who are members of an organization of epilepsy specialists is 0.17 in South-East Asia and Africa, and 0.31, 0.33 and 0.35 in the Western Pacific, the Eastern Mediterranean and the Americas, respectively, compared with 2.15 in Europe.
- ◆ Professional organizations of epilepsy specialists do not exist in 64.6% of low-income countries compared with 22.9% of high-income countries. Also, the median number of professionals per 100 000 population who are members of an organization of epilepsy specialists varies across different income groups of countries (0.19 in low-income countries, compared with 1.83 in high-income countries).
- ◆ The professional organizations of epilepsy specialists are involved in various activities including: organizing professional meetings and conferences on epilepsy (97.9% of responding countries), publishing guidelines and recommendations on epilepsy (77.9%), advocacy on epilepsy-related issues (72.9%), advising government (70.8%), constructing curricula for postgraduate training in epileptology (27.4%), recognizing or certifying specialists in epileptology (17.7%) and accrediting epilepsy centres for postgraduate training in epileptology (16.7%).

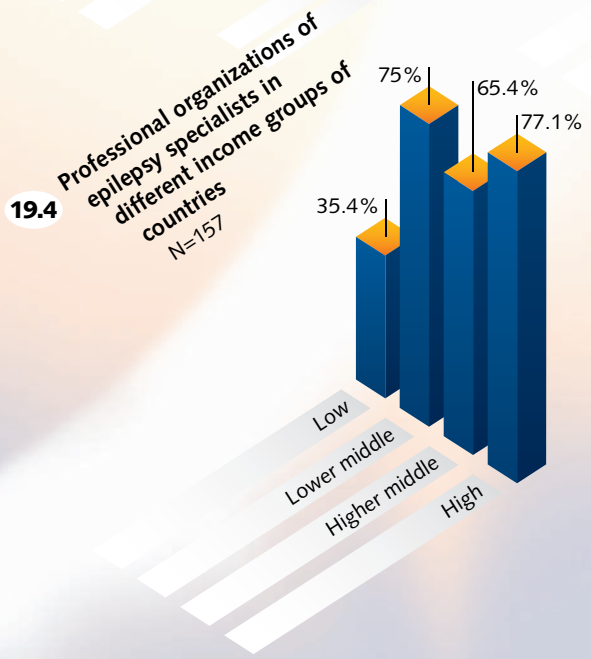
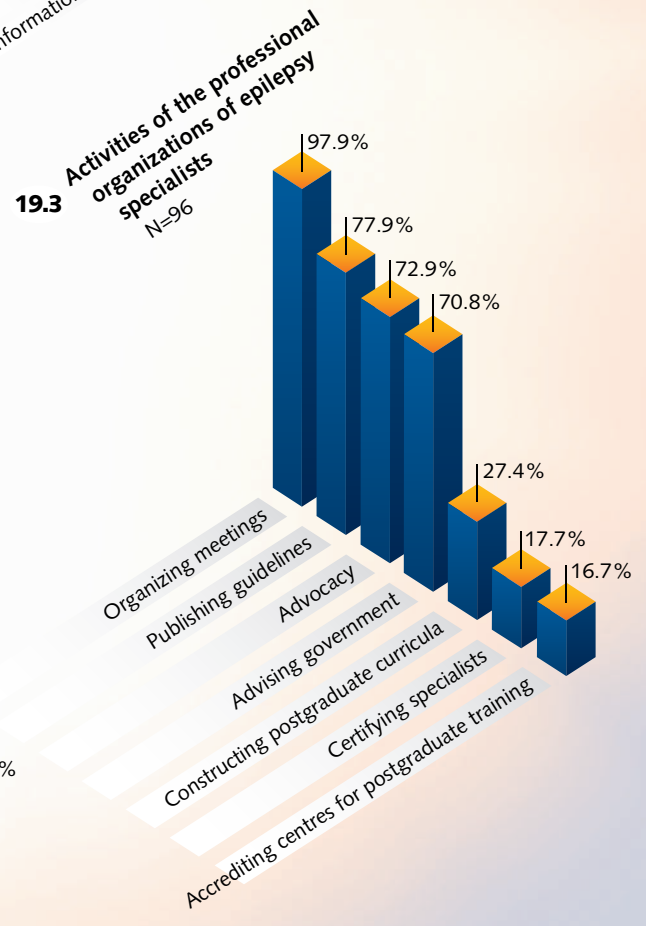
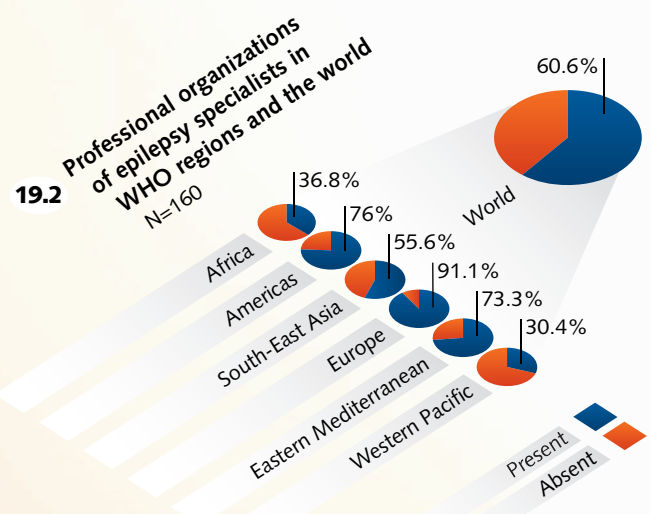
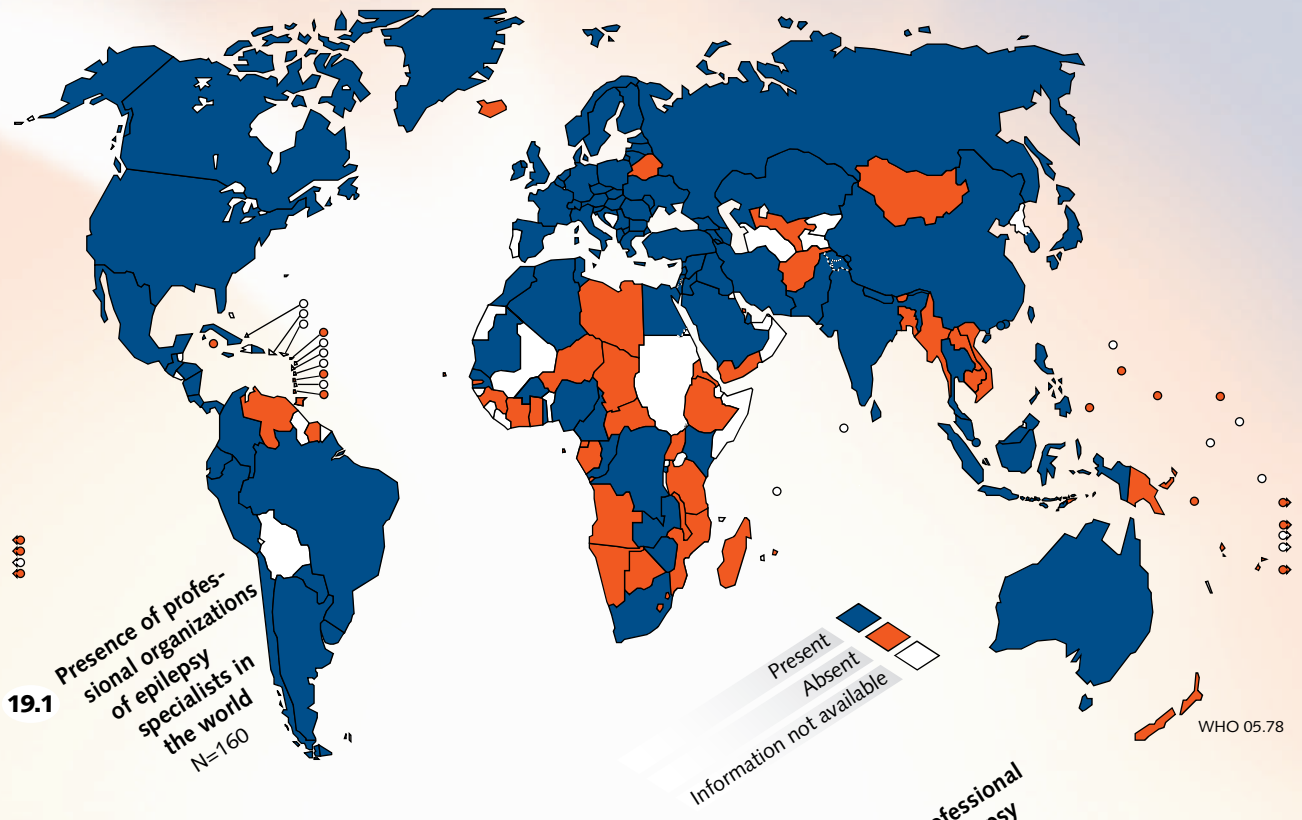
## Limitations

- ◆ Because the sources of information in most countries were key persons working in the field of epilepsy and possibly members of a professional organization, the data pertain mainly to countries where there are physicians or neurologists with an interest in epilepsy. It is therefore possible that the above figures are overestimated.
- ◆ Some of the epilepsy specialists working in the country might not be members of any organization. The number of members would therefore underestimate the total number of professionals working in the field of epilepsy care.
- ◆ Information is lacking regarding the coverage of the population by the activities specified within the countries.
- ◆ Information concerning the quality of services is not available.
- ◆ Many of the professional organizations reported that they are also involved in providing services and care for people with epilepsy; as it was not asked for, this activity has not been brought out by the results of the survey.

## Conclusions

- ◆ The presence of professional organizations of epilepsy specialists is an important aspect of the provision of the highest quality of care and improved well-being for those afflicted with epilepsy and other related seizure disorders. Efforts should be made to encourage the development of such professional organizations.
- ◆ The professional organizations should be more involved in promoting the education, training and research activities in epilepsy.
- ◆ A large number of professional organizations of epilepsy specialists work under the umbrella of ILAE (which has Chapters in over 90 countries), leading to collaborative efforts in various activities related to patient care, education, training and research.





## Introduction

- ◆ Lay associations refer to voluntary organizations, charitable groups or advocacy groups working in the area of epilepsy, and groups of patients and service carers.

## Salient findings

- ◆ Of the responding countries, 60% have at least one patient or lay association working in the field of epilepsy.
- ◆ No patient or lay epilepsy association exists in 60% of the responding countries in the Eastern Mediterranean, 52.6% in Africa, 47.8% in the Western Pacific, 44.4% in South-East Asia, 32% in the Americas, and 17.8% in Europe.
- ◆ Patient or lay epilepsy associations are absent in 54.2% of low-income countries, compared with 20% of high-income countries.
- ◆ The patient or lay epilepsy associations are involved in a range of activities in responding countries including: education (95.8%), awareness and advocacy (91.6%), treatment (56.8%), rehabilitation (53.7%) and prevention (53.7%).

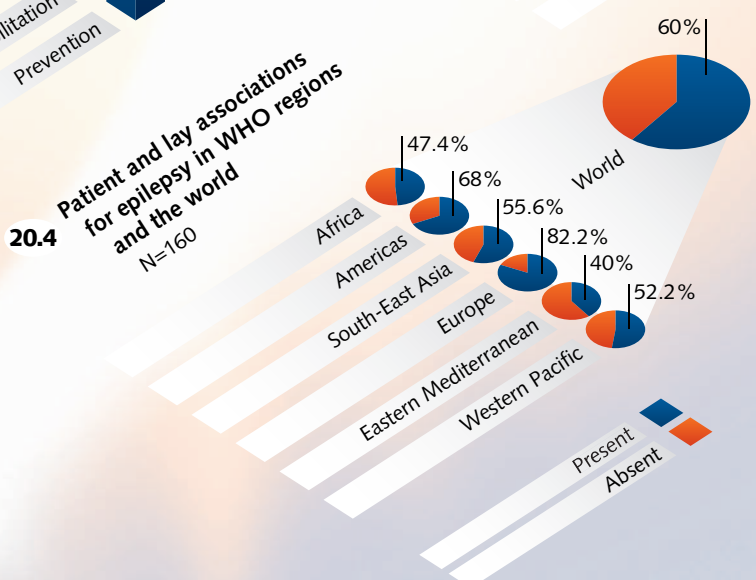
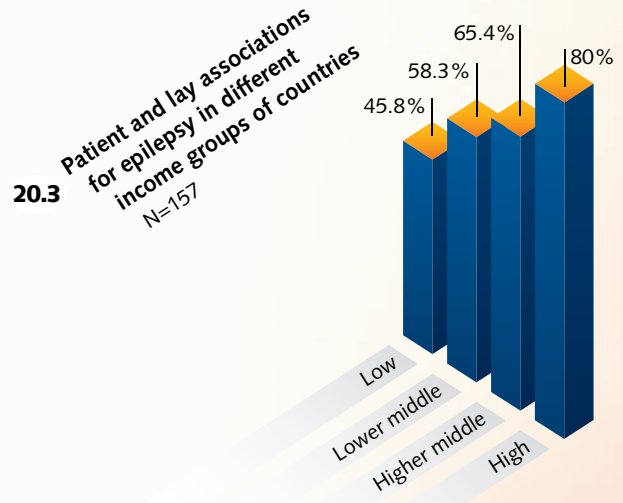
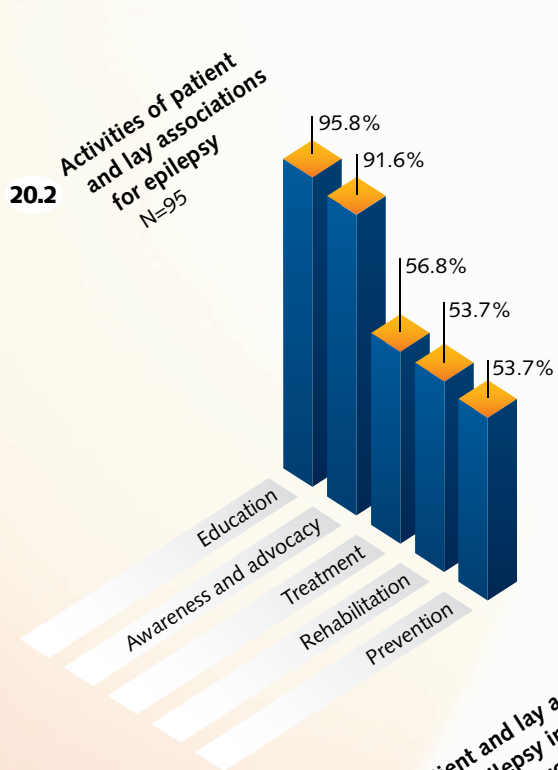
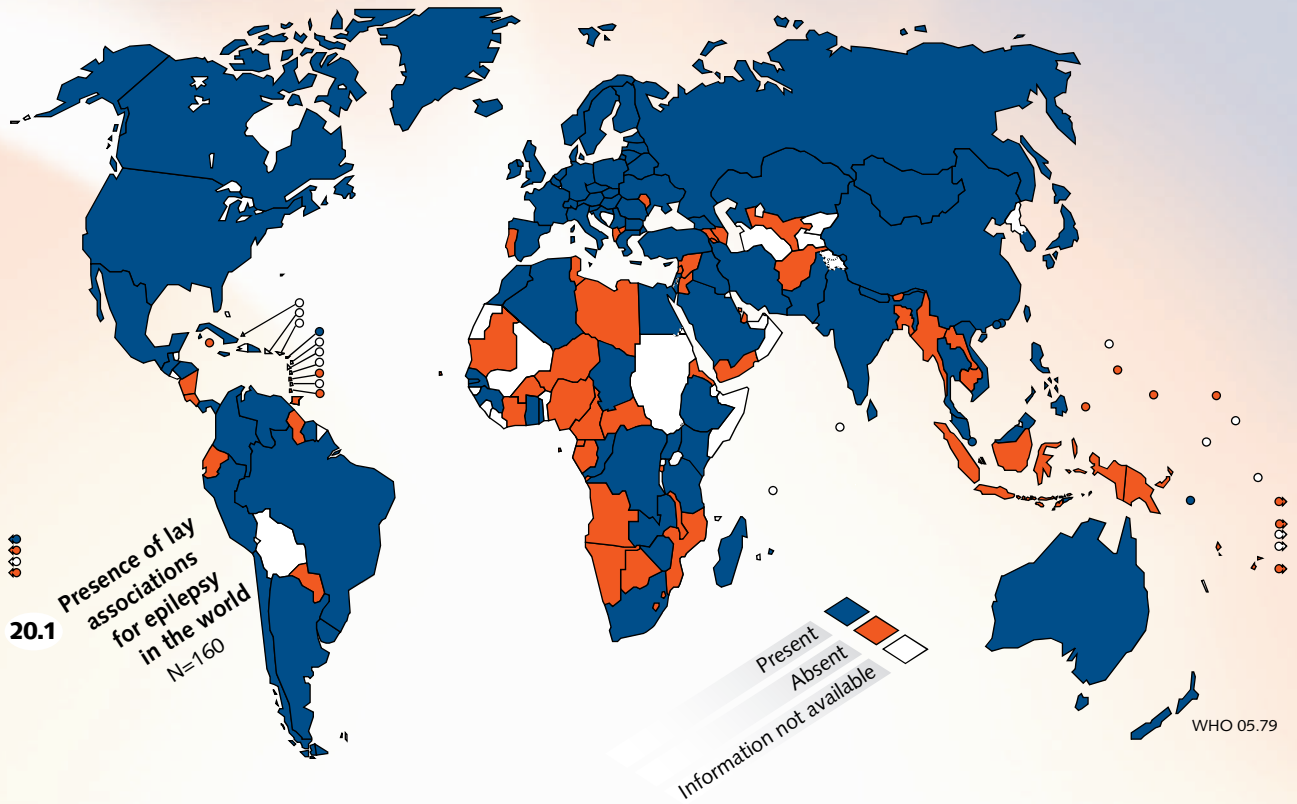
## Limitations

- ◆ Because the sources of information in most countries were key persons working in the field of epilepsy, the data pertain mainly to countries where there are persons with an interest in epilepsy. It is therefore possible that the above figures are overestimated.
- ◆ Many countries mentioned the presence of a patient or lay association, but information regarding coverage of the population is lacking. In most cases these organizations are working only in selected areas of a country.
- ◆ Some of the patient or lay associations mentioned by the respondents are wide ranging welfare organizations with a much broader scope than assistance to people with epilepsy.
- ◆ Information concerning the quality of services is not available.

## Conclusions

- ◆ The lay associations are important in providing care for people with epilepsy. They have a significant role in dealing with non-medical aspects (education, employment, insurance, driving, etc.) which are crucial issues in providing epilepsy care.
- ◆ The patient associations may also complement the activities of professionals working in the field of epilepsy by providing the above-mentioned services.
- ◆ Many of the local patient associations are members of IBE.
- ◆ The role of patient and lay associations in improving the quality of life of people with epilepsy needs to be recognized and supported.
- ◆ There is an urgent need to establish more patient groups, especially in low-income countries, to improve consumer participation in health care and promote self-management.





## Prof Giuliano Avanzini

Founded in Budapest, Hungary, on 29 August 1909, the International League Against Epilepsy (ILAE) includes at present over 90 national Chapters in all parts of the world. It collaborates with the International Bureau for Epilepsy (IBE) and the World Health Organization (WHO) with the aim of reaching the following objectives:

- ◆ advancing and disseminating knowledge of epilepsies throughout the world;
- ◆ encouraging epilepsy research;
- ◆ promoting the prevention, diagnosis and treatment of epilepsy, advocacy on epilepsy issues, and the care of everybody suffering from epileptic disorders;
- ◆ improving education and training in the field of epilepsy.

Throughout its nearly 100 years of existence, ILAE has continued its efforts to encourage the establishment and maintenance of new national Chapters, and to create and maintain the administrative and financial infrastructures necessary to allow it to reach its main goals. One important step has been the establishment of periodic worldwide or regional ILAE Chapter meetings (Chapter Conventions) to discuss and design ILAE policies on the basis of emerging needs and the recommendations of the Resource and Problem Oriented Commissions nominated by the ILAE President.

The ILAE Chapters are currently organized in six regions: Africa, Asia, the Eastern Mediterranean, Europe, Latin America and North America. Each of these has an ILAE Regional Commission whose officers are elected every four years by their respective Chapters.

In order to pursue its aims, ILAE works closely with IBE; since 1997, this collaboration has been reinforced and reoriented by the launch of the Global Campaign Against Epilepsy (GCAE) in partnership with both IBE and WHO. As many of the major achievements of the GCAE are reported elsewhere in the Atlas, I concentrate here on the specific contributions of ILAE.

In line with its constitutional objectives, the main strategic priority of ILAE is to improve epilepsy care throughout the world. The results of a number of assessments of the extent to which national and international health-care systems can meet the needs of patients with epilepsy demonstrate that there is a significant gap between the number of people with active epilepsy and the number whose seizures are being appropriately treated, particularly in developing countries. The various reasons for this include the insufficient education of caregivers about epilepsy, the lack of comprehensive epilepsy care programmes and facilities, financial problems leading to insufficient equipment and AED supplies, and the limited use of epilepsy surgery.

The treatment gap has been tackled by supportive actions aimed at facilitating the access of patients to specialized epilepsy services and increasing the level of existing health-care facilities. ILAE has also promoted and supported Chapter activities designed to encourage governments and health ministries to respond to the needs for greater epilepsy awareness, education, diagnosis, treatment, care, services and prevention.

Within the context of GCAE, a number of Demonstration Projects have been started with the aim of optimizing epilepsy care in Africa, Asia and Europe. Demonstration Projects assess the needs and resources of a given territory and offer training and technical information for local health-care providers that have an immediate impact on the quality of local epilepsy care. In more general terms, they create the basis for the development of a successful model of epilepsy care that can be integrated with national, regional and, finally, global health-care systems. Demonstration Projects have so far been developed in Argentina, Brazil, China, Pakistan, Senegal and Zimbabwe.

## Education

ILAE has paid considerable attention to the establishment of local, national, regional and international education programmes aimed at improving the expertise of epilepsy care providers throughout the world. Every national Chapter promotes local epilepsy courses for neurologists, general practitioners, technicians and nurses, and organizes at least one annual course at national level. Moreover, regional programmes are being implemented on the basis of the pioneering experience of the European Epilepsy Academy (EUREPA), which was created by the ILAE European Commission and now acts as ILAE's educational agency. In addition to promoting and accrediting courses in various parts of Europe, and helping other ILAE Regional Commissions to organise similar initiatives, EUREPA has developed two innovative educational models: train-the-trainers courses and European Epileptology Certification.

The aim of the train-the-trainers courses is to turn experienced personnel into qualified teachers of epileptology. The activities carried out by the trainers prepared by the courses organized over the last five years have significantly contributed to raising the profile of epilepsy care across Europe, and this success has prompted other ILAE regions to launch similar courses whose initial impact on epilepsy care also appears to promise further positive results. European Epileptology Certification can be obtained by completing an 18-month educational programme based on periods of training in selected institutions that allow the accumulation of credits. This ongoing initiative will lead to the establishment of a list of accredited epileptologists to whom patients with epilepsy can refer.



The biennial International Epilepsy Congress and Regional Epilepsy Congresses, which take place in alternate years, are also educational events as they include specifically designed educational activities organized by EUREPA and the ILAE commissions. In addition, in 2002, an annual residential epilepsy summer school for young epileptologists from throughout the world was started at the International School of Neurological Sciences, Venice, Italy. Since its foundation, the School has trained students from 64 countries, including six which do not yet have an ILAE Chapter, belonging to all ILAE regions. The interaction between students and teachers and among the students themselves resulted in several ongoing international collaborative projects which are contributing to raising awareness of epilepsy care in several developing areas.

The feedback provided by national Chapters at the Chapter Conventions has demonstrated that these educational activities have made a significant impact on the improvement of epilepsy care, in large part because of the efforts made to ensure that programmes are tailored to the specific needs of different areas. An important contribution has been made by the ILAE Task Force for Subregional and Interregional Organizations, which facilitates spontaneous aggregations of countries with common cultural backgrounds even if they belong to geographically different regions.

## Research

Any action aimed at making optimal epilepsy care available to patients throughout the world must take into account the advances made as a result of the synergy of basic and clinical multidisciplinary research; this requires a critical evaluation of the results that are continuously being made available to the scientific community. ILAE has created various commissions and task forces of authoritative specialists who assess how the new information can be translated in diagnostic and therapeutic terms, and produce ad hoc guidelines and recommendations. A crucial role in evaluating the clinical applicability of neurobiological results is played by the Neurobiology Commission. All of the commissions are

required to make sustainable recommendations that take into account the economic difficulties of the developing world and, furthermore, a Healthcare Policy Commission chaired by an economics expert has been appointed with the task of assisting ILAE to develop a worldwide affordable epilepsy care policy.

The main problems are the costs of diagnostic equipment and AEDs, and the difficulties in organizing epilepsy surgery programmes in countries with limited resources. Minimal requirements in terms of drug availability and diagnostic facilities have been recommended by Epidemiology, Therapeutic Strategies and Diagnostic Methods and Paediatrics Commissions, and the Commission of Neurosurgery has made recommendations for countries with limited resources.

In elaborating their health-care strategy, epileptology communities should not simply draw on the available scientific information but should also contribute to it by means of their own original investigations. I strongly believe that this is crucial if we are to meet specific local requirements and take into account specific socioeconomic situations. The ILAE Genetics, Neurobiology and Psychobiology Commissions have therefore been engaged in actions aimed at helping developing countries to establish research projects to face their individual problems. ILAE is active in promoting international collaborative research networks, facilitating partnerships between developed and developing countries, and sensitizing the relevant international institutions (the World Bank, WHO, UNESCO, the European Union, governments, etc.) to epilepsy research. Fellowships and grant programmes are being developed to allow young epileptologists to visit foreign laboratories.

This is only a short and by no means complete account of ILAE's role in fostering epilepsy care throughout the world. Much has already been done, but there is still more that needs to be done in order "to achieve a world in which no person's life is limited by epilepsy", to quote the masthead of ILAE's strategic plan, which is and will continue to be our inspirational mission.

**Mr Philip Lee**

The International Bureau for Epilepsy (IBE) collaborates closely with the International League Against Epilepsy (ILAE). Whereas ILAE is an association of physicians and other health professionals dealing with the medical aspects of the condition (see Section 21), IBE's focus is on the overall quality of life of people with epilepsy, especially as it relates to the social aspects of the condition.

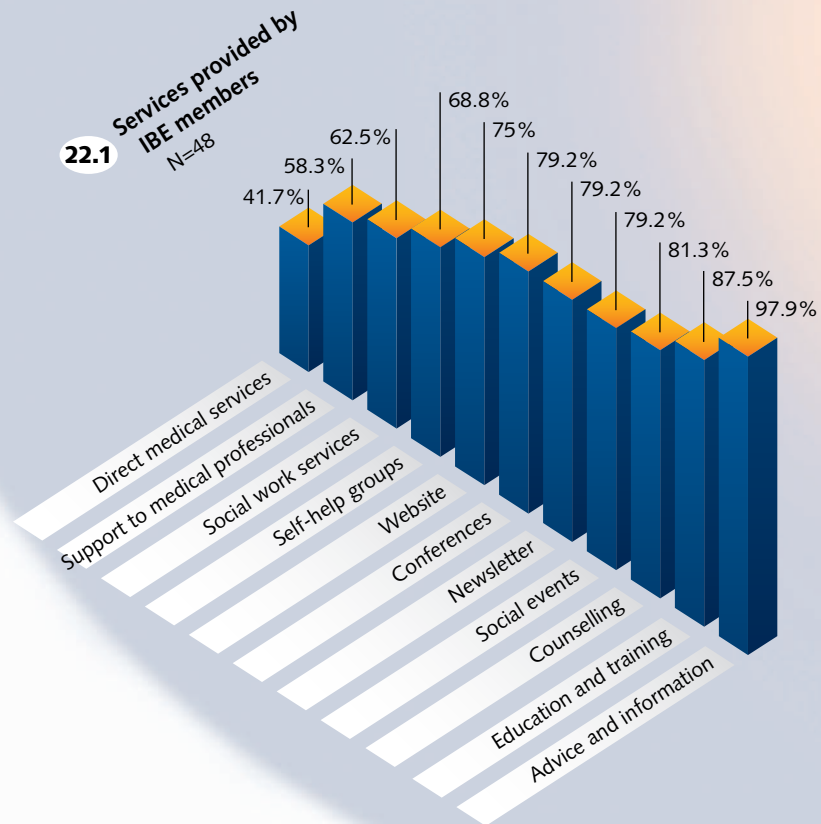
IBE comprises more than 100 member organizations around the world. Most of these are national epilepsy associations which between them represent millions of people with epilepsy and their families and carers. IBE provides a reference point for all its members, offering a global network of support, information and coordination. It also acts as an international advocate for epilepsy, promoting better care and treatment, increasing knowledge about the condition and working to achieve greater public acceptance of epilepsy to reduce the stigma that still attaches itself to the condition.

Patient-based nongovernmental organizations such as IBE's members play a dual role: firstly, as providers of direct medical and non-medical services; secondly, as influencers of policy, advocating on behalf of people with epilepsy as to their needs and wants from health-care providers.

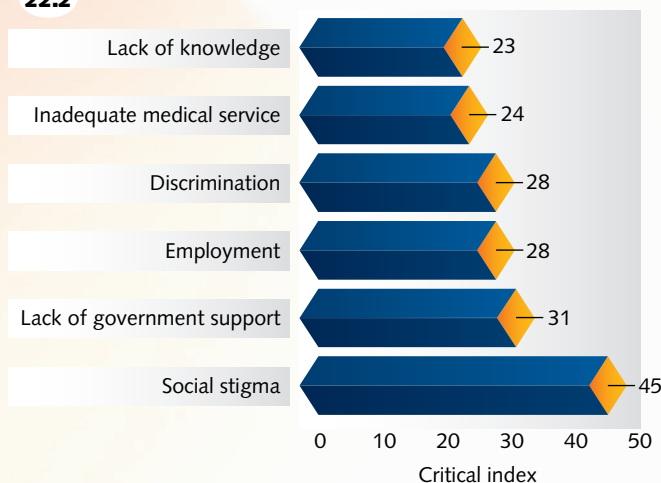
Figure 22.1 shows the results of a survey of 48 IBE members in January–February 2005. It indicates their range of direct service activities and the percentage of members active in each area.

While the large amount of information, training and communication work based around patient and public awareness might be expected, it is worth noting that 41.67% of IBE member associations are engaged in providing direct medical services and 58.33% provide support to medical professionals. For example, in the United Kingdom, Epilepsy Action has funded more than 80 positions for specialist nurses in epilepsy within the National Health Service. In Chile, LICHE operates a drug bank to supply antiepileptic drugs to people with epilepsy; the success of this operation over the years has led LICHE to become one of the foremost suppliers in the country. Even more ambitiously, perhaps, IBE members in Mauritius and Romania have aspirations to establish their own national epilepsy centres.

In addition to direct services, 80% of IBE members surveyed reported that they are actively engaged in seeking to influence their governments and other decision-making and policy-making bodies in their countries. Figure 22.2 indicates the key advocacy and campaign issues as identified by IBE members. Clearly, the most important is combating the social stigma of epilepsy, followed by an apparent lack of government support for epilepsy in relation to providing financial resources and the political will to change things. Other social issues – poor employment opportunities for people with epilepsy and social discrimination – are ranked as being more critical than an inadequate medical service.



**22.2** Critical advocacy issues identified by IBE members



One of the challenges in developing countries is that epilepsy might not be perceived as such a threatening condition as HIV/AIDS, for example. In parts of sub-Saharan Africa this is rightly the case. Even in such circumstances, however, people with epilepsy cannot be ignored: they still need care and treatment for their condition. To ignore epilepsy because there are other more important health issues is not a reasonable or acceptable position to take.

The value of nongovernmental organizations with a specific interest in epilepsy is that they can help to identify the issues for politicians; to assess the scope of the problems, and to signpost practical, affordable and realistic strategies that can be applied and be integrated within a national health-care and social care policy. Such organizations therefore have a crucial part to play in collecting data to inform the political debate about health-care and social care priorities and in educating those in positions of power and influence to realize the things they can do to improve the lives of people with epilepsy.

IBE members provide a focus around which people with epilepsy can organize themselves, articulate their wants and needs and develop a sense of identity and common purpose. The proliferation of information technology (in particular the Internet) has enabled more people than ever before to be better informed about their condition. IBE members are playing a key role in the transfer of information and in facilitating people's understanding of the information they receive: this is knowledge management, and this is what empowers people. A patient-centred approach requires that patients be involved in their health care and be seen by others as equal partners and not merely the passive recipients of care and treatment. Patients are now more demanding of their health-care providers, be they medical professionals who deliver the care or politicians and policy-makers who decide what should be available and who should get it. Patients are increasingly seen as consumers of health care and, as consumers, they have an influence on both the providers and the policy-makers.


The emerging influence and role of patient-based nongovernmental organizations in direct health care is perhaps reflective of a wider change. Throughout the world, but acutely so in developing countries, there is a distinct and recognizable gap in terms of what resources are available and what resources are needed. Health care universally is marked by limited resources having to meet seemingly unlimited demand. As a result, the public sector is under increasing pressure. The private sector can and does fill some of the gap, but this level of provision brings its own problems and constraints, not least affordability and access for the poor who are most likely to be in need of care.

Epilepsy organizations are in a position to help, not just by articulating people's needs but also by identifying the resource gaps and helping to close them by contributing money, technical knowledge, professional expertise, training, equipment and people. By incorporating nongovernmental organizations and their resources into national plans to deal with epilepsy, governments can reduce the gap and bring about the possibility of real improvement.









# **Epilepsy: the public health aspects**

## Introduction

- ◆ The respondents were asked about the presence of a separate budget for epilepsy care and services in the health

budget and the primary method of financing epilepsy services in the country.

## Salient findings

- ◆ A separate budget for epilepsy care and services is present in only 6.4% of the responding countries.
- ◆ Out-of-pocket payments, tax-based funding and social insurance are the primary methods of financing epilepsy care, each method in about one third of the responding countries. Private insurance and private foundations constitute only 1.9% and 1%, respectively, of the primary method of financing.
- ◆ Out-of-pocket expenses are the primary source of financing epilepsy care in Africa (62.5% of the responding countries), South-East Asia (66.7%) and the Eastern Mediterranean (50%), while tax-based funding is the most important source of financing epilepsy care in the Western Pacific (57.1%).
- ◆ Social insurance is the most important source of financing in Europe (58.8% of the responding countries) and the Americas (43.8%), while none of the responding countries

in South-East Asia and only 4.2% in Africa use social insurance as the primary method of financing.

- ◆ Out-of-pocket expenditure is the primary method of financing epilepsy care in 72.7% of low-income countries, compared with 4% of high-income countries.
- ◆ While social insurance is the primary method of financing in 55.6% and 56% of higher middle-income and high-income countries, respectively, none of the low-income countries employs it as the primary method of financing.
- ◆ Of the responding countries, 37.6% have private insurance as a method of financing epilepsy care. Only 11.1% and 17.7% of the countries in South-East Asia and Africa, respectively, have private insurance, compared with the Americas where private insurance is available as a method of financing in 70.8% of the countries. Social insurance as one of the methods of financing is present in 25% of low-income countries, compared with 66.7% of high-income countries.

## Limitations

- ◆ This information is based on best estimates by the respondents and not on a review of actual expenditure or budget figures.
- ◆ The information regarding primary methods of financing is presented from 106 countries; these countries represent 82% of the world's population.

- ◆ Although definitions were provided with the questionnaire, it is possible that they may not have been used accurately.

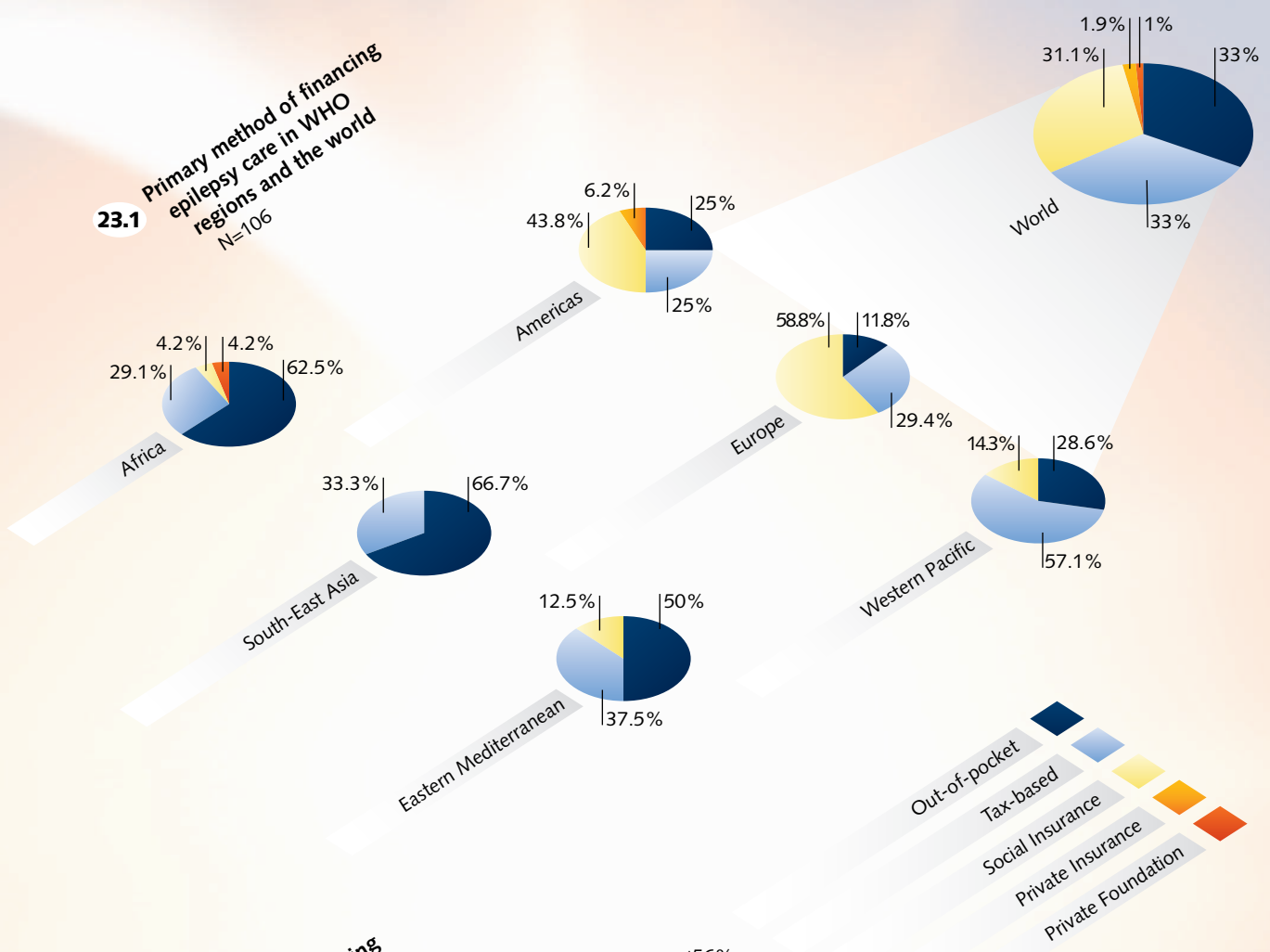
## Conclusions

- ◆ Although a separate budget for epilepsy care is not essential, when present it assists in earmarking the resources and in planning the services effectively. In many countries, the budget for epilepsy care is included in that for mental health.
- ◆ In most low-income countries, out-of-pocket payment is the major source of financing. Epilepsy services are scarce

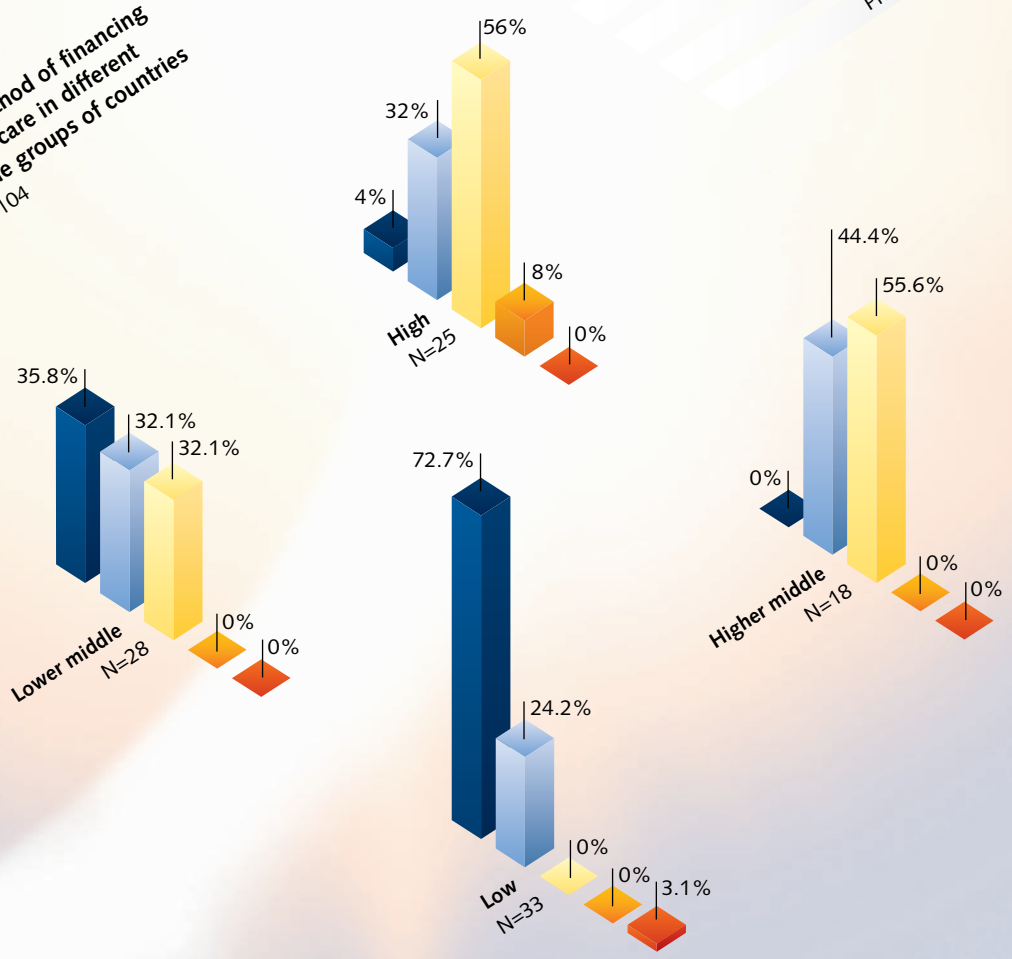
in low-income countries; in addition, patients are required to pay, so further inequity results in the utilization of these services. Efforts need to be made to introduce some form of public financing into the health infrastructure of these countries to cover epilepsy services.



**23.1** Primary method of financing epilepsy care in WHO regions and the world  
N=106



**23.2** Primary method of financing epilepsy care in different income groups of countries  
N=104



## Introduction

- ◆ Disability benefits are payable from public funds as part of a legal right in cases of epilepsy that cause physical,

mental or intellectual impairment leading to functional limitations.

## Salient findings

- ◆ Disability benefits in some form are available for people with epilepsy in 46.5% of the responding countries.
- ◆ Disability benefits are available in only 14.6% of low-income countries compared with 82.4% of high-income countries.
- ◆ Availability of disability benefits for people with epilepsy varies across regions. While 11.1% of the responding countries in South-East Asia, 13.3% in the Eastern Mediterranean, and 21.1% in Africa reported availability of some form of disability benefits for people with epilepsy,

such benefits are available in 36.4% of responding countries in the Western Pacific, 54.2% in the Americas, and 86.4% in Europe.

- ◆ Of the types of disability benefits reported by countries, monetary benefits (82.5%) and rehabilitation and health benefits (54.8%) are the most commonly reported, followed by other benefits including housing, transport, education and special discounts (42.5%) and benefits at the workplace (34.2%). Specific benefits for caregivers are reported to be available in 12.3% of the countries.

## Limitations

- ◆ Information on the exact type of disability benefit for people with epilepsy was not obtained in a structured format. The figures might therefore be underestimated.

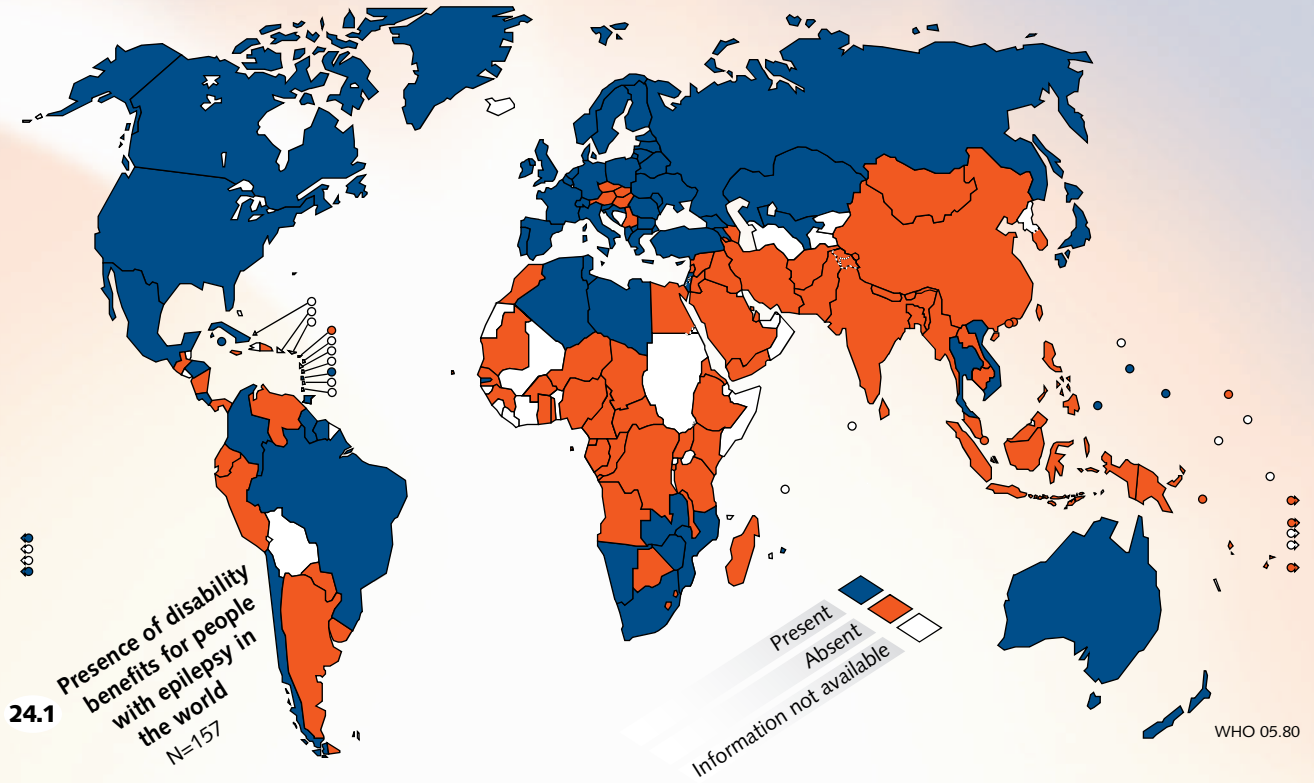
- ◆ Data regarding coverage within the countries were not available.

## Conclusions

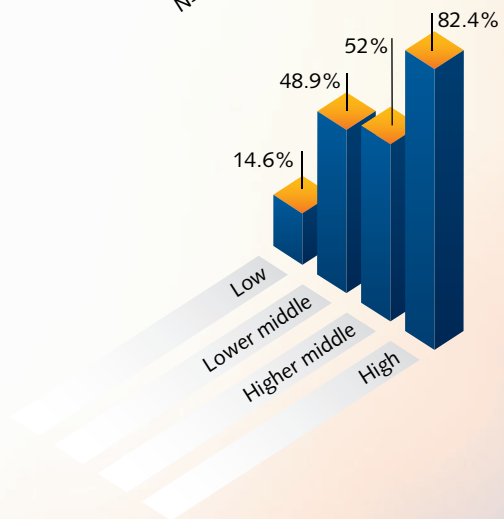
- ◆ In many countries, despite the availability of disability benefits for many conditions, people with epilepsy are not covered. The situation must be assessed and action must be taken.
- ◆ In many countries, few people actually receive disability benefits for epilepsy even when they are available, because of a lack of public information about such benefits and the procedure for claiming them, which is sometimes very complicated.

- ◆ For enhanced social and professional integration of people with epilepsy, drafting of appropriate legislation in countries is vital. Efforts should be made to advocate better provision of benefits for functionally disabled people with epilepsy, especially in resource-poor countries where such benefits are most needed.

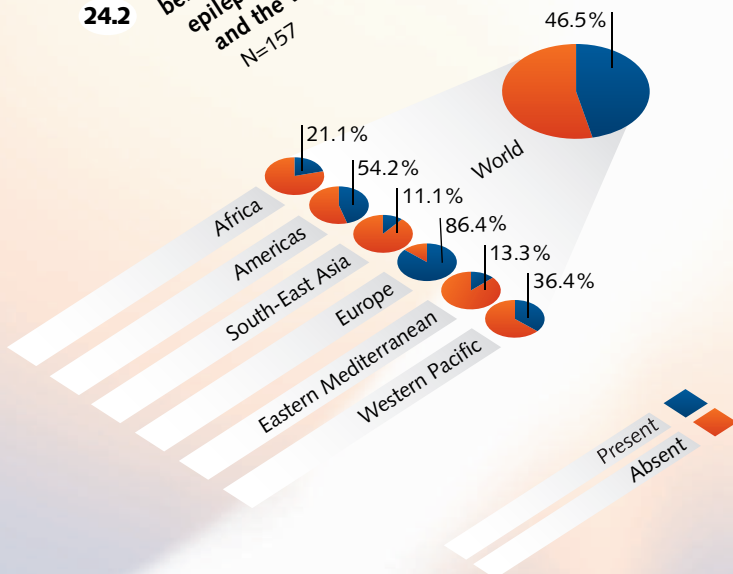




**24.3** Presence of disability benefits for people with epilepsy in different income groups of countries  
N=154



**24.2** Presence of disability benefits for people with epilepsy in WHO regions and the world  
N=157



### Mrs Kathryn Pahl and Mrs Hanneke de Boer

People with disabilities are among the most vulnerable in any society; this is even more true of people with hidden disabilities such as epilepsy and other neurological conditions and intellectual disabilities. While the vulnerability of people living with epilepsy may be partly attributed to the disorder itself, as Ann Jacoby remarked, “all chronic medical conditions have an impact on daily life, but the impact of epilepsy is greater” (90), the particular stigma associated with epilepsy brings a susceptibility of its own. Stigmatization leads to discrimination and people with epilepsy experience prejudicial behaviour in many spheres of life, throughout many centuries and across many cultures. It is as Rajendra Kale said: “the history of epilepsy can be summarised as 4,000 years of *ignorance*, superstition and stigma, followed by 100 years of *knowledge*, superstition and stigma”.

People with epilepsy experience violations and restrictions of both their civil and human rights. Civil rights violations such as unequal access to health and life insurance or prejudicial weighting of health insurance provisions, withholding of the right to obtain a driving licence, limitations to the right to enter particular occupations and the right to enter into certain legal agreements, in some parts of the world even marriage, are severely aggravated by epilepsy. Discrimination against people with epilepsy in the workplace and in respect of access to education is not uncommon for many people affected by the condition. Violations of human rights are often more subtle and include social ostracism, being overlooked for promotion at work, and denial of the right to participate in many of the social activities taken for granted by others in the community. For example, ineligibility for a driving licence frequently imposes restrictions on social participation and choice of employment.

Civil and human rights violations are more evident in developing countries, especially where there has been a history of generalized rights abuse. Such practices are not limited to developing countries and traditional societies, however, and there is evidence of occurrences of rights violations in developed countries and societies which are regarded as having impeccable human rights records in other respects.

Failure to secure insurance protection leaves people with epilepsy unnecessarily exposed to risks which largely have no bearing at all on their epilepsy, and refusals and restrictions to obtaining insurance are not limited to developing countries. As many as 36% of people with epilepsy were refused one or more types of insurance in the United Kingdom (91). This discriminatory behaviour translates as a restriction to the right to make adequate financial provision in guarding against risks to the individual and his or her family. People with developmental disabilities, including epilepsy, experience a heightened risk of becoming victims of violence and abuse, according to Petersilia (92), who

reported on a study by Sobsey & Doe which found that 70% women with developmental disabilities are sexually assaulted in their lifetime – not in South Africa or another country where sexual assaults are among the highest in the world, but in the United States in 1991.

Research into the vocational interests of people with epilepsy shows, that people with epilepsy often are not recommended to follow their training of choice due to the suspected consequences of having epilepsy (93). Job restrictions are still very common in all European countries. Scharfenstein and Thorbecke found for instance severe epilepsy related job restrictions in the records of the Berlin Labour Exchange, which indeed were in sharp contrast with the consistent world wide research reports of low accident rates in people with epilepsy (94).

Legislation based on centuries of stigmatisation existed until recently or still does in many countries. During the reign of King Hammurabi in Babylonian Society in a text on medicine, Sakikku (All Diseases), which was written in 1700 B.C. (95) there was a line in criminal and commercial law, enabling slave owners to return a slave who had a seizure within a month after purchase, receiving back the sum of money paid.

In many countries, laws impacting on the lives of people with epilepsy are outdated, failing to adequately promote and protect their human rights and in some cases even violating these rights. Anti marriage laws, with penalties for infringement were introduced in various countries over 200 years ago. They have remained, but have not been implemented for many years (96). In the United States for instance, until 1956, 17 states prohibited people with epilepsy to marry (97). The last state to repeal its law forbidding marriage to people with epilepsy did so only in 1980. In 1956 18 states provided for eugenic sterilisation of people with epilepsy. In the United Kingdom a law prohibiting people with epilepsy to marry was repealed in 1970. In some parts of the world epilepsy is still commonly viewed as a reason for annulling marriages or simply prohibiting them.

Unemployment and underemployment exists worldwide. In the U.S. the first law that prohibited discrimination against people with physical handicaps passed in 1973, however this law only had a limited scope and it was not until 1990 with the passage of the Americans with Disabilities Act, that provided a more uniform remedy to persistent discrimination (98). Until the 1970s for instance it was still legal in the U.S. to deny persons with seizures access to restaurants, theatres, recreational centres and other public accommodations. These employment and legal devaluations further authenticated the stigma attached to epilepsy in the modern western, eastern and southern culture (99).



The recent reports on epilepsy in the African Region (68) and the Western Pacific Region (100) provide numerous accounts of civil and human rights violations against people with epilepsy across these regions, which comprise mainly developing countries. However, examples of legislation based on centuries of stigmatisation are found in many countries all over the world. From reading the accounts it becomes clear that, while specific practices may vary from country to country, discriminatory attitudes and prejudicial behaviour towards people with epilepsy are common across the globe.

The Global Campaign Against Epilepsy, under the auspices of ILAE, IBE and WHO, has played a very important role in raising awareness about the quality of life for people with epilepsy throughout the world. The Campaign provides an excellent platform from which national interest groups can launch comprehensive movements to deal with rights violations in their own countries.

Informing people with epilepsy themselves of their rights and recourse is an essential activity. Considering the frequency of rights violations, the number of successful legal actions is very small. People are often reluctant to be brought into the public eye, so a number of cases are settled out of court. The successful defence of cases of rights abuse against people with epilepsy will serve as precedents, however, and will be helpful in countries where there are actions afoot to review and amend legislation.

While the epilepsy movement has made great advances in the physiological understanding of the condition and improving drug therapy, progress in creating a more understanding and accommodating world for people with epilepsy has sadly not kept pace. It would seem appropriate that people with epilepsy themselves should be at the forefront of this battle, and that all those involved in managing the condition should lend their support to ensure that the gap between medical and social advances is bridged rather than broadened.

## Introduction

- ◆ The respondents were asked about the inclusion of epilepsy in the country's annual health reporting system and the presence of an epidemiological data collection system for epilepsy.

## Salient findings

- ◆ Epilepsy is included in the annual health reporting system of 39.9% of the responding countries. However, it is sub-classified in 33.3% of these countries.
- ◆ Epilepsy is included in the annual health reporting system in 13.3% of the responding countries in the Eastern Mediterranean, while it is included in 55.6% of the responding countries in South-East Asia.
- ◆ A data collection system for epilepsy exists in 40.1% of the responding countries.
- ◆ Whereas about half of the responding countries in the Western Pacific (56.5%), Europe (48.9%) and the Americas (45.8%) have a data collection system for epilepsy, 30.6% in Africa, 26.7% in the Eastern Mediterranean and only 11.1% in South-East Asia have an epidemiological data collection system.

## Limitations

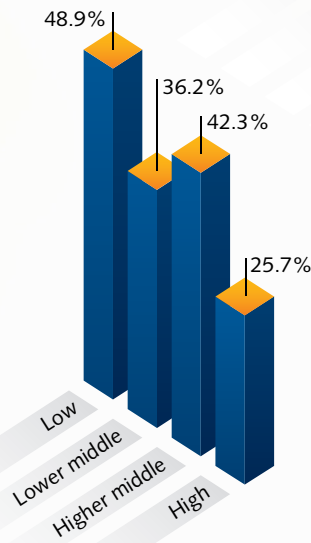
- ◆ Details regarding the type of data collection system were not obtained. It is possible that they vary between countries.
- ◆ Information about the quality or adequacy of the health reporting system for epilepsy is not available.
- ◆ The epidemiological or service data collection system does not include the epidemiological studies carried out in various countries.

## Conclusions

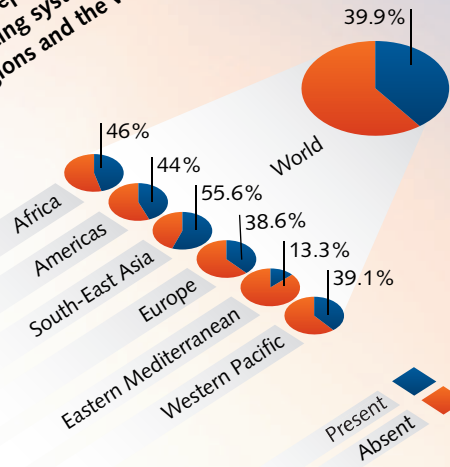
- ◆ An organized health reporting system is essential in order to assess the situation and thus enable health planners to decide how to use their various resources.
- ◆ There is a need to establish standard guidelines for the health reporting system to enable comparison across countries and over time.
- ◆ Epidemiological data facilitate the gathering of information regarding the disease burden and trends and help to identify the high priority issues. This information is highly useful for planning health services and monitoring trends over time.



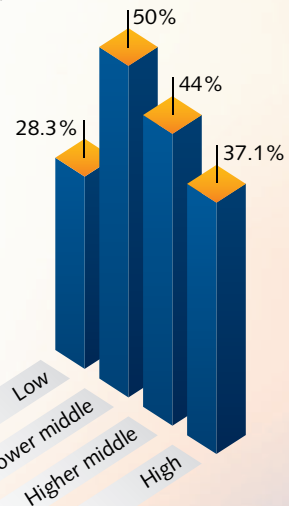
**26.2** Presence of epilepsy in the health reporting system in different income groups of countries  
N=154



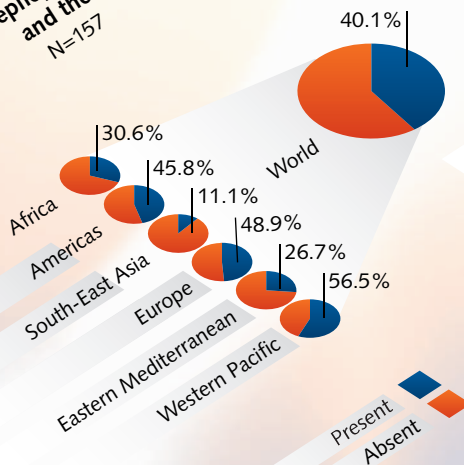
**26.1** Presence of epilepsy in the health reporting system in WHO regions and the world  
N=158



**26.3** Presence of data collection system for people with epilepsy in different income groups of countries  
N=153



**26.4** Presence of data collection system for people with epilepsy in WHO regions and the world  
N=157



## Introduction

- ◆ The respondents were asked to provide the five major problems encountered by health professionals and people with epilepsy in the country. Ignoring the order of the

individual responses, the proportion of countries that mentioned each problem was calculated globally and for each of the regions.

## Salient findings

- ◆ Lack of drug supply for reasons of either logistics or economy is identified as a major problem faced by health professionals as well as people with epilepsy in 53.2% and 52.3%, respectively, of the responding countries.
- ◆ Other major problems faced by both health professionals and people with epilepsy are identified as: poor community knowledge and awareness, cultural beliefs, and stigma (43.6% and 52.9%, respectively) and government lack of resources, poor economy and lack of infrastructure (39.1% and 32.3%, respectively).
- ◆ Factors related to health services, including capital and human resources, are identified more commonly as major problems by health professionals than by people with epilepsy. These factors include lack of diagnostic facilities (51.9% and 18.1%, respectively), non-availability of health personnel (35.9% and 20.7%, respectively), lack of appropriate training of health personnel (40.4% and 11%, respectively), epilepsy being a low priority (24.4% and 9%, respectively) and lack of epilepsy surgery programmes (17.3% and 4.5%, respectively).
- ◆ Lack of social and rehabilitation support and social burden of the disorder, are identified more commonly by people with epilepsy (79.4%) compared with health professionals (23.7%). The social issues identified by respondents include employment, driving, marriage, social isolation and education opportunities.
- ◆ Other problems less commonly identified are noncompliance, non-availability of newer antiepileptic drugs, lack of educational services to patients and patient associations, lack of continuity of care, delayed consultation (delay by doctors or patients; treatment by traditional healer), and disease and treatment side-effects.
- ◆ Lack of social and rehabilitation support and social burden of the disorder are identified among the five major problems encountered by health professionals providing epilepsy care in 42.4% of high-income countries compared with 15.2% of low-income countries.
- ◆ Lack of drug supply is indicated as a major problem by people with epilepsy by 75.6% of low-income countries compared with 17.7% of high-income countries.

## Limitations

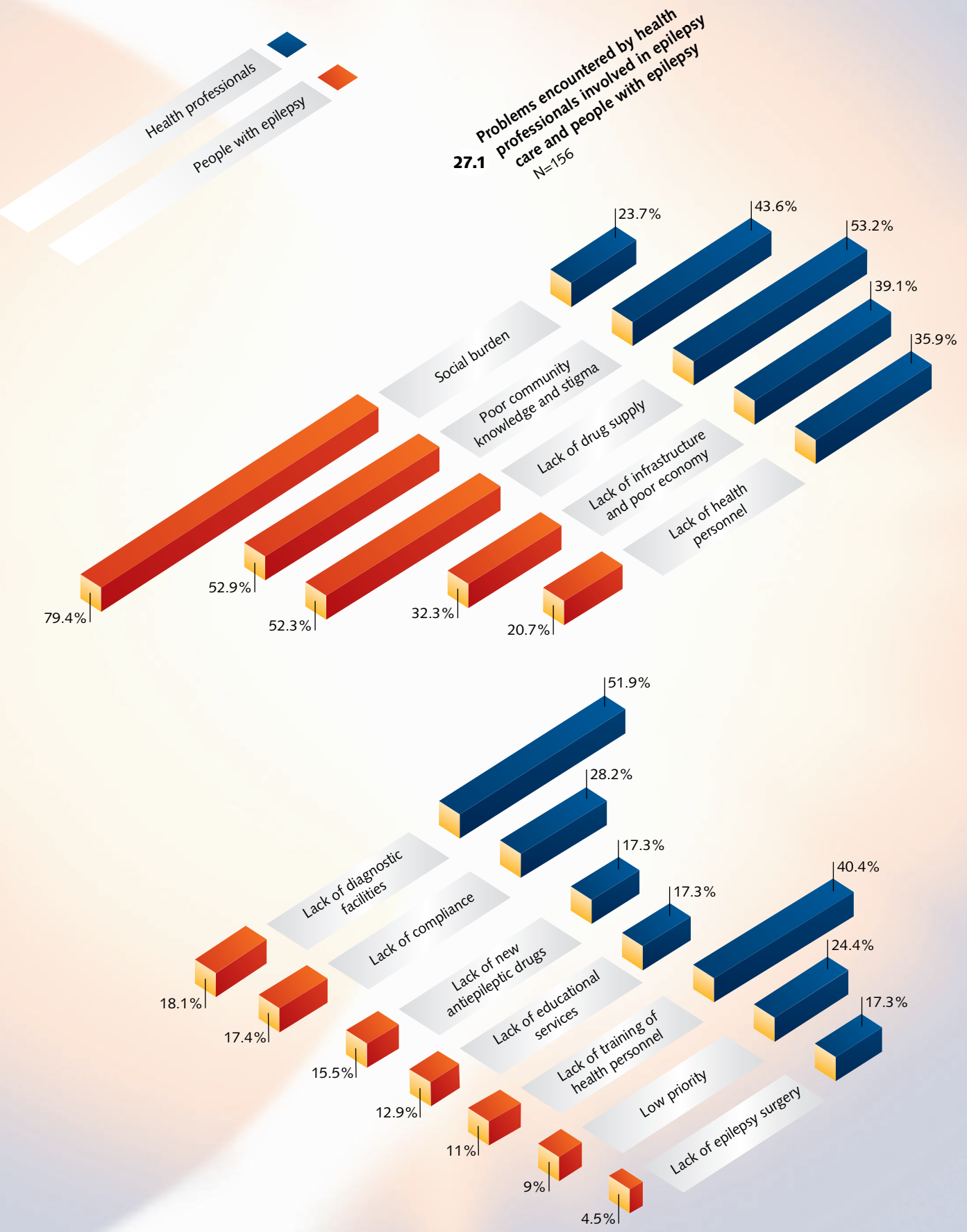
- ◆ The information is based on the experience and impression of a key person in a country working in the area of epilepsy and not on actual data from responding countries.
- ◆ It is possible that the problems related to access and utilization of services may differ between rural and urban areas. This information from different areas within countries is not available.
- ◆ Because the question was open-ended and responses were converted into categories for purposes of

presentation in the Atlas, there is a possibility of some misinterpretation.

- ◆ The difference in the problems encountered among various regions or income categories may suggest the relative importance of a particular issue rather than its absolute importance; e.g. in low-income countries, availability of epilepsy surgery is considered an ideal and not a primary asset that should be available. The data also represent the issues of highest priority that need improvement.

## Conclusions

- ◆ Epilepsy is a condition with high psychosocial and economic costs. To improve the overall management of epilepsy, concerns of both health professionals and people with epilepsy need to be taken into account.
- ◆ The data report health professionals' perceptions of patients' views, which can be different. There are clear differences, however, between the problems identified by health professionals and those raised by people with epilepsy.
- ◆ Strategies focusing on stigma, public awareness and knowledge, and social and rehabilitation support within the context of the community are foremost designed to decrease the social burden, prejudice and discrimination faced by people with epilepsy.
- ◆ Because community perceptions and cultural beliefs are identified among important problems faced in providing epilepsy care, it is essential that communities are brought into the planning and implementation processes of any intervention. This is necessary to ensure sustainability.





### Ms Dee Snape, Prof Ann Jacoby & Prof Gus A Baker

Epilepsy is not just a clinical disorder but also has a highly relevant social label (101). People diagnosed with the condition not only have to learn to deal with the physical impact of seizures, but also to cope with the associated – frequently negative – social and psychosocial consequences, which are not directly related to the actual disease process. The role of the stigma associated with having epilepsy in determining the social prognosis of those with the condition has increasingly been the focus of public campaigns to improve their quality of life. The limitations imposed by statute, prejudice, fear and lack of understanding have major implications for social functioning and life choices. Not surprisingly, the challenges this presents are easier for some individuals to cope with than for others.

The term “stigma” originated in ancient Greece and referred to a sign or mark, cut or burned into the body, which designated the bearer as a person who was morally defective and should be avoided. The sociologist Irving Goffman has defined stigma as “an undesired differentness” (102). People are stigmatized because they have an attribute that is undesired and so “deeply discrediting”. This attribute causes problems for individuals whose virtual social identity (the one they aspire to) then does not match their actual social identity. Goffman recognized three types of stigmatizing conditions: abominations of the body, blemishes of individual character, and the tribal stigma of race, nation and religion, arguing that irrespective of the prevailing attribute, the stigmatized individual is viewed by others as “not quite human” and therefore a legitimate target for discrimination.

#### Dimensions of stigma

<b>Concealability</b>	The extent to which the condition becomes obvious or can be hidden from others
<b>Course of the mark</b>	The way the condition changes over time, and its ultimate outcome
<b>Disruptiveness</b>	The degree of strain and difficulty stigma adds to interpersonal relationships
<b>Aesthetics</b>	How much the attribute makes the character repellant or upsetting to others
<b>Origin</b>	How and who was responsible for the acquired stigmatizing condition
<b>Peril</b>	Perceived dangers, both real and symbolic, of the stigmatizing condition to others

Source: (103)

Jones and colleagues have identified a set of six dimensions along which stigmatizing conditions differ (103); each has relevance to epilepsy (see box). In this analysis of how stigma affects social relationships, disruptiveness is the crucial dimension, and it is certainly the case that seizures create an obvious disruption to social interaction. Disruptiveness overlaps, however, with other dimensions in their framework for stigma – for example, depending on their specific manifestations, seizures may also be aesthetically unpleasant. Misconceptions about epilepsy deriving from early fears and superstitions contribute to the ambiguity often associated with its origin, and the issue of peril is echoed in old ideas of epilepsy as contagion (104). Such ideas are generally no longer held in industrialized countries, but supernatural conceptions as an explanation for epilepsy remain dominant in many of the developing countries where four fifths of the world’s population of people with epilepsy live. In these countries, cultural beliefs about the contagious nature of epilepsy and the mechanisms by which it is transmitted (for example, by drinking water from the same cup as a person with epilepsy, eating food prepared by a person with epilepsy, contact with saliva and physical contact with a person during a seizure) often result in the social exclusion of people with epilepsy (105, 106). The consequences of this exclusion can be significant, creating a vicious circle of stigma: for example, fears about the nature of transmission may mean that they are abandoned during a seizure, increasing their risk of incurring seizure-related injuries and, in turn, the likelihood of their disorder becoming more visible to others.

Other important dimensions of stigma for the experience of both the stigmatized and the stigmatizer are the attributes of visibility and controllability (107). Again, both these dimensions bear great relevance to epilepsy, especially in relation to generalized seizures, which are difficult to conceal and may become more prominent over time, depending on the clinical course of the condition.

It has been suggested that people with epilepsy are seen as somehow morally responsible for their condition; and there is evidence to suggest that family members themselves are partly responsible for instilling a sense of guilt and shame into those with the disorder (108). In a study in the People’s Republic of China, conducted by Kleinman et al. (109), the issue of shame was seen to extend beyond the individual with epilepsy to the entire family. The fear of family disgrace within this society meant that people with epilepsy were usually kept at home and their condition kept secret. Kleinman’s work clearly reinforces the cultural nature of stigma and the relationship between culture-based health beliefs and stigma. Interestingly, despite positive changes worldwide in public attitudes towards people with epilepsy (110) the condition still appears to evoke greater responses

to rejection than other stigmatizing chronic conditions such as mental illness or AIDS/HIV infection (111).

Scambler (112) and, more recently, Jacoby (113) have drawn an important distinction between “felt” and “enacted” stigma in epilepsy. The former refers to the shame associated with having epilepsy and the fear of experiencing enacted stigma, the latter to actual episodes of discrimination against people with epilepsy solely on the basis of their condition. Scambler’s “hidden distress” model suggests that, following diagnosis, adults with epilepsy generate an acute sense of felt stigma even before any exposure to enacted stigma; those who feel stigmatized by their condition attempt to conceal it when possible, in order to protect themselves from active discrimination. In doing so, however, they increase the stress of managing their disorder, with the result that felt stigma has a far more disruptive effect on their lives. Again, evidence suggests that cultural and clinical contexts shape the way these two distinct aspects of stigma will be played out. For example, despite improvements in seizure control, felt stigma remains a major concern to people with epilepsy living in the developed world (113). Conversely, poor seizure control and increased visibility means enacted stigma is a greater worry to those in developing countries.

The impact of stigma on impaired social function and quality of life of people with epilepsy has been well documented (109, 113, 114). Schneider & Conrad (108) point out that an individual’s experience of epilepsy is not simply a direct result of the medical severity of the seizures, but is also related to its social meaning and reality. Stigma in epilepsy is associated with both legitimated and non-legitimated discrimination and social exclusion, often with marked impacts on quality of life. Although in many developed countries people with epilepsy are protected by law, they are also subject to legal discrimination, especially with regard to employment and driving. These restrictive laws and regulations operate sometimes without firm evidence to support their maintenance and are often matched by informal rules and sanctions, for example in the workplace or in schools. Measuring the severity of such informal discrimination is problematic, as the number of people experiencing it is likely to be far greater than the number of reported acts of discrimination.

The situation for people with epilepsy in the developing world remains even more problematic. The misrepresentation of epilepsy often results in people with the condition being socially ostracized. Furthermore, as a consequence of both stigma and economic circumstance, most people with epilepsy do not receive the treatment they require to bring their seizures under control and render their epilepsy less visible to others.

Not surprisingly, studies exploring the association between stigma and health suggest that there are important negative health-related consequences of stigma. Baker and colleagues, in a study involving over 5000 respondents across 15 European countries (115), reported 51% of people with epilepsy feeling stigmatized, with 18% feeling highly stigmatized. The researchers also showed that people who reported higher levels of perceived stigma were more likely to report long-term health problems, injuries as a result of seizures, increased side-effects from medication, and non-adherence to antiepileptic drug treatments. In a similar study conducted by Baker et al. in the Eastern Mediterranean (116), far fewer respondents reported feeling stigmatized by having epilepsy, which emphasizes the cultural basis of stigma perceptions and the extent to which such judgements may depend on prior expectations.

As suggested by theoretical discussions of stigma, stigma in epilepsy appears to be strongly associated with seizure control; with perceptions of stigma being greater for people still experiencing seizures (115). Individuals who report more frequent seizures are more likely to express feeling of stigma and are also more likely to report other impairments that are potentially linked to quality of life; for example, they are less likely to be employed. Among adults with epilepsy, stigma has been associated with impaired self-esteem and self-efficacy; greater perceived levels of helplessness, anxiety and depression; and reduced life satisfaction (101, 113). There is also evidence to suggest that, as a consequence of social withdrawal and isolation, people with epilepsy have reduced opportunities for social interaction and consequently are less likely to marry or have children (112).

Jalava and colleagues report good social adjustment to be significantly reduced in people with epilepsy (117). In their study epilepsy was also associated with problems in education, employment, marital status and leisure activities; patients rated their own ability to control their lives as “poor or missing” four times more frequently than did the controls. Furthermore, patients with continuing seizures were significantly less satisfied with their present lives.

The purpose of understanding stigma is to provide the means by which to overcome it. Both personal and public adaptation is required if the impact of stigma is to be lessened. Efforts to educate people with epilepsy and their families need to focus on the relation between knowledge, stigma and adjustment, and public education initiatives need to be further developed and implemented so as to promote increased awareness of epilepsy as both a social and a medical disorder. Whatever approaches are employed to achieve these tasks, interventions must focus on reducing the misconceptions and misinformation about epilepsy that pose threats to the identity, self-esteem, security and life opportunities of persons with epilepsy.



## Dr Dan Chisholm

The “burden” of epilepsy can be considered at a number of levels and from a number of different viewpoints, so it is as well to distinguish between these different perspectives when thinking about what measured burden is likely to show. Most directly, the burden will be felt at the individual or household level in terms of the physical pain and psychological stress associated with epileptic seizures, the potentially catastrophic financial implications of treatment or lost work opportunities, and, in all too many societies, the social stigma attached to this condition. By contrast, burden at the community or population level is typically expressed in terms of the epidemiological profile of the disease (numbers of new or existing cases in the population), the financial resources devoted to prevention and treatment, and societal productivity losses resulting from premature mortality or morbidity. In line with the purpose of Project Atlas, the focus here is on aggregate or population-level estimates of both the epidemiological and economic burden attributable to epilepsy at the national and international levels, but this should not detract from the importance of establishing and sharing better information concerning the household burden of epilepsy, particularly in low-income countries where the risk of catastrophic out-of-pocket expenditures is highest.

### Epidemiological assessment of the global burden of epilepsy

From the epidemiological perspective, epilepsy is a significant cause of disability and disease burden in the world. Using a metric called disability-adjusted life years (DALYs), in which a DALY can be thought of as one lost year of healthy life, WHO has calculated the global burden of disease and injury that is attributable to different causes or risk factors. This measure of burden assesses the gap between current health status and an ideal situation where everyone lives into old age free of disease and disability. Overall, epilepsy contributed more than 7 million DALYs (0.5%) to the global burden of disease in 2000 (118, 119). Figure 29.1 shows the distribution of DALYs or lost years of healthy life attributable to epilepsy, both by age group and by level of economic development. It is apparent that close to 90% of the worldwide burden of epilepsy is to be found in developing regions, with more than half occurring in the 39% of the global population living in countries with the highest levels of premature mortality (and lowest levels of income). An age gradient is also apparent, with the vast majority of epilepsy-related deaths and disability in childhood and adolescence occurring in developing regions, while later on in the life-course the proportion drops on account of relatively greater survival rates into older age by people living in more economically developed regions. In terms of the absolute number of healthy life years lost per million population, estimates range from fewer than 500 in early childhood and older age in developed regions to as many as 2000 in the younger age groups of high-mortality developing

regions. Owing to the consistent and comparative nature of this work, summary estimates of population health such as these provide the most appropriate measure of the relative burden of epilepsy at the international level.

### Economic assessment of the national burden of epilepsy

Economic assessments of the national burden of epilepsy have been conducted in a number of high-income countries (120, 121) and more recently in India (122), each of which has clearly shown the significant economic implications of the disorder in terms of health-care service needs, premature mortality and lost work productivity. For example, the Indian study calculated that the total cost per case of these disease consequences for epilepsy amounted to US\$ 344 per year (equivalent to 88% of average income per capita), and that the total cost for the estimated 5 million people with epilepsy resident in India was equivalent to 0.5% of gross national product. Because such studies differ with respect to the exact methods used, as well as underlying cost structures within the health system, they are currently of most use at the level of individual countries, where they can serve to draw attention to the wide-ranging resource implications and needs of people suffering from epilepsy. As with epidemiological estimates using DALYs or some other measure of population health, however, cost-of-illness studies are not in themselves an appropriate mechanism for allocating resources to specific treatment strategies.

### The avertable burden of epilepsy

Having established the attributable burden of epilepsy, two subsequent questions for decision-making and priority setting relate to avertable burden (the proportion of attributable burden that is averted currently or could be avoided via scaled-up use of proven efficacious treatments) and resource efficiency (determination of the most cost-effective ways of reducing burden). Analysis of these two issues can reveal the technically most efficient response to the attributable burden of a particular disease. A schematic overview of these concepts (123, 124) breaks down the total burden of epilepsy into the following separate components: disease burden that is already being averted via existing strategies; disease burden that could be averted via scaled-up implementation of available cost-effective interventions; and disease burden that cannot currently be averted by the set of interventions under consideration.

A small number of cost-effectiveness studies have been carried out in high-income countries with such a purpose in mind, but there are no published economic evaluations of epilepsy treatment in developing countries, despite the likelihood that they may well represent a very cost-effective use of scarce health-care resources. Recently, however, information has been generated as part of a wider WHO



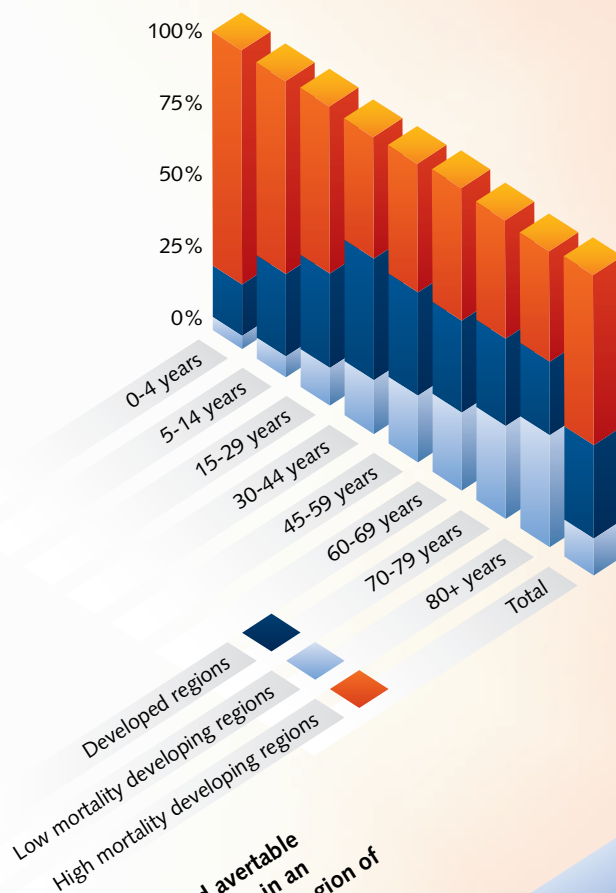
cost-effectiveness work programme (125) on the amount of burden averted by the current or scaled-up use of antiepileptic drugs (AEDs), together with estimates of cost and cost-effectiveness (124). Effectiveness was expressed in terms of DALYs averted, and costs were expressed in international dollars (which take into account differences in purchasing power between countries or world regions). Compared with a “do nothing” scenario (i.e. the untreated natural history of epilepsy), results from nine developing epidemiological subregions in the WHO African Region suggest that extending AED treatment coverage to 50% of primary epilepsy cases would avert 150–650 DALYs per million population (equivalent to 13–40% of the current burden), at an annual cost per case of 55–192 international dollars. Older first-line AEDs (phenobarbital and phenytoin) were most cost-effective on account of their similar efficacy but lower acquisition cost (800–2000 international dollars for each DALY averted). In all nine subregions, the cost of securing one extra healthy year of life was less than average per capita income. Extending coverage further to 80% or even 95% of the target population would evidently avert more of the burden still, and would remain an efficient strategy despite the large-scale investment in manpower, training, and drug supply and distribution that would be required to implement such a programme. The results for one developing epidemiological subregion in Africa – consisting of 20 countries with high levels of child mortality and very high levels of adult mortality – are depicted in Figure 29.2 (123, 124), which divides the total attributable burden of epilepsy as follows: (a) burden that is averted by AEDs at current levels of effective treatment coverage (19%); (b) burden that is avertable via the scaling up of AEDs (to a further 41% if complete coverage were reached); and (c) burden that is not avertable via AEDs (estimated to be 40%, although this assumes that the current level of drug compliance would prevail).

**Conclusion**

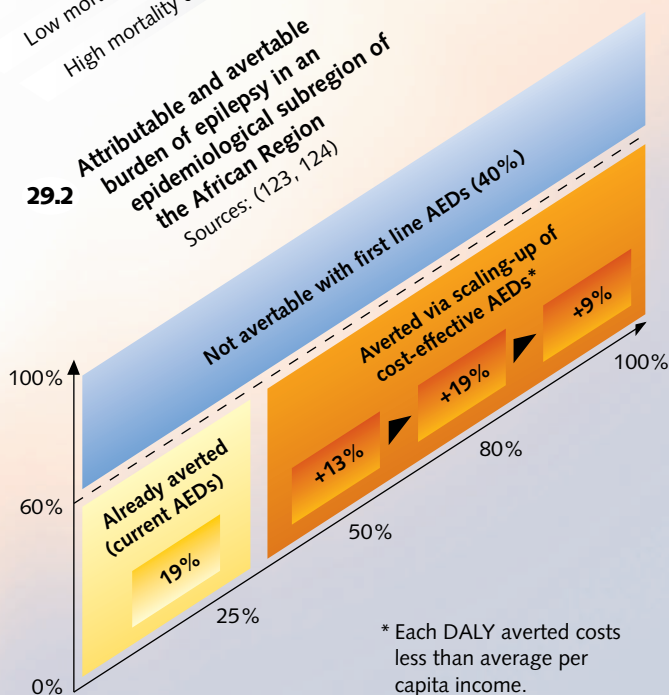
The burden of epilepsy manifests itself at a number of different levels. Taking a population-level approach, both epidemiological and economic studies have revealed the extent of the negative impact of epilepsy on existing levels of health and health care. It is an unfortunate truth that the current burden, often couched in terms of the “treatment gap” in epilepsy, is concentrated in regions with the greatest health challenges and the least resources with which to respond to them. More positively, however, one can conclude that it is in these very regions that there exists the greatest opportunity to reduce current levels of epilepsy-related deaths and disability, employing efficacious treatments which have been shown to be a highly cost-effective use of scarce resources. Critical factors in the successful implementation of such a scaled-up level of service delivery, apart from renewed political support and investment,

can be expected to relate to appropriate training, continuity of drug supply, and enhanced consumer or community involvement (126).

**29.1** Distribution of the global burden of epilepsy, by age group and level of economic development  
Source: (118)



**29.2** Attributable and avertable burden of epilepsy in an epidemiological subregion of the African Region  
Sources: (123, 124)



## Mrs Hanneke de Boer, Prof Jerome Engel Jr and Dr Leonid Prilipko

According to WHO estimates, over 50 000 000 people worldwide have epilepsy. Of these people with epilepsy, 80–90% are not diagnosed or treated properly; over 80% of them live in low-income countries where the control of epilepsy is even more difficult.

These problems proved to be too complex to be solved by individual organizations, therefore the three leading international organizations working in the field of epilepsy joined forces in the Global Campaign Against Epilepsy (GCAE) (127). The aims of the Campaign, conducted by the World Health Organization (WHO), the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE), are to provide better information about epilepsy and its consequences and to assist governments and those concerned with epilepsy to reduce the burden of the disorder. To date, over 90 countries are involved in the Campaign.

The Campaign objectives are:

- ◆ to increase public and professional awareness of epilepsy as a universal and treatable brain disorder;
- ◆ to raise epilepsy to a new plane of acceptability in the public domain;
- ◆ to promote public and professional education about epilepsy;
- ◆ to identify the needs of people with epilepsy at national and regional levels;
- ◆ to encourage governments and departments of health to meet the needs of people with epilepsy, including awareness raising, education, diagnosis, treatment, care, services and prevention.

The Campaign strategy includes two parallel and simultaneous tracks: providing a platform for general awareness, and assisting departments of health in the development of national programmes on epilepsy. Accordingly, its main activities include:

- ◆ organization of regional conferences, followed by regional declarations;
- ◆ assessment of country resources for epilepsy worldwide;
- ◆ assistance with the development of regional reports;
- ◆ development of educational materials;
- ◆ coordination of Demonstration Projects.

## CAMPAIGN HIGHLIGHTS

### Regional conferences

As part of raising general awareness, regional conferences on public health aspects of epilepsy have been organized in all six WHO regions with the participation of over 1300 delegates from the epilepsy organizations (IBE and ILAE), public health experts from governments and universities and representatives from WHO headquarters and regions.

The goals of the conferences were to review the present situation of epilepsy care in the region, to identify country needs and resources to control epilepsy at a community level, and to discuss the involvement of countries in the Campaign. As a result of these conferences, regional declarations of perceived needs and proposed actions were developed and adopted by the conference participants. Participants included:

- ◆ delegates of national and international IBE/ILAE;
- ◆ public health experts of governments and universities;
- ◆ representatives of Regional WHO Offices and WHO Headquarters.

### Country resources and regional reports

A questionnaire was developed by an international group of epilepsy experts, in order to make an inventory of country resources for epilepsy worldwide. On the basis of the data collected in this way, regional reports were developed that provide an overview of the epilepsy situation in the region, outline the various initiatives taken to deal with the problems, define the current challenges and offer appropriate recommendations.

The next step in the assessment of the data on country resources was the comprehensive analysis that is summarized in this Atlas within the framework of Project Atlas, which was launched by WHO in 2000 to provide information about health resources in different countries. The Epilepsy Atlas has been produced under the ILAE/IBE/WHO Global Campaign Against Epilepsy using ILAE and IBE Chapters and WHO networks. The objectives of the Atlas include the collection, compilation and dissemination of relevant information on epilepsy resources in the majority of countries in the world. Its global and regional analyses are the result of fruitful collaboration between ILAE, IBE and WHO.

## Demonstration Projects

One of the main activities aimed at assisting countries in the development of their national programmes on epilepsy is the initiation and implementation of Demonstration Projects. The ultimate goal of the Demonstration Projects is the development of a variety of successful models of epilepsy control that may be integrated into the health-care systems of the participating countries and regions.

In general terms, each demonstration project has four aspects:

- ◆ assessing whether knowledge and attitudes of the population are adequate, correcting misinformation and increasing awareness of epilepsy and how it can be treated;
- ◆ assessing the number of people with epilepsy and estimating how many of them are appropriately treated;

- ◆ ensuring that people with epilepsy are properly served by health personnel equipped for their task;
- ◆ analysing the outcome and preparing recommendations for those who wish to apply the findings to the improvement of epilepsy care in their own and other countries.

In summary, it may be concluded that the collaboration of ILAE, IBE and WHO within the framework of the Global Campaign Against Epilepsy has been very successful and has led to significant achievements in various areas such as raising public and professional awareness and education, developing effective modules for epilepsy control, and assessing and analysing epilepsy resources in all countries in the world, as presented in this Atlas.



- ◆ **Active epilepsy:** two or more unprovoked epileptic seizures on different days in the prior year that are disabling to the individual.
- ◆ **Annual health reporting system:** the preparation of yearly reports covering health service functions, including the use of allocated funds.
- ◆ **Awareness and advocacy:** a combination of individual and social actions designed to raise awareness and gain political commitment, policy support, social acceptance and health systems support for people with epilepsy.
- ◆ **Budget:** a separate regular source of money, available in a country's health budget allocated for actions directed towards epilepsy care in the country.
- ◆ **Aetiology of epilepsy:** the underlying abnormality of the brain, as epileptic seizures are nonspecific responses of the brain to all kinds of insult.
- ◆ **Daily defined dose (DDD):** the assumed average maintenance dose per day for a drug used for its main indication in adults. The DDDs were obtained from the WHO Collaborating Centre for Drug Statistics Methodology (<http://www.whocc.no/atcddd/>).
- ◆ **Disability benefits:** benefits payable as a part of legal right from public funds in cases of epilepsy that cause physical, mental or intellectual impairment leading to functional limitations.
- ◆ **Education:** improving the knowledge of patients and society about epilepsy and its consequences and their understanding of psychosocial and occupational problems, so as to encourage them to cope actively with the disorder and live with as few limitations as possible.
- ◆ **Epidemiological or service data collection system:** an organized information-gathering system for service activity data for epilepsy; usually incorporates incidence and prevalence rates of diseases, admission and discharge rates, numbers of outpatient and community contacts and other activities.
- ◆ **Epilepsy specialists:** persons in the health sector devoted to providing epilepsy care.
- ◆ **Epilepsy surgery:** any neurosurgical intervention with the primary goal of relieving intractable epilepsy.
- ◆ **Epileptic seizure:** transient occurrence of signs or symptoms caused by abnormal excessive or synchronous neuronal activity in the brain.
- ◆ **Essential drug list:** the officially approved list of essential drugs that a country has implemented; usually adapted from the WHO Model List of Essential Drugs.
- ◆ **Government policy of licensing of antiepileptic drugs:** authorization by the government of antiepileptic drugs that are either purchasable over the counter or necessitate a prescription from a general practitioner or a specialist.
- ◆ **Hospital bed for epilepsy care:** a hospital bed maintained only for use by patients with epilepsy as a primary diagnosis on a continuous basis. These beds may be for short-term use for diagnostic purposes or for residential long-term care; usually they are located in neurological services or hospitals or special epilepsy centres.
- ◆ **International dollar:** a hypothetical currency that is used as a means of translating and comparing costs from one country to another using a common reference point, the US dollar. An international dollar has the purchasing power of the US dollar in the United States. To convert international dollars to local currency units, multiply the international dollar figure by the purchasing power parity (PPP, see below) exchange rate. For example, 2 international dollars are equal to 24.102 Thai bhat for the year 2000 (2 x 12.051). To convert local currency units to international dollars, divide the local currency unit by the PPP exchange rate.
- ◆ **Lay organizations:** voluntary organizations, charitable groups, service user or advocacy groups working in the area of epilepsy.
- ◆ **Long-term video/EEG monitoring:** the continuous recording of electroencephalography (EEG) patterns for hours, days or weeks combined with continuous recording of audio and video signals from a closed-circuit television system for the analysis of seizure semiology.
- ◆ **Neurological nurse:** a registered nurse who has successfully completed the required additional training in neurological nursing.
- ◆ **Neurologist:** a medical graduate who has successfully completed at least two years of postgraduate training in neurology.
- ◆ **Neuropaediatrician:** a specialist (neurologist or paediatrician) with at least one year of recognized sub-specialist training in child neurology.
- ◆ **Neuropsychological services:** facilities where the evaluation and assessment of cognitive strengths and weaknesses are carried out.
- ◆ **Neurosurgeon:** a medical graduate who has successfully completed at least two years of postgraduate training in neurosurgery.
- ◆ **Out-of-pocket payments:** payments made for epilepsy care by patients or their families.

- ◆ **Prevalence of epilepsy:** proportion of people with epilepsy in a given population at a specified time (point prevalence) or during a defined time interval (period prevalence).
- ◆ **Prevention:** all organized activities in the community to prevent occurrence as well as progression of epilepsy and to minimize the psychosocial consequences.
- ◆ **Primary care:** the provision of basic preventive and curative health care to people with epilepsy at the first point of entry into the health system.
- ◆ **Private foundations:** privately owned institutions that provide funding or financial support for epilepsy care and epilepsy services in the country.
- ◆ **Private insurance:** voluntary payment of a premium by health-care consumers to a private health insurance company which, in return, pays for part or all of their epilepsy care.
- ◆ **Professional organizations:** associations of physicians and other health professionals in the field of patient care, research or education in epilepsy and whose principal concern is with the problems of epilepsy; such associations are usually nongovernmental.
- ◆ **Promotion:** a process of enabling people to increase control over the determinants of their health and well-being and to effect improvement.
- ◆ **Psychiatrist:** a medical doctor who has successfully completed at least two years of postgraduate training in psychiatry.
- ◆ **Psychologist:** a graduate from a university-level school of psychology with specialization in clinical psychology.
- ◆ **Purchasing power parity (PPP) exchange rate:** the number of units of a country's currency required to buy the same amount of goods and services in the domestic market as US\$ 1.00 would buy in the United States. The PPP exchange rates used in this analysis were developed by WHO and are available on the web site <http://www.who.int/evidence/cea>.
- ◆ **Rehabilitation:** care given to patients with epilepsy to help them achieve their optimum level of functioning.
- ◆ **Sheltered work:** protected environments where people with disabilities can experience the stimulation and learning required to work and earn their living, without the pressure that exists in usual settings.
- ◆ **Social insurance:** a fixed percentage of income that everyone generally above a certain level of income is required to pay to a government-administered health insurance fund which, in return, pays for part or all of consumers' epilepsy care.
- ◆ **Social rehabilitation:** services as part of a programme aimed at enhancing social skills, facilitating integration into working life and developing independent living skills.
- ◆ **Social worker:** a graduate from a university-level school of social work.
- ◆ **Special education:** education facilities within specialist settings aimed at children with learning difficulties.
- ◆ **Special equipment:** tools for the rehabilitation of people with epilepsy to allow them a better quality of life, such as seizure alarms, non-suffocating pillows and protective helmets.
- ◆ **Tax-based funding:** money for health services raised by general taxation or through taxes earmarked specifically for epilepsy services; includes health services that are fully financed by government.
- ◆ **Therapeutic drug monitoring:** the use of antiepileptic drug measurements in biological fluids as an aid to the management of patients receiving antiepileptic drug therapy.
- ◆ **Training in epileptology:** specialist training in the diagnosis, treatment, prevention, care, rehabilitation and research in epilepsy, for medical graduates and professionals allied to medicine.
- ◆ **Treatment:** relevant clinical and non-clinical care aimed at reducing the impact of epilepsy and improving the quality of life of people with epilepsy.
- ◆ **Treatment gap:** the difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given point in time, expressed as a percentage; this definition includes diagnostic and therapeutic deficits.



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Country, territory or area	Name
<b>Afghanistan</b>	<i>M. Sayed Azimi</i>
<b>Albania</b>	<i>Jera Kruja</i>
<b>Algeria</b>	<i>Abdelhafid Bouslimane</i>
<b>Andorra</b>	<i>Joan Obiols</i>
<b>Angola</b>	<i>Albino Cunene Coelho de Carvalho</i>
<b>Argentina</b>	<i>Roberto H. Caraballo</i>
<b>Armenia</b>	<i>Vahagn Darbinyan</i>
<b>Australia</b>	<i>Angela O'Connor</i>
<b>Austria</b>	<i>Christoph Baumgartner</i>
<b>Azerbaijan</b>	<i>Sharif S. Magalos</i>
<b>Bahrain</b>	<i>Kameshwar Prasad</i>
<b>Bangladesh</b>	<i>Md Rezaul Karim</i>
<b>Barbados</b>	<i>Sean Marquez</i>
<b>Belarus</b>	<i>Roman Evsegneeve</i>
<b>Belgium</b>	<i>Paul A. J. M. Boon</i>
<b>Bhutan</b>	<i>P. Bhandari</i>
<b>Botswana</b>	<i>Patson N. Mazonde</i>
<b>Brazil</b>	<i>Carlos Eduardo Silvano</i>
<b>Bulgaria</b>	<i>Melania Radionova</i>
<b>Burkina Faso</b>	<i>Jean B. Kabore</i>
<b>Burundi</b>	<i>Léopold Nzisabira</i>
<b>Cambodia</b>	<i>Chea Lahoeurn</i>
<b>Cameroon</b>	<i>Louis Dongmo</i>
<b>Canada</b>	<i>Elout Starreveld</i>
<b>Cape Verde</b>	<i>Daniel Silves Ferreira</i>
<b>Cayman Islands</b>	<i>Bryan Jefferson Heap</i>
<b>Central African Republic</b>	<i>Joel Selguetia</i>
<b>Chad</b>	<i>Bolsane Egip</i>
<b>Chile</b>	<i>Tomas Mesa</i>
<b>China</b>	<i>Wenzhi Wang</i>
<b>Colombia</b>	<i>Jaime Faniño-Franky</i>
<b>Congo</b>	<i>Stéphane Ngampo</i>
<b>Cook Islands</b>	<i>Roro Daniel</i>
<b>Costa Rica</b>	<i>Franz Chaves Sell</i>
<b>Côte d'Ivoire</b>	<i>Joseph Délafosse</i>
<b>Croatia</b>	<i>Drago Škarpa</i>
<b>Cuba</b>	<i>Salvador González Pal</i>
<b>Cyprus</b>	<i>Andriane Flourentzou</i>
<b>Czech Republic</b>	<i>Milan Brázdil</i>
<b>Democratic Republic of the Congo</b>	<i>Mampunza Ma Miezi</i>
<b>Denmark</b>	<i>J. Alving</i>
<b>Dominican Republic</b>	<i>Diógenes Santos-Viloria Carlos Santoni William</i>

Country, territory or area	Name
<b>Ecuador</b>	<i>Arturo Carpio</i>
<b>Egypt</b>	<i>Mohamed Ghanem</i>
<b>Equatorial Guinea</b>	<i>Daisy Maria Bory Savigne</i>
<b>Eritrea</b>	<i>Fetsumberhan Gebrenegus</i>
<b>Estonia</b>	<i>Andre Õun</i>
<b>Ethiopia</b>	<i>Zenebe Gedlie Damtie</i>
<b>Fiji</b>	<i>J. Nasaroa</i>
<b>Finland</b>	<i>Reetta Kälviäinen</i>
<b>France</b>	<i>Pierre Genton</i>
<b>French Polynesia</b>	<i>Vincent Dupont</i>
<b>Gabon</b>	<i>Marie Laure Ntsame Ebang Gertrude Mouangue</i>
<b>Gambia</b>	<i>Ann Marie Mendy</i>
<b>Georgia</b>	<i>Natela Okujava</i>
<b>Germany</b>	<i>Christian E. Elger J. Bauer</i>
<b>Ghana</b>	<i>Paul Ayisu</i>
<b>Greece</b>	<i>Athanasios Covanis</i>
<b>Grenada</b>	<i>Robert Yearwood</i>
<b>Guam</b>	<i>Ramel A. Carlos</i>
<b>Guatemala</b>	<i>Henry B. Stokes</i>
<b>Guinea</b>	<i>Mariama Barry</i>
<b>Guyana</b>	<i>Bhiro Harry</i>
<b>Honduras</b>	<i>Claudia Amador</i>
<b>Hungary</b>	<i>Bèla Clemens</i>
<b>Iceland</b>	<i>Jon S. Gudnason</i>
<b>India</b>	<i>Satish Jain</i>
<b>Indonesia</b>	<i>Rusdi Maslim</i>
<b>Iran, Islamic Republic of</b>	<i>Kurosh Gharagozli</i>
<b>Iraq</b>	<i>Sarmed Al-Fahad</i>
<b>Ireland</b>	<i>Mike Glynn</i>
<b>Israel</b>	<i>Chani Baror</i>
<b>Italy</b>	<i>Paolo Tinuper</i>
<b>Jamaica</b>	<i>Amza Ali</i>
<b>Japan</b>	<i>Kazuichi Yagi</i>
<b>Jordan</b>	<i>AbdelKarim Al-Qudah</i>
<b>Kazakhstan</b>	<i>Aldungarova Roza</i>
<b>Kenya</b>	<i>David Musau Kiima Gachegu Gitonga</i>
<b>Lao People's Democratic Republic</b>	<i>Vikham Sengkignavong</i>
<b>Latvia</b>	<i>Egils Vitols</i>
<b>Lebanon</b>	<i>Naji Riachi</i>
<b>Lesotho</b>	<i>S. P. Shaikh</i>
<b>Libyan Arab Jamahiriya</b>	<i>Gheth M. Elworfally</i>
<b>Lithuania</b>	<i>Milda Endziniene</i>

Country, territory or area	Name
Madagascar	Adeline Raharivelo
Malawi	Theresa G. Mwale
Malaysia	Azmi Abdul Rashid
Malta	Janet Mifsud
Marshall Islands	Donald F. Capelle
Mauritania	Hamidou Traore
Mauritius	Gaya Geeaneswar Y. Noormamode
Mexico	Lilia Núñez Orozco
Micronesia, Federated States of	Imaculada J. Gonzaga Annette Zimmern
Mongolia	D. Baasanjav
Morocco	Abdeslam El Khamlichi
Mozambique	Paula Mogne
Myanmar	Nyan Tun
Namibia	Antonia Kangumine
Nepal	N. M. Shrestha
Netherlands	Gerrit-Jan De Haan
Netherlands Antilles – Curacao	Oscar Phillip Moen
New Zealand	Karen Covell
Nicaragua	Jorge Martínez Cerrato
Niger	Sadio Barry Hamid Assadeck
Nigeria	Mustapha A. Danesi
Niue	Athena de la Cruz Andrews
Norway	Karl O. Nakken
Pakistan	Hasan Aziz
Palau	Willie Tokon Stevenson Kuartei
Panama	Mario A. Larriátegui Arosemeroa
Papua New Guinea	David Mokela
Paraguay	Carlos Arbo Oze de Moruil
Peru	Patricia Campos Olazábal
Philippines	Leonor Cabral-Lim
Poland	Wendorff Janusz
Portugal	Francisco Pinto
Qatar	Ahmed Hamad
Republic of Korea	Lee Byung In
Republic of Moldova	Stanislav Groppa
Romania	Radu Rogozea
Russian Federation	Alla Guekht
Samoa	Satupaitea Viali
Sao Tome and Principe	Marta Maria Pósser
Saudi Arabia	D. R. McLean
Senegal	Amadou Gallo Diop

Country, territory or area	Name
Serbia and Montenegro	Nebojsa J. Jovic Marija Popovic
Singapore	Andrew Pan
Slovakia	Vladimir Donath
Slovenia	Dušan Butinar
Solomon Islands	Dick Boara
South Africa	Kathryn Pahl Bryan Kies
Spain	Antonio Gil-Nagel
Sri Lanka	Ranjanie Gamage
Suriname	Marian J. A. MacNack Eric Kafiluddin
Swaziland	R. Mdlangamandla
Sweden	Ingrid Olsson
Switzerland	Ernst N. Zweifel
Syrian Arab Republic	Ahmad Khalifa
Thailand	Surang Chiemchanya Bhakhaporn Bhirommai
The former Yugoslav Republic of Macedonia	Radoslav Naumovski
Timor-Leste	John Chinwuba Anaje E Somerville
Togo	Eric Kodjo Grunitzky
Tokelau	Fenuafala Faafoi
Tonga	Toakase Fakakuvietau
Trinidad and Tobago	Premchand Ratan Rohit Doon
Tunisia	Amel Mrabet
Turkey	S. Naz Yeni
Uganda	Augustine
Ukraine	Sergey Kcharchuk
United Kingdom (including Scotland)	Hilary Mounfield Josemir W. Sander Shelley Wagstaff
United Republic of Tanzania	Joseph Mbatia
United States of America	Susan Spencer M. Suzanne Berry
Uruguay	Alejandro Scaramelli
Uzbekistan	Shukhrat Khashimov
Vanuatu	Theto Moses
Venezuela, Bolivarian Republic of	Beatriz González Del Castillo
Viet Nam	Le Duc Hihn
Yemen	Abdulrahmen Muhammed Sallam Alkabati
Zambia	Anthony Mulenga Zimba
Zimbabwe	J. Mielke