

EPILEPSY
out of the shadows



A Global Campaign
Against Epilepsy

EPILEPSY ATLAS presents for the first time, the most comprehensive collection and compilation of information on resources for epilepsy care across 160 countries. 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".

It reinforces the need for urgent, substantial and systematic action to enhance resources for epilepsy care within countries.

This report has been developed within the framework of the ILAE/IBE/WHO Global Campaign Against Epilepsy.

World Health Organization
Programme for Neurological Diseases and Neuroscience
Department of Mental Health and Substance Abuse
Avenue Appia 20
1211 Geneva 27, Switzerland
Website: www.who.int/mental_health

Global Campaign Against Epilepsy
Stichting Epilepsie Instellingen Nederland (SEIN)
Achterweg 5
2103 SW Heemstede, The Netherlands
Website: www.globalcampaign-epilepsy.org

ISBN 92 4 156303 6



Atlas

**EPILEPSY CARE
IN THE WORLD
2005**





World Health
Organization



Global Campaign Against Epilepsy

Atlas

**EPILEPSY CARE
IN THE WORLD
2005**

Programme for Neurological Diseases and Neuroscience
Department of Mental Health and Substance Abuse
World Health Organization
Geneva

WHO Library Cataloguing-in-Publication Data

World Health Organization.

Atlas: Epilepsy Care in the World.

1.Epilepsy – epidemiology 2.Epilepsy – therapy 3.Health care surveys 4.Mental health services – statistics 5.Atlases I.Title II.Title: Atlas of epilepsy care in the world.

ISBN 92 4 156303 6

(NL classification: WL 385)

© World Health Organization 2005

All rights reserved. Publications of the World Health Organization can be obtained from WHO Press, World Health Organization, 20 Avenue Appia, 1211 Geneva 27, Switzerland (tel: +41 22 791 2476; fax: +41 22 791 4857; email: bookorders@who.int). Requests for permission to reproduce or translate WHO publications – whether for sale or for noncommercial distribution – should be addressed to WHO Press, at the above address (fax: +41 22 791 4806; email: permissions@who.int).

The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by the World Health Organization in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

All reasonable precautions have been taken by the World Health Organization to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either express or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall the World Health Organization be liable for damages arising from its use.

Printed in Switzerland

Designed by Tushita Graphic Vision Sàrl, CH-1226 Thônex

For further details on this project or to submit updated information, please contact:

Dr L. Prilipko
Programme Leader
Neurological Diseases and Neuroscience
Department of Mental Health and Substance Abuse
World Health Organization
Avenue Appia 20, CH-1211 Geneva 27, Switzerland
Tel: +41 22-791 36 21, Fax: +41 22-791 4160, e-mail: prilipkol@who.int

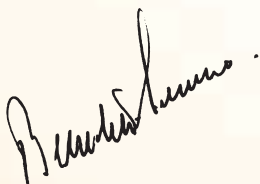
Epilepsy is one of the most common serious disorders of the brain, affecting about 50 million people worldwide. Epilepsy accounts for 1% of the global burden of disease; 80% of the burden of epilepsy is in the developing world, where in some areas 80–90% of people with epilepsy receive no treatment at 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.



Dr Benedetto Saraceno
Director
Department of Mental Health and
Substance Abuse
World Health Organization



Professor Giuliano Avanzini
President
International League Against Epilepsy



Mr Philip Lee
President
International Bureau for Epilepsy

Acknowledgements	6
Preface	7
Executive summary	8
Introduction	11
Methodology	12
■ Epilepsy: the disorder	15
1. Milestones in the history of epilepsy	16
2. Number of people with epilepsy	20
3. Epidemiology	22
4. Aetiology of epilepsy – reported frequency	24
5. Aetiology and risk factors	26
■ Epilepsy: the services	29
6. Diagnostic services	30
7. Primary care	32
8. Provision of care	34
9. Inpatient care	36
10. Epilepsy specialist services	38
11. Antiepileptic drugs	40
12. The treatment gap	42
13. Sub-specialized services	44
14. Epilepsy surgery	46

■	Epilepsy: the care providers	49
15.	Medical professionals	50
16.	Professionals allied to medicine	52
17.	Training in epileptology	54
18.	Education in epileptology	56
19.	Professional organizations	58
20.	Lay associations	60
21.	Role of ILAE in fostering epilepsy care	62
22.	Role of IBE in providing epilepsy care	64
■	Epilepsy: the public health aspects	67
23.	Budget and financing	68
24.	Disability benefits	70
25.	Epilepsy and rights	72
26.	Reporting and data collection	74
27.	Problems encountered	76
28.	Stigma and social issues	78
29.	The attributable and advertable burden of epilepsy	80
30.	Global Campaign Against Epilepsy	82
■	Glossary of terms	84
■	References	86
■	List of Respondents	90

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 Thérèse Agossou, Regional Office for Africa; Dr Claudio Miranda and Dr José Miguel Caldas de Almeida, Regional Office for the Americas; Dr Vijay Chandra, Regional Office for South-East Asia; Dr Wolfgang Rutz and Dr Matthijs Muijen, Regional Office for Europe; Dr Ahmed Mohit and Dr R. Srinivasa Murthy, Regional Office for the Eastern Mediterranean; and Dr Helen Hermann and Dr Xiangdong Wang, Regional Office for the Western Pacific, 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 ILAE 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.

A number of colleagues at WHO gave advice and guidance during the course of the project, in particular Dr José Bertolote, Dr Michelle Funk and Dr Vladimir Poznyak.

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.

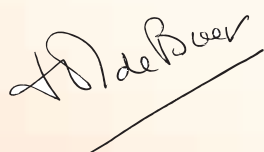
In order to map the resources available for epilepsy care, WHO decided to produce an Atlas on country resources for epilepsy, within the framework of the Global Campaign Against Epilepsy. The Global Campaign Against Epilepsy

– 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.



Mrs Hanneke M. de Boer
Co-Chair
ILAE/IBE/WHO Global Campaign
Against Epilepsy



Dr Leonid L. Prilipko
Programme Leader
Neurological Diseases and
Neuroscience
Department of Mental Health and
Substance Abuse
World Health Organization



Dr Shekhar Saxena
Coordinator
Mental Health: Evidence and
Research
Department of Mental Health
and Substance Abuse
World Health Organization

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 organizations do 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 members. 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.