

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

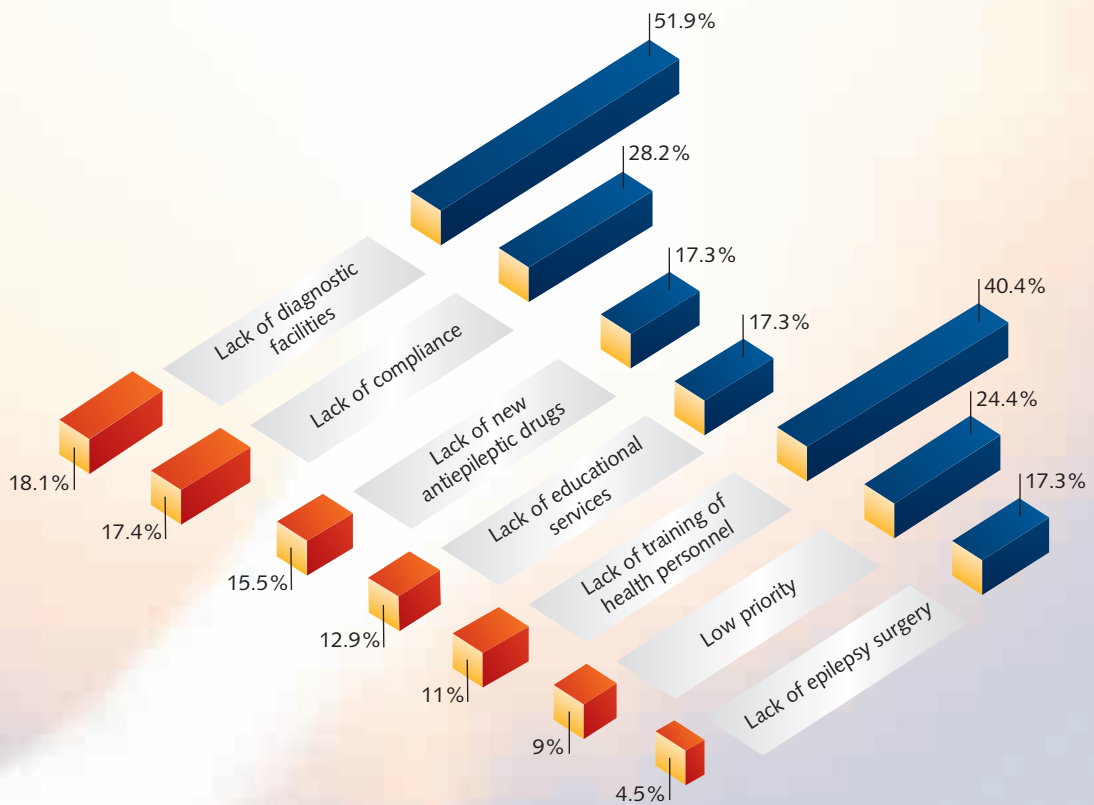
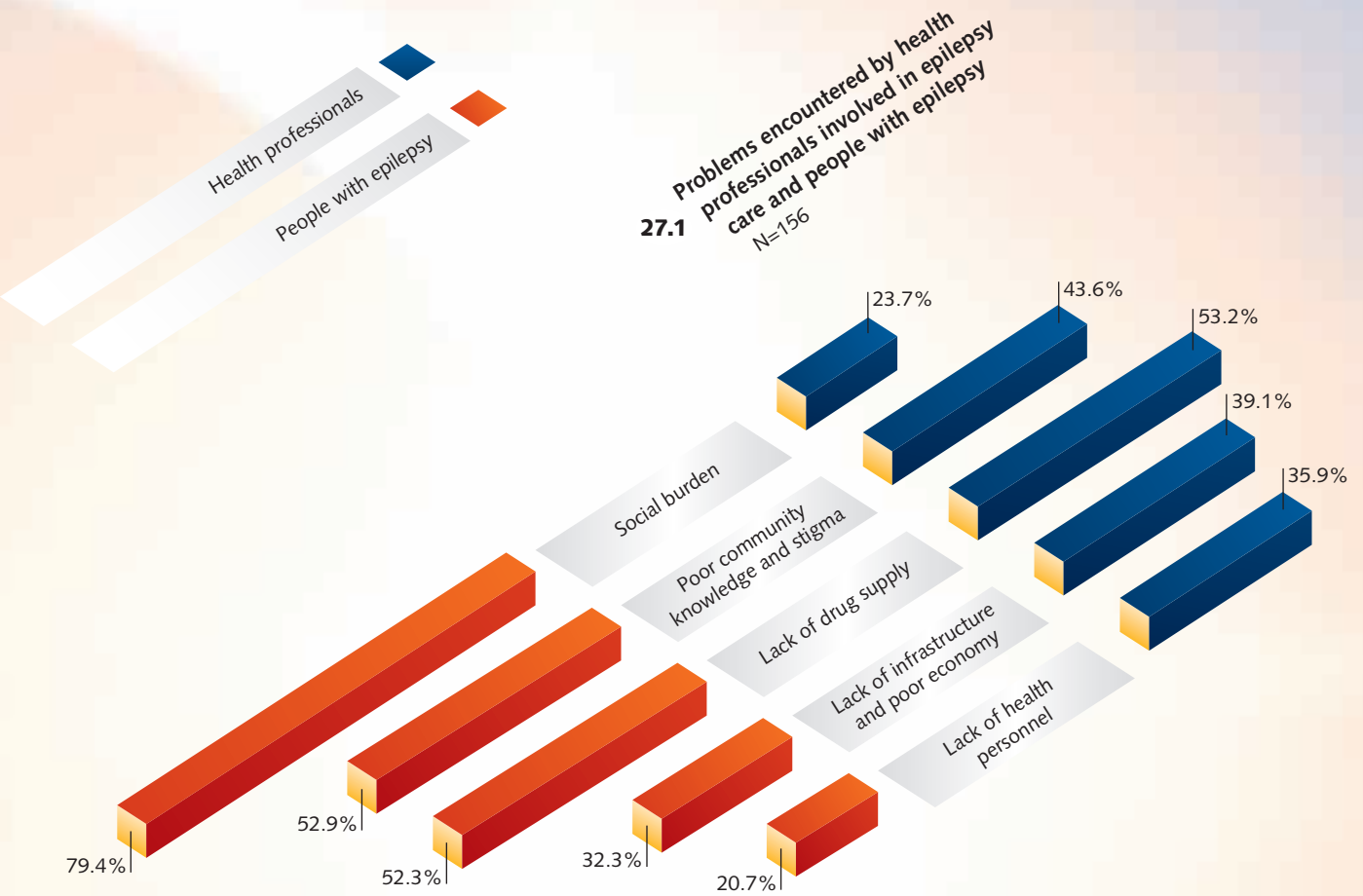
- ◆ The information is based on the experience and impression of a key person in a country working in the area of epilepsy and not on actual data from responding countries.
- ◆ It is possible that the problems related to access and utilization of services may differ between rural and urban areas. This 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

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

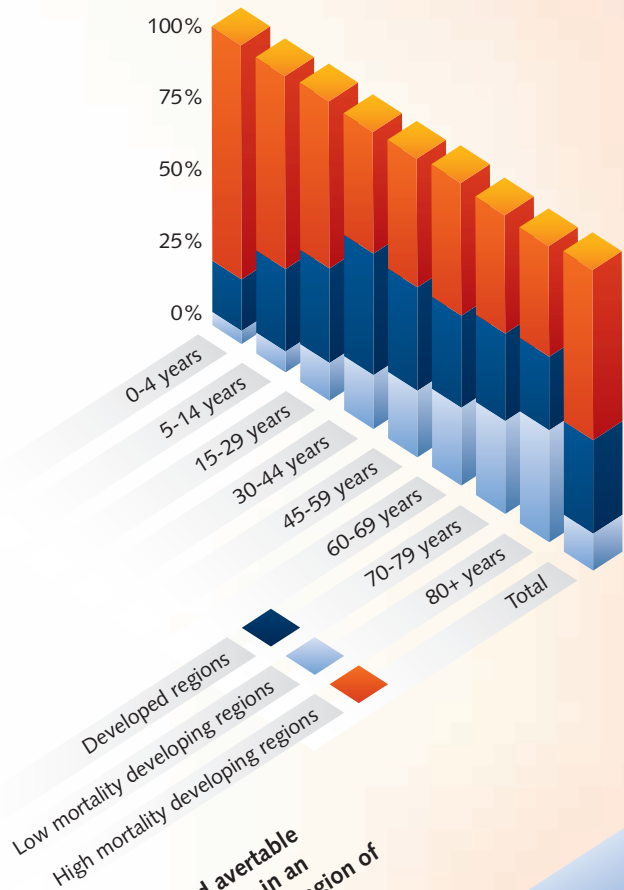
cost-effectiveness work programme (125) on the amount of burden averted by the current or scaled-up use of antiepileptic drugs (AEDs), together with estimates of cost and cost-effectiveness (124). Effectiveness was expressed in terms of DALYs averted, and costs were expressed in international dollars (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

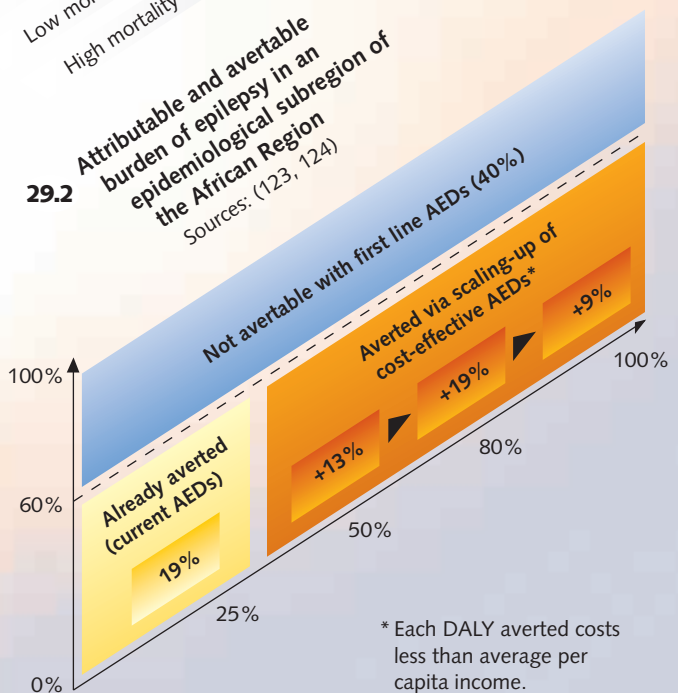
The burden of epilepsy manifests itself at a number of different levels. Taking a population-level approach, both epidemiological and economic studies have revealed the extent of the negative impact of epilepsy on existing levels of health and health care. It is an unfortunate truth that the current 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.