Global Campaign against Epilepsy

An Introduction to The Global Campaign and its Demonstration Projects

International Bureau for Epilepsy
World Health Organisation
International League Against Epilepsy
Bringing Epilepsy out of the Shadows

The Global Campaign against Epilepsy is a joint initiative of the World Health Organisation (WHO), the International League Against Epilepsy (ILAE), and the International Bureau for Epilepsy (IBE) to bring epilepsy "Out of the Shadows" by improving the diagnosis, treatment, prevention and social acceptability of the disorder world-wide.

Printed by: Paswerk Bedrijven Cruquius, the Netherlands
A sheltered workshop employing people with epilepsy

Copyright: ILAE/IBE/WHO Global Campaign against Epilepsy
February 2001
Why have a Global Campaign?  page 2
· Introduction
· The Burden of Epilepsy

The Global Campaign Against Epilepsy  page 4
· The Campaign’s Objectives
· Raising Awareness

Reasoning Behind the Demonstration Projects  page 6
· Supporting Departments of Health
· The Treatment Gap

The Demonstration Projects’ Management Structure  page 9
· Overview
· The Project’s Objectives

The Project’s Design and Activities  page 10
· Case Ascertainment
· Intervention to Improve Treatment
· Education
· Outcome Measures

Glossary of Terms  page 12

Reference List  page 14

Contact Information  page 15
The ILAE/IBE/WHO Global Campaign Against Epilepsy

Introduction

Epilepsy is the most common serious neurological disorder. It is also one of the world’s most prevalent non-communicable diseases. The word epilepsy comes from a Greek word epilambanein which means to seize or attack, and it is these seizures which have come to characterise the condition.

Ancient documents from the Middle East and Far East show that epilepsy is not a new phenomenon. It is, however, alarming that many people with epilepsy in developing countries still die from the condition in a manner not dissimilar to that recorded centuries ago. It is also the case that these countries have a higher incidence of epilepsy than developed countries.

The higher incidence suggests that a different spectrum of causes of epilepsy may exist there. Parasitic and infectious diseases such as malaria, neurocysticercosis or meningitis, are important risk factors for epilepsy. Birth complications and malnutrition may also be factors. High levels of these different diseases and conditions have been found in people with epilepsy in developing countries.

The Burden of Epilepsy

The use of Disability Adjusted Life Years has revealed the large global burden of neurological and psychiatric disorders, of which epilepsy is a part. These disorders have been estimated to cause 11% of all the days lost to health problems across the world. Epilepsy itself is thought to contribute around 1% of the total days lost. It is also estimated that there are up to 50 million people with epilepsy worldwide – with 40 million living in developing countries.

Whilst these figures may show the extent of epilepsy, they do not reveal its full burden as experienced by people with epilepsy.

Seizures themselves obviously have a physical effect on people. They can also have a further physical impact, such as injuries sustained during a seizure. In parts of Africa, for...
example, epilepsy is known as the *burns disease* because people experiencing a seizure often fall into their open fire used for cooking. This type of naming is taken one stage further in Indonesian communities living on or near rivers and where epilepsy is known as the *drowning disease*.

Epilepsy will also often have a psychological or an emotional impact. It is increasingly recognised that people with epilepsy may be affected far more by such social and psychological aspects than by the seizures themselves. Uncontrolled seizures can be very unsettling. People with epilepsy may fear going outside their homes unaccompanied. They may also fear what people might think of them if they are seen having a seizure.

Throughout the world’s history epilepsy has been a culturally devalued condition. Such devaluing often leads to people with epilepsy being stigmatised and causes a psychosocial burden on those affected. Many studies from around the world have shown people with epilepsy as having a lower annual income, a lower quality of life, lower school performance, low self esteem, worse chances of marriage and be generally excluded from social life. Fig. 2 below contains specific instances of these psychosocial effects.

**Fig. 2 Specific Examples of the Psychosocial Impact of Epilepsy**

<table>
<thead>
<tr>
<th>Country</th>
<th>Specific Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canada</td>
<td>Lower annual income and quality of life than other people with chronic illnesses.</td>
</tr>
<tr>
<td>China</td>
<td>Difficulties finding a spouse; families of people with epilepsy feel disgrace.</td>
</tr>
<tr>
<td>Ecuador</td>
<td>Social exclusion; altered relationships with spouses/parents; housing difficulties; employment problems.</td>
</tr>
<tr>
<td>Ethiopia</td>
<td>Treated as outcasts or “lepers” (showing leprosy to be equally stigmatised).</td>
</tr>
<tr>
<td>Kenya</td>
<td>Difficulties finding a marriage partner.</td>
</tr>
<tr>
<td>Netherlands</td>
<td>Children have lower school attendance &amp; performance.</td>
</tr>
</tbody>
</table>
Epilepsy can, in many cases, be successfully treated by antiepileptic drugs (AEDs). Despite this, the great majority of people with epilepsy in developing countries are not receiving appropriate treatment. In fact, many people do not know that AEDs exist, and those that do know are often unable to obtain them. In developing countries the “treatment gap” (the difference between the total number of people with active epilepsy and the number of people whose epilepsy is being treated, expressed as a percentage) has been recorded at 60-90%.[1]

Much recent knowledge about epilepsy is also not being applied for the benefit of patients. Since it is unlikely that there will be enough specialist neurologists to provide treatment in most countries, other health professionals will need to be trained to do so.

Awareness about epilepsy is generally very low right across the world. This will often be the case for both local communities and health professionals. This can often lead to public discrimination and exclusion of people with epilepsy, as well as inappropriate treatment.

Since the 1990s, members of the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE) and representatives of the World Health Organisation (WHO) have increasingly recognised these needs. In asking themselves how this situation could be improved, they were led to working together. This resulted in the collaborative programme of the Global Campaign Against Epilepsy, with its aim of bringing epilepsy out of the shadows.

The long-term goal of the Global Campaign is:

To improve health care services, treatment, prevention and social acceptance of epilepsy, the world’s most common serious, – yet treatable – brain disorder.

The Campaign’s Objectives

This goal is worked out in five key objectives:

1. To increase public and professional awareness of epilepsy as a universal and treatable brain disorder.
2. To raise epilepsy to a new plane of acceptability in the public domain.

3. To promote public and professional education about epilepsy.

4. To identify the needs of people with epilepsy at national and regional levels.

5. To encourage governments and departments of health to address the needs of people with epilepsy including awareness, education, diagnosis, treatment, care, services and prevention.

In order to pursue the achievement of these five objectives, the Global Campaign has adopted a strategy of two parallel tracks.

- Raising general awareness and understanding of epilepsy.

- Supporting Departments of Health in identifying needs and promoting education, training, treatment, services, research and prevention nationally.

**Raising Awareness**

In June 1997 the three collaborative partners (ILAE, IBE and WHO) launched the Global Campaign Against Epilepsy. Since 1997 the Campaign’s objectives have been pursued at national and international levels.

Internationally, this has led to conferences in WHO Regions at which member states have signed up to improve the treatment of people with epilepsy. Since 1998 five Declarations have been signed in Europe, Africa, Latin America, Asia and North America.

Further conferences and Declarations have been planned for 2001.

These Declarations, and the collaborative nature of the Global Campaign itself, show that partnership is a key aspect of raising awareness. The Global Campaign is a good working example of a partnership between WHO, ILAE, IBE, governments, agencies from the United Nations and other non-governmental organisations, as well as their national chapters in various countries all over the world.
Supporting Departments of Health

The Global Campaign is not, however, simply about awareness-raising. Whilst almost every country’s epilepsy services could be improved, the greatest need would appear to be in developing countries. It was, therefore, suggested that in order to practically help and support Departments of Health, the Global Campaign should develop demonstration projects. These projects should help to illustrate good practice in providing epilepsy care.

These projects are being developed alongside Health Departments and within the Global Campaign. The Campaign’s demonstration project officers provide advice, validate the projects’ proposals and monitor their progress. If these projects are successful their approach will then be disseminated to other countries and adopted, where appropriate. Countries are selected for demonstration projects on the basis of their willingness to participate, availability of a WHO Centre or WHO Country Representative, an ILAE and an IBE chapter, as well as an adequate supply of AEDs. Those countries currently involved are Argentina, China, Senegal and Zimbabwe. These begin their implementation in 2001 and are being publicly launched at WHO Headquarters in Geneva in February 2001. Some countries in other geographical regions are also under consideration.

External funds will be used to initiate the demonstration projects, but will not be used to provide services or drugs in the long term. This is because the provision of anything but minimal outside funding is likely to mean that a project is not locally sustainable.

The Epilepsy Treatment Gap

The mainstay of epilepsy treatment is AEDs. AEDs try to prevent further seizures or to reduce their frequency and severity. Studies from around the world have shown that up to 80% of people developing epilepsy may become free of seizures through AEDs\(^2\). Many of these people may eventually have their medication withdrawn. Other people, however, may have to take AEDs for the rest of their lives.

Some people with forms of epilepsy
which do not respond to AEDs may be suitable for surgery. However, as with many of the newer AEDs, this surgery is often not available in developing countries.

Whilst epilepsy affects around 50 million people worldwide and treatment is generally successful, a large proportion of people remain untreated in developing countries. In India, for example, it is estimated that approximately 5 million of the 10 million people with epilepsy do not receive any appropriate treatment. Fig. 3 below shows this treatment gap for various countries. These gaps result from people with epilepsy not being correctly diagnosed and/or not receiving appropriate treatment.

In addition to the treatment gap, a wide gap exists between the need for AEDs and their availability. Whilst only 20% of the potential market for AEDs is in developed countries, they receive over 80% of the total global supply of AEDs. This means that developing countries receive only 10-20% of AEDs, yet they have a greater need for them.

Whilst the treatment gap is connected with national and international income inequalities and poverty, the gap is also the result of a number of other factors and constraints. Some of these factors are listed on the next page:

Fig. 3 Percentage of People with Epilepsy Not Receiving Appropriate Treatment
* Different perceptions about epilepsy, which influence people’s health seeking strategies. For example, if epilepsy is not seen as a treatable medical condition people will not seek AEDs from health professionals.

* Lack of prioritisation in health budgets. Where governments have low health budgets, resources are prioritised for conditions perceived to be more important, such as infectious diseases.

* Lack of training for health professionals.

* Lack of infrastructure AND Governments are often unlikely to be able to afford to supply the cheapest AEDs.

* Limited supply of AEDs. The majority of AEDs are used in developed countries, despite the majority of people with epilepsy living in developing countries.

* Limited choice of AEDs. Very few of the newer AEDs are generally available. This is partly due to their cost.

It is these constraints and the very fact that a treatment gap exists which has spurred on the construction of demonstration projects. As described on pages 9-11, identifying and closing the treatment gap in individual countries will be the key objective and activity for each project.
The Demonstration Projects’ Management Structure

Overview

The Campaign’s Secretariat oversees the day-to-day running of the Campaign. This involves raising awareness and ensuring adequate funding. Management duties for the demonstration projects have been delegated to the Scientific Project Leader supported by an Assistant Scientific Project Leader.

The Project Leader liaises with local ILAE and IBE chapters in order to foster local ownership and community participation. This liaison also involves the relevant WHO Offices and Departments of Health. The Project Leader is then responsible for helping to design and evaluate the projects’ protocol. An important aspect of the evaluation is ensuring that each project has sustainability built into its design. The Project Leader is also responsible for monitoring the projects to see how they are performing, and for writing up this performance for scientific journals.

Each project will be led locally by Principal Investigators. They are responsible for constructing the project’s protocol and ensuring that its implementation keeps to its budget and timescales. They are the focal points of the Campaign’s relationship with the project and the people through whom information will flow. Crucial to their work is ensuring that the project meets its outcome measures. Regional Facilitators will support them in their project’s implementation.

The Projects’ Objectives

To support Departments of Health in identifying needs and promoting education, training, treatment, services, research and prevention nationally, the following objectives have been set for each demonstration project:

1. To reduce the treatment gap and the physical and social burden of people with epilepsy by intervention at a community level.

2. To train and educate health professionals.

3. To dispel stigma and promote a positive attitude to people with epilepsy in the community.

4. To identify and assess the potential for prevention of epilepsy.

5. To develop models for promotion of epilepsy control worldwide and for its integration in the health systems of participating countries.
In China, village doctors will use a diagnostic questionnaire with those people identified as possibly having epilepsy. Senior primary health care physicians will confirm their diagnoses. People who are confirmed to have epilepsy and who are not receiving regular treatment will then be considered for inclusion in the project. Those people included will receive the AED phenobarbitone in accordance with a checklist of technical norms. Patients will be educated about their condition, and possible side-effects, in order to encourage compliance with their treatment.

3. Education
Incorrect perceptions about epilepsy often lead to people with epilepsy being stigmatised. Epilepsy is also often neglected in medical training. Therefore, communities’ and health professionals’ awareness about epilepsy needs to be raised.

The project in China will ensure that all physicians and a number of village doctors receive basic epilepsy training. This will cover: epidemiology, causes, diagnosis and management of epilepsy. Activities aimed at decreasing stigma will be targeted at school teachers. Attitudes
regarding causes of epilepsy and shame associated with the condition will be covered. Local advocacy and support groups for people with epilepsy and their families will also be encouraged to develop.

**Outcome Measures**

It is expected that the projects will be successful and provide suitable approaches for other countries to adopt. Their success will be seen in terms of the following outcomes:

1. **Diminishing the treatment gap.**
2. **Reduction in the economic burden of epilepsy.**
3. **Reduction in the individual burden of epilepsy.**

In order to discern whether a project is meeting these outcomes, its performance will be more specifically measured using the following variables:

1. Population and treatment characteristics (age of onset, sex, education and ethnicity)
2. The treatment (who provided the treatment, what services were offered, etc.)
3. Immediate effects of treatment (such as, on seizures, side-effects etc.)
4. Functional impact of treatment (on hours of work, training, travel capability, social activities, etc.)
5. Perceived impact (on relationships, employment, living standards, future plans, etc.)
Glossary of Terms

Anti-epileptic drugs (AEDs) – medicines used to treat the seizures of people with epilepsy. Phenobarbitone, phenytoin, carbamazepine and sodium valproate are some of the common types of AEDs. The cheapest across the world tends to be phenobarbitone.

Burden of epilepsy – the extent to which epilepsy impacts people who experience the condition. This impact can be felt physically, emotionally, socially, economically, educationally and so on.

Disability Adjusted Life Years (DALYs) – this is a measure which helps to quantify the burden of particular illnesses. It combines the potential number of life years lost due to premature death from the illness with the number of years of productive life lost due to disability produced by the illness.

Epidemiology – this is the study of the incidence, distribution and determinants of illnesses with the aim of identifying their causes and working towards their prevention.

Epilepsy – a malfunction in the brain leading to a temporary change in the electrical activity of the brain which in turn leads to a seizure. For a diagnosis of epilepsy to be confirmed, seizures need to be unprovoked and recurrent (i.e. not just a single instance).

International Bureau for Epilepsy (IBE) – established in 1961 by members of the ILAE, the Bureau aims to improve the quality of life of people with epilepsy. It does so through raising public awareness about epilepsy and the needs of people with epilepsy (particularly relating to the social aspects of epilepsy). It has many affiliated chapters (national based IBE organisations) in many countries.
The ILAE/IBE/WHO Global Campaign Against Epilepsy

International League Against Epilepsy (ILAE) – established in 1909, the League is mainly for health professionals. It works to advance scientific and medical knowledge about epilepsy. It also has many chapters across the world.

Principal Investigator – person responsible for the activities of the demonstration projects in each of their countries.

Psychosocial effects of epilepsy – the impact which epilepsy has on people which goes beyond the experience of the seizures themselves. This includes the way people feel about themselves or problems with education, relationships or maintaining employment.

Regional Facilitator – the person responsible for helping to establish and monitor demonstration projects in particular regions. They are required in regions where there is more than one project.

Scientific Project Leader – the person with the overall duties of establishing, advising, monitoring, overseeing and writing-up the demonstration projects.

Seizure – a change in perception or behaviour resulting from abnormal electrical activity in the brain.

Treatment gap – the difference between the number of people with active epilepsy (i.e. two or more unprovoked seizures on a different day in the previous year) and the number of people whose seizures are being appropriately treated in a given population at a given point in time, expressed as a percentage.
Contact Information

**International League Against Epilepsy (ILAE)**
Contact for the Global Campaign:
E H Reynolds, Centre for Epilepsy, Kings College Hospital, Denmark Hill, London, SE5 9RS, UK, tel: +44 20 7848 5756, fax: +44 20 7848 5530, email: reynolds@buckles.u-net.com.

**International Bureau for Epilepsy (IBE)**
Contact for the Global Campaign:
H M de Boer, Stichting Epilepsie Instellingen Nederland, Achterweg 5, 2103 SW Heemstede, The Netherlands, tel: +31 23 5 237 418, fax: +31 23 5 470 119, email: ibe@xs4all.nl.

**World Health Organisation (WHO)**
Contact for the Global Campaign:
L L Prilipko, Team for Neurosciences, Department of Mental Health, World Health Organisation, 1211 Geneva 27, Switzerland, tel: +41 22 791 3627, fax: +1 22 791 4160, email: prilipkol@who.ch.

WHO Regional Office for Africa (AFRO), Parirenyatwa Hospital, PO Box BE 773, Harare, Zimbabwe, tel: +263 407 733 9244, fax: +263 407 726 5062, email: mandlhatec@whoafr.org

WHO Regional Office for the Americas (PAHO), 525 23rd Street, NW Washington, DC 20037, USA, tel: +1 202 974 3000, fax: +1 202 974 3663

WHO Regional Office for Eastern Mediterranean (EMRO), PO Box 1517, Alexandria – 21511, Egypt, tel: +203 48 202 23/24, fax: +203 48 300 96/97

WHO Regional Office for Europe (EURO), 8 Scherfigswei, DK-2100 Copenhagen Æ, Denmark, tel: +45 39 17 17 17, fax: +45 49 17 18 18

WHO Regional Office for South-East Asia (SEARO), World Health House, Indraprastha Estate, Mahatma Gandhi Road, New Delhi 110002, India, tel: +91 11 331 7804/7823, fax: +91 11 332 7972

WHO Regional Office for the Western Pacific (WPRO), PO Box 2932, 1099 Manila, Philippines, tel: +632 52 88 001, fax: +632 52 11 036