

Epilepsy in the WHO Eastern Mediterranean Region



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Epilepsy in the WHO Eastern Mediterranean Region

Bridging the gap

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Foreword

The World Health Organization (WHO) estimates that 50 million people of all ages around the world are affected by epilepsy, with more than 85% living in the developing world. An estimated 4.7 million people with epilepsy live in the WHO Eastern Mediterranean Region.

The social, physical and psychological implications of epilepsy are immense. Stigma and discrimination dominate social attitudes towards epilepsy. The sociocultural dimensions of epilepsy are important determinants of its clinical course, and are often among the major barriers to appropriate treatment.

Despite the seemingly gloomy picture, we should not lose hope. Most of the causes of symptomatic epilepsy are preventable and treatable. Antiepileptic medicines can provide effective treatment that is both available and relatively inexpensive. In up to 70% of people, epilepsy can be fully controlled by antiepileptic medicines.

In developing countries, however, up to 90% of people with epilepsy may not receive the treatment they need. The resultant wide treatment gap remains a cause of tremendous individual, family, social and economic burden.

Against this backdrop, the Global Campaign Against Epilepsy was launched in 1997 as a joint initiative of WHO, the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) with an overarching aim of bringing epilepsy “out of the shadows”.

Under the auspices of the Campaign the Eastern Mediterranean Region launched its Declaration on Epilepsy in 2003. The declaration called on the governments of the Member States of the Eastern Mediterranean Region, national and regional, public and private organizations, all health care providers, and the general public to participate in taking strong and decisive action to meet the objectives of the Global Campaign Against Epilepsy.

The availability of essential information will hopefully lead to greater awareness among policy-makers. I hope that this report will succeed in encouraging more Member States and partners to be involved in the efforts to reduce stigma, affirm dignity and bridge the current treatment gap for people with epilepsy.



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WHO Regional Director
for the Eastern Mediterranean

Preface

Epilepsy is one of the most common neurological disorders and knows no geographical, racial or social boundaries. It can begin at any age, but is most frequently diagnosed in children, adolescents and the elderly.

Epilepsy provides the finest example of a neurological disorder for which cost-effective treatment is available. Up to 70% of people with this condition could live productive and fulfilling lives, free from seizures, if appropriately diagnosed and treated. Yet epilepsy continues to take a heavy toll on those who suffer from the condition. The cost of epilepsy is by no means restricted to the individuals suffering from the condition but also extends to their families. The costs are not only the direct costs of providing care and services but also indirect costs in terms of lost opportunities and productivity. Furthermore the imperceptible costs of stigma and discrimination add immeasurably to the physical, psychological, social and economic consequences of individuals and their families. One of the common consequences of discrimination and the associated stigma, is that patients and their families do not seek treatment even when it is available, accessible and affordable.

Since its launch in 1997 by ILAE, IBE and WHO, the Global Campaign Against Epilepsy has been gathering momentum. In its first phase it led to many awareness-raising activities, such as the regional conferences on epilepsy as a public health priority. During its second phase (2001) the Campaign moved from raising

awareness to implementing demonstration projects in order to support ministries/departments of health in identifying needs and promoting education, training, treatment, service delivery, research and prevention to reduce the treatment gap at the national level.

It is evident that the collaboration between ILAE, IBE and WHO has given the Campaign the opportunity to build a framework for concerted action at global, regional and national levels to raise awareness for epilepsy and reduce the treatment gap.

This is one of a series of similar reports published in the WHO regions. The report is aimed at both lay and professional readers. It contains information on epilepsy epidemiology, needs and resources, thus providing an overview of the epilepsy situation in the Eastern Mediterranean Region. The results of a questionnaire on country resources for epilepsy are also included. It outlines the initiatives taken by ILAE, IBE, WHO and other partners through the Global Campaign Against Epilepsy to address the problems, it defines the current challenges and offers appropriate recommendations.

We hope that the information in the report will provide a spur for improving services at country level in the Region and that the report will serve as a potent advocacy tool for taking epilepsy "out of the shadows" in the Eastern Mediterranean Region.

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1. Eastern Mediterranean Region

The World Health Organization (WHO) Eastern Mediterranean Region comprises 22 countries with varied population and demographic profiles (Figure 1). The population of the Region's countries ranges from less than 1 million in Djibouti to more than 160 million in Pakistan. A high proportion of the population is young, with approximately 31% aged 15 years or younger. The percentage of the population aged over 60 years ranges from 1.1% in Qatar and 1.6% in Kuwait to 9.6% in Lebanon (1).

Gross domestic product per capita ranges from less than US\$ 352 in Afghanistan to over US\$ 84 500 in Qatar (1). Annual population growth rates in the Region in 2007 ranged from 1.2% in Tunisia to 9.3% in Kuwait (1). The total fertility rate is less than 2.5 children per woman in the Islamic Republic of Iran, Kuwait, Lebanon, Tunisia and the United Arab Emirates and 6.7 in Somalia. Life expectancy at birth ranges from 46 years in Afghanistan to 77.8 years in Qatar. Under-5 child mortality rates range from 191 per 1000 live births in Afghanistan to less than 10 per 1000 live births in Qatar and United Arab Emirates. Maternal mortality is still high in some countries of the Region.

Total expenditure on health as a percentage of gross domestic product ranges from 2% in Pakistan to 8.8% in Lebanon.

The Region has a long way to go to attain the Millennium Development Goals. According to the World Bank, 30% of the population of the Middle East and North Africa still lives on less than US\$ 2 per day (2). With respect to gender equity and empowerment of women, disparity between the sexes is still wide in some countries. Even though maternal mortality is decreasing, intensified efforts will be needed in some countries of the Region to attain the target of Millennium Development Goal 5 to reduce by three quarters, between 1990 and 2015, the maternal mortality ratio. Good progress is being made in the Region towards achieving universal primary education, and moderate progress is being made in reducing child mortality.

Environmental issues, particularly rapid urbanization and the scarcity of water resources, are a source of concern for many countries. Although data on the magnitude of environmental hazards are lacking, there is evidence that rural water and sanitation coverage is less than 50% in several low-income and some middle-income countries (1).

Additional contributors to ill-health in the Region are disasters and complex emergencies. During the past decade, at least eight countries have been in some sort of conflict or emergency condition. Such situations result in destruction of infrastructure and increasing poverty, and contribute to a relatively high prevalence of mental health conditions.



Figure 1. WHO Eastern Mediterranean Region

2. Epilepsy: the disorder

2.1 Introduction

Epilepsy, one of the most common chronic neurological disorders, has no age, race, social class or geographical boundaries. Ten per cent (10%) of the world's population who live a normal lifespan can expect to have at least one epileptic seizure (3). At least 50 million people in the world have epilepsy and approximately 85% of these live in developing countries (4–7).

The global burden of epilepsy (including epilepsy and status epilepticus) is determined by estimating the number of productive life years lost due to disability or premature death resulting from the disease (known as disability-adjusted life years, or DALYs). Mathers, Lopez and Murray (8) estimate the DALYs lost annually due to epilepsy as 6 223 000 worldwide. A notable observation is the reportedly low burden in the Middle East and North Africa (248 000), despite the fact that parts of these regions are relatively underdeveloped.

Epilepsy is among the three most frequently encountered neurological disorders in primary health care settings in 20 of the 22 countries of the Eastern

Mediterranean Region (9). There are an estimated 4.7 million people suffering from epilepsy in nine countries of the Region (5) (Box 1).

Although epilepsy is a largely treatable brain disorder and relatively cheap medication is available, between 60% and 98% of individuals with this disorder in developing countries receive no treatment. People with epilepsy present with health problems, while also having to cope with a wide range of psychosocial difficulties that affect almost every aspect of their lives. Many of these difficulties are a consequence of public misconceptions, prejudice and stigma (6,11).

2.2 Historical background

Currently the earliest known detailed description of various seizure types is contained within the stone tablets of the *Sakikku* (meaning “all diseases”), a Babylonian text compiled around 1000 BC which is held in the British Museum, London. A Sumerian term referring to descriptions of seizures has been translated as the “falling sickness”. The Babylonians thought that each seizure type represented possession by a particular demon or departed spirit

BOX 1. Availability of country resources for neurological disorders and epilepsy care

The WHO publication *Atlas: country resources for neurological disorders 2004* (9) presents a comprehensive collection and compilation of information on country resources for neurological disorders across 109 countries, covering over 90% of the world's population. The information was primarily gathered from key experts in the area of neurology in each country identified by the World Federation of Neurology as their official delegates and, in some cases, by WHO regional offices. It is one of the most comprehensive compilations of neurological resources ever attempted. The results obtained from the study confirm that the available resources for neurological service in most countries of the world are insufficient compared with the global need for neurological care. The Atlas presents the facts and figures and highlights the large inequalities across regions and countries, with low-income countries having extremely meagre resources.

The WHO publication *Atlas: epilepsy care in the world 2005* (10) was developed within the framework of the Global Campaign Against Epilepsy and maps the resources available for epilepsy care across 160 countries, covering over 97% of the world's population. This atlas is one of the most comprehensive compilations of available resources for epilepsy ever attempted, providing an illustrative presentation of information on the current status of epilepsy services and care in the world. 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.

and hence treatment focused on spiritually-based methods (12).

The two major Middle Eastern practitioners who dealt with epilepsy in medieval times were Ibn Sina (980–1037) and Al-Razi (circa 865–925), and they considered epilepsy a medical illness. Their writings had a profound influence in Europe, and as late as the 1700s this material was still fundamental for medical students in universities around the world. Ibn Sina, the “Prince of Doctors”, was scientific and rational in his treatment of epilepsy and left an abundance of pertinent details. He was the first person to coin the term “epilepsy”, using a passive Latin verb. In his *Canon of Medicine*, Ibn Sina speaks of epilepsy in exhaustive detail, describes its various forms and symptoms and its apparent causes, and offers a long list of pharmacological products for its treatment. His prescriptions are a repertory of herbal and pharmacological recipes and of dietary rules based on the principle that it is necessary to create personalized treatments, adapted to each individual, consisting of medicinal and dietetic therapy and incorporating hygienic norms (13,14).

The view that has dominated thinking about epilepsy in many parts of the world, including the Eastern Mediterranean Region, until quite recently is that epilepsy is caused by supernatural forces. This view remains, even now, deeply rooted in society with negative social consequences. It was not until the 17th and 18th centuries that the Hippocratic concept of epilepsy as a brain disorder began to take root. During these two centuries epilepsy was one of several key areas of debate in the gradual identification and separation of “nervous disorders” from “mental disorders”, which led to the beginnings of modern neurology in the 19th century (15–17).

■ 2.3 Epidemiology, diagnosis and etiology

■ *Epidemiology of epilepsy*

Epidemiological data provide understanding about the incidence, prevalence and potential risk factors for epilepsy, and can be used to assist in planning health services for people with epilepsy. However, many epidemiological studies of epilepsy published worldwide lack standardized definitions,

diagnostic accuracy and seizure classification, which impedes meaningful comparison. Analysis of risk factors is also a source of confusion, and basic epidemiological measures are frequently misquoted. Several measures have been used to describe the frequency of epilepsy, but often these indices are inappropriately used or are used without definition. All these measures require a numerator that should reflect complete case ascertainment, as well as a clearly defined denominator.

A few studies reporting on the prevalence of epilepsy have been conducted in the Eastern Mediterranean Region. One of the major problems faced when analysing these studies is that most of the reports have not followed standardized definitions and thus their results are difficult to compare. This leads to confusion as in many countries higher reported rates reflect more sensitive case-finding methods, while in others they may signify higher prevalence.

Studies (with population size more than 1000) conducted in the Region (18–22) have shown that the prevalence of epilepsy ranges from as low as 4.04 per 1000 population (18) to those as high as 12 or more per 1000 population (20,21) (Table 1). Furthermore, higher rates are reported in young age groups (17,22) and in rural populations (20,22). In a study in rural Pakistan, the prevalence of epilepsy reached 14.8 per 1000 population (20), and even higher rates were reported in children in low socioeconomic classes (23.1 per 1000 population) (23). In their study, Aziz et al. (24) reported that more than 70% of the adult population with epilepsy had the onset of their disease in childhood.

The nine countries in the Eastern Mediterranean Region that responded to the survey for the atlas on epilepsy care in the world, covering over 70% of the population in the Region, reported a total of 3 483 000 people with epilepsy (10). In the responding countries, the median number of people with epilepsy per 1000 population was 8.16 (interquartile range 5.75–9.98).

Benamer and Grosset carried out a systematic review of epidemiological aspects of epilepsy in Arab countries (25). Medline and Embase were searched, and six papers were identified: one incidence report from Qatar and five prevalence reports (two from

Sudan and one each from Libyan Arab Jamahiriya, Saudi Arabia and Tunisia). An incidence of 174 per 100 000 persons in 2001 was reported in a hospital-based study from Qatar. Prevalence ranged between 0.9 per 1000 in Sudan and 6.5 per 1000 in Saudi Arabia, with a median of 2.3 per 1000. An estimated 724 500 people with epilepsy live in the Arab world. All studies report higher prevalence in males (26–29), which was statistically significant in the Saudi study. Epidemiological data from Arab States are lacking, especially from populous countries such as Algeria, Egypt and Syrian Arab Republic. Well-designed studies are needed to determine more accurately the burden of epilepsy in the Arab world (25).

Local variations in the prevalence of risk factors and genetic factors that may predispose individuals to develop epilepsy have undoubtedly contributed to the marked heterogeneity in epilepsy prevalence and incidence throughout the world. Data on epilepsy are more consistent for industrialized countries, the prevalence ranging between 5.6 and 7 per 1000 in studies in Europe and the United States of America (30–31). Studies in developing countries reveal much higher rates. Most of the studies published from Central and South America show prevalence rates between 16 and 57 per 1000 (32–35). The highest prevalence rates in Africa were reported in the United Republic of Tanzania at 20 per 1000 (36), Nigeria at 37 per 1000 (37) and Liberia at 26–40 per 1000 (38). Some areas of rural Uganda have recorded rates as high as 57 per 1000 (39).

It should once more be noted that accurate data are difficult to obtain. Some non-convulsive seizures are often missed and because of the delay in seeking medical advice, especially in rural areas, the data often underestimate the problem. Furthermore, cultural factors influence the results. If epilepsy carries social stigma, people with the condition will not admit it to researchers. It is therefore not surprising that several researchers have suggested that seizures – and even the diagnosis of epilepsy – might be concealed. In a study in the United Kingdom, 53% of people with epilepsy would choose concealment as a strategy (40).

Information on the incidence of epilepsy is widely available for developed countries, but the same information for developing countries is less complete. Unfortunately, there are no published data regarding incidence rates in countries of the Eastern Mediterranean Region except that reported from Qatar. Worldwide reported figures range from 30 to 100 per 100 000 population in Europe (30,41), to rates ranging from 109 to 190 per 100 000 in Ecuador (27–42); rates as high as 232 per 100 000 per year have been reported for some zones in west Uganda (43).

Definitions, diagnosis and case ascertainment

Epilepsy is a brain disorder characterized by recurrent epileptic seizures, unprovoked by an immediate identified cause. Multiple seizures occurring in a 24-hour period are considered a single event. A person with prevalent active epilepsy is defined as a

Table 1. Summary of studies of epilepsy prevalence by country

Country	Population size	Criteria	Crude prevalence (per 1000 pop.)	Authors
Tunisia (1993)	341 900	Active epilepsy	4.04	Attia-Romdhane, Mrabet and Ben Hamida (18)
Saudi Arabia (2001)	23 700	Active epilepsy	6.54	Al Rajeh et al. (19)
Pakistan (1994)	24 130	Recurrent non-febrile active seizures	9.99	Aziz, Akhtar and Hasan (23)
Islamic Republic of Iran (2004)	35 014	Unspecified	12.00	Noorbala et al. (21)
Sudan (2004)	50–100 000	Unspecified	10.6–21.2	Perenchio et al. (22)

person with epilepsy who had at least one epileptic seizure in the previous five years, regardless of antiepileptic medicine treatment (44–45). Diagnosis of epilepsy is essentially clinical, based on a clear history of epileptic seizures. Diagnosis should be confirmed by a trained health professional using available medical history, seizure description and neurological examination. Standardized study methods should be used to obtain information about the above diagnostic elements and standardized criteria should be used for their interpretation. If available, electroencephalography (EEG) records and other diagnostic tools should be used to assist in classifying seizures, epilepsies and epilepsy syndromes more accurately. However, lack of these instruments should not preclude the diagnosis of epilepsy, especially as they are not always sensitive or specific tools (46,47).

The currently used Classification of Epilepsies and Epileptic Syndromes was accepted in 1989 (48) and a revision was proposed in 2001 (49). Syndromes are characterized by several features, including seizure type, specific EEG characteristics, age at onset and presence of an underlying cause (or etiology).

The causes of unprovoked seizures or epilepsy are summarized in Box 2 (45,49).

Causes of epilepsy

Data collection on the epidemiology, etiology and natural history of epilepsy has increased understanding of this devastating disease. Further investigation and identification of risk factors in developing country populations will be important in the development of efficacious and comprehensive programmes for the prevention and treatment of epilepsy.

Studies from different countries in the Region show that the cause of epilepsy was not identified in the majority of cases (50,51), especially in studies in the paediatric population. Similarly, in studies carried out in developed countries, even with the availability of investigative tools, more than 60%–70% of all children with epilepsy were diagnosed as having idiopathic or cryptogenic epilepsy (52–54).

Studies in the Eastern Mediterranean Region have shown that epilepsy in children was attributed to

BOX 2. Causes of unprovoked seizures or epilepsy

The causes or etiologies of unprovoked seizures or epilepsy are divided into two main categories, and a third category where causes are uncertain.

Remote symptomatic. Remote symptomatic (or, simply, symptomatic) seizures are unprovoked or spontaneous; that is, there is no acute precipitating event or insult that causes the brain to seize. However, symptomatic epilepsies are considered the consequence of a known or suspected cerebral disease. Some well-recognized and established remote symptomatic causes include brain malformations, prior stroke, prior intracranial infection and prior head trauma.

Idiopathic. This term is reserved for certain partial or generalized epileptic syndromes with particular clinical characteristics and specific EEG findings. Idiopathic epilepsies are presumed to have a genetic basis. As more is learnt about the genetic basis of the epilepsies, this concept is undergoing significant revision.

Cryptogenic (probably symptomatic). This term literally means that the cause is hidden. This group includes patients who do not conform to the criteria for the symptomatic or idiopathic categories. They are believed to be symptomatic but no etiology has been identified. The ongoing work worldwide in molecular genetics and into the understanding of how the brain becomes epileptic – from the ionic basis of membrane excitability to the role of deep mid-brain structures in generalized seizures – may one day provide the information needed to classify causes more precisely within this heterogeneous grouping.

perinatal medical problems in most cases (24,55,56), and the same is true even in reports on adults with epilepsy. Studies have suggested that perinatal encephalopathy may be responsible for 13% to 23% of the identified causes of epilepsy (19,50,57). The causes of perinatal encephalopathy include maternal cardiovascular disease, placental and umbilical cord disorders, prolonged labour, and airway obstruction at birth. In many developing countries, most deliveries in rural areas are performed by traditional birth attendants. Complications with delivery are common, and the incidence of preterm deliveries is at least twice that in developed countries (58). Mothers in developing countries are frequently malnourished, anaemic, and exposed to a variety of infections that could affect the baby in utero or at delivery and increase the risk for epilepsy (59).

Other reported causes of epilepsy include head trauma (4% to 11%), especially in the adult population (as high as 20% of causes in patients over 20 years old) (19,50). Traumatic brain injury has been recognized as a cause of epilepsy since antiquity, and it remains one of the most common and important causes of acquired epilepsy today. Epidemiological studies have demonstrated a clear relationship between the severity of injury and the likelihood of developing epilepsy, with the risk approaching 50% in cases of traumatic brain injury associated with direct injury to brain parenchyma. The importance of traumatic brain injury and epilepsy deserves special attention in the Region due to the increase in severe head trauma associated with violence in the context of complex emergencies (60).

Central nervous system infections were reported as a cause of epilepsy in 2% to 28% of cases (19,50,51). In a study carried out in Turkey, intractable epilepsy, mental retardation, cerebral palsy and visual disturbance were found to be the most common and severe conditions affecting sufferers of neonatal hypoglycaemia (61). Another recent study documents the etiologies of seizures in young children in an urban reference hospital in a developing country. Hypocalcaemia has an important place in the etiology of afebrile seizures among patients in the Eastern Mediterranean Region, in contrast to many developed countries. Nutritional status should therefore be kept in mind

when evaluating the etiologies of seizures in young children in developing countries (62).

The risk of epilepsy is increased threefold for individuals who have a first-degree relative with the condition (63). In addition, a number of diseases that follow Mendelian patterns of inheritance may have seizures as one of their manifestations or as their only manifestation. In many countries of the Region, consanguinity is relatively common – first cousin unions are even the most common form of cousin marriage. Such practices are likely to increase the risk of seizure disorders in any offspring. In studies in countries of the Region, authors have noted a significant association between consanguinity of the parents and epilepsy (24,50,55,56,64–66).

It is important to note that a recent study in Jordan showed that the etiologies of epilepsy include hypoxic-ischaemic encephalopathy, cortical malformations, neurocutaneous syndromes, metabolic disorders, leukodystrophy and craniosynostosis. The risk factors for epilepsy included parental consanguinity ($P=0.0003$), a family history of global developmental delay ($P=0.0002$), a family history of epilepsy ($P=0.010$) and a positive perinatal history ($P=0.011$) (67). Other studies in the Eastern Mediterranean Region support these findings (68–70).

The nine countries of the Region that responded to the atlas survey reported the following factors to be among the five most frequently encountered causes of epilepsy: trauma (reported by all the responding countries); central nervous system infections (excluding parasitic infestations) (reported by 85%); and idiopathic epilepsies (64%), cerebrovascular disorders (64%) and tumours (57%). Perinatal problems (including neonatal infection) were reported by 43% of the countries as one of the five major causes of epilepsy (Figure 2) (10).

Differences reported among studies regarding the etiology of epilepsy may not be true differences as diagnosis of the cause of epilepsy requires the availability of different investigative tools. Results may not accurately reflect the situation, especially in rural areas and in low-income countries with poor accessibility, even to basic investigations.

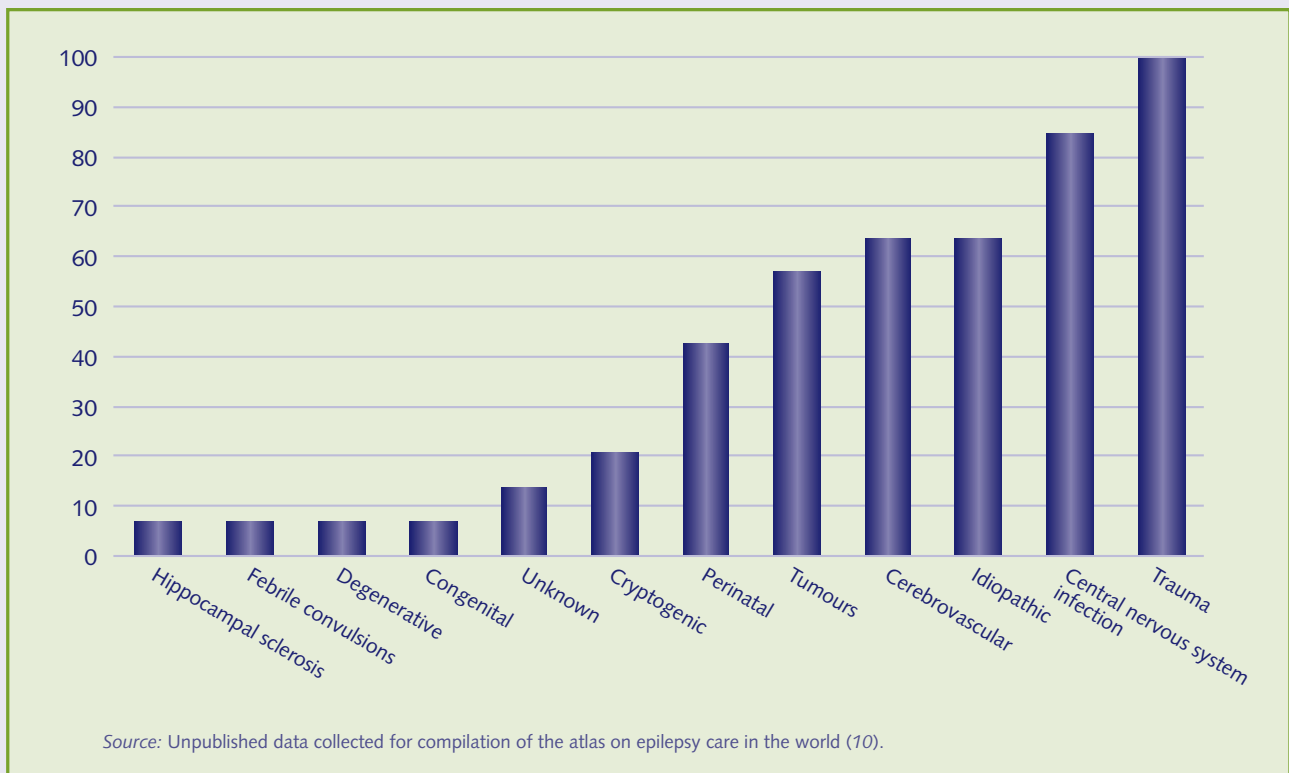


Figure 2. Most frequently reported etiology of epilepsy

Diagnostic services

There is an increasingly sophisticated range of investigations that can be used in patients with epilepsy. The principal objectives of investigating patients with new and chronic epilepsy referred for evaluation are to:

- clarify the diagnosis of epilepsy or non-epileptic attacks;
- determine the nature of the seizure types, epilepsies and epilepsy syndrome;
- in the case of partial seizures, identify the localization;
- identify the etiology of epilepsy;
- identify concomitant problems, both neurological and psychological;
- monitor the progression and consequences of the epilepsy and its treatment.

Investigations of epilepsy may be grouped into those that are:

- structural, for example magnetic resonance imaging (MRI) or X-ray computerized axial tomography (CAT);

- functional, for example electroencephalography (EEG), positron emission tomography (PET) and single photon emission computed tomography (SPECT);
- biochemical or histological, for example blood tests, cerebrospinal fluid (CSF) examination and muscle biopsy.

It is important to ensure that the results are considered in the clinical context and with regard to each other and not in isolation (71). Application of diagnostic technology is a careful choice that goes beyond even clinical management. A public health approach is required in planning for procurement, and must take into consideration factors pertaining to cost-effectiveness, as well as availability of trained personnel and appropriate protocols (72).

According to the atlas on epilepsy care in the world (10), CAT is available to health professionals in all the nine responding countries of the Eastern Mediterranean Region, while MRI is available in 86.7% of them. MRI was not available in only one of the responding countries (a low-income country). While EEG was available to health professionals

dealing with patients with epilepsy in 93.3% of the responding countries, long-term video/EEG monitoring was available in 57.1%. Facilities for therapeutic medicine monitoring were available in 85.7% of the responding countries. In about one third of these countries such facilities were reported to be available to people with epilepsy free of charge or without any special condition.

An important limitation of the atlas data is that even though a diagnostic facility may be reported as available in a country, it may be present in only very limited numbers, insufficient to provide adequate services, especially in rural areas. The fact that only a percentage of the service is available free of charge, through insurance or public health systems, limits its utilization to the population in need.

It should be noted that the diagnosis of epilepsy is not always straightforward and a misdiagnosis can be easily made, even by specialists. Studies carried out in various settings have reported misdiagnosis rates of between 4.6% and 30% (73,74). Misdiagnosis can lead to serious consequences, including driving and employment restrictions and inappropriate treatment. Most studies focus on ways of reducing misdiagnosis. However, in some cases, diagnosis may be difficult for a number of reasons, including overlapping clinical features with other conditions, inadequate available history and limitations of investigations.

Epilepsy management

Provision of care

Quality of life of people with health problems is strongly linked to the quality of their care. In the treatment of a chronic condition such as epilepsy, the clinician is not so much concerned with “cure” as with preventing adverse consequences of the condition and optimizing the person’s functioning. When the outcome is narrowly conceptualized to be optimal seizure control, care is solely based on assessment of seizures and treatment to reduce seizures. When the outcome is conceptualized to include also the patient’s quality of life, it will lead to the provision of not only the very important optimal seizure control but also comprehensive care of the patient and family.

Treatment gap

Estimation of the treatment gap, an important outcome measure, is the first step toward reducing it; therefore prevalence studies of epilepsy should include questions to determine the treatment gap (Box 3). The treatment gap is very high in most developing countries. In a multinational study in 2004 involving seven developing countries (Brazil, China, Egypt, Ghana, India, Mexico and Thailand), the aggregated estimate for current treatment coverage was 60% for epilepsy (75). However, other studies have reported a treatment gap as high as 98% (in rural Pakistan and Ethiopia) (23,76).

To achieve optimal seizure control in a population, it is essential to know, or at least to suspect, the causes of the treatment gap. Some potential factors could be cultural beliefs, level of health care development, economy, supply of antiepileptic medicine and degree of prioritization.

Cultural values affect people’s health-seeking strategies. Such beliefs may mean that people with epilepsy seek treatment from traditional or faith healers or that continued compliance with antiepileptic medicines is difficult to achieve (80–82). These decisions may be rational within these people’s cultures, but they may also lead to epilepsy being untreated or not treated successfully.

The problem of distance from health care facilities is linked to the know-how available at the community health care level. It has been shown that a reasonable level of seizure treatment can be achieved by primary health care workers (77).

The majority of developing countries also have an extremely limited choice of antiepileptic medicines, with the newer medicines generally being unavailable. The reasons for this are more based on income (both personal and governmental) and inequalities. It would seem that it is non-availability of antiepileptic medicines, rather than shortcomings in the diagnosis of epilepsy, that is the primary cause of the treatment gap in developing countries, as well as being the probable main obstacle in bridging this gap (77).

BOX 3. Definition and estimation of the treatment gap

The Commission on the Developing World of the International League Against Epilepsy (ILAE) convened a workshop in Marrakesh, Morocco, 1–2 May 1999, to discuss the issue of the treatment gap and potential ways of addressing the situation.

The following definitions were accepted (77):

Seizure treatment gap. The difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given point of time, expressed as a percentage. This definition includes diagnostic and therapeutic deficits.

Appropriate treatment. Diagnosis and treatment of underlying causes; treatment of recurrent seizures according to international standards. (It should be noted that were the epilepsy treatment gap to be discussed, then appropriate diagnosis and treatment would also have to include the influence of having epilepsy on mental and social well-being.)

Estimation of seizure treatment gap. An estimate of the number of people treated for epilepsy (based on dividing the amount of antiepileptic medicines sold in a year by one defined daily dose of each type of medicine) subtracted from an estimate that at least 0.5% of any population has active epilepsy. This difference is then divided by 1% of the estimated number of people with epilepsy (78,79).

Pharmacotherapy

Antiepileptic medicines are the primary form of treatment for seizures and epilepsy. They can suppress the occurrence of seizures and can also abort ongoing seizures. For each patient, the decision to start treatment must take into account the likelihood and severity of medicine side-effects, the risk of further seizures and the consequences if such seizures should occur and what treatment can realistically do to reduce those risks to a significant level. All these factors must be weighed together and the balance for each patient determined (83).

Approximately 70% of patients can achieve complete freedom from seizures with appropriate treatment. Most of the rest will experience a significant reduction in seizure frequency and sometimes seizure severity. The resulting impact on psychosocial, educational and other quality-of-life measures is substantial (84).

Studies in different countries in the Eastern Mediterranean Region show that the first-line antiepileptic medicines (phenobarbital, phenytoin, carbamazepine and valproic acid) (10) are still

the most frequently prescribed. Use of the new generation of antiepileptic medicines is increasing but is still low compared to use of the first-line medicines. High cost and inadequate experience limit their usage (85–88). Similar findings reported from other countries show that first-line antiepileptic medicines remain in most common use throughout the world (77,78).

Variations occur in the first-line antiepileptic medicines that are included in a country's list of essential medicines. Phenobarbital is included in all the countries' lists in the Eastern Mediterranean Region. Low doses of phenobarbital are very effective in the treatment of epilepsy. However, there is an urgent need for programmes involving an increased number of physicians and trained primary care workers in rural areas and, at the national level, for the inclusion of epilepsy treatment in the activities of health care facilities. Even in low resource countries, an epilepsy control programme providing free treatment is advisable (89). Valproic acid and carbamazepine are included in 87.5%, and phenytoin in 75%, of the essential lists of medicines of Eastern Mediterranean countries (10).

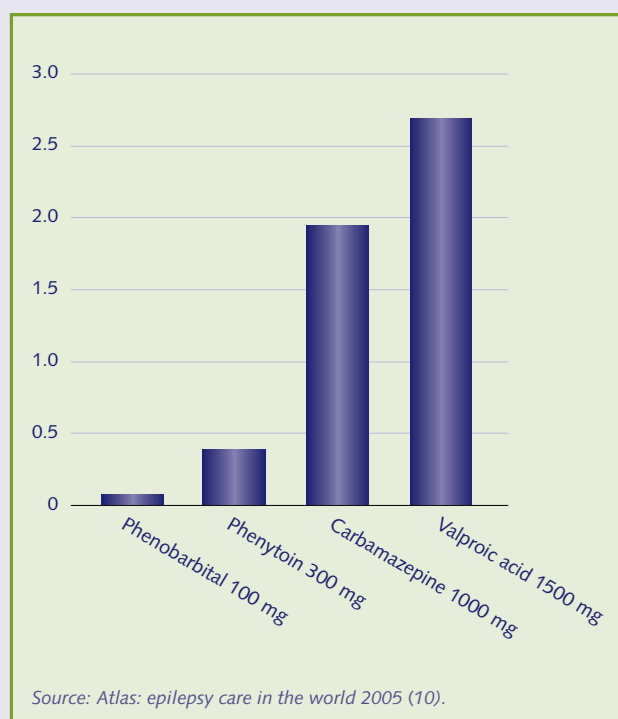


Figure 3. Median cost of daily defined adult dose of antiepileptic medicines in the Eastern Mediterranean Region (2000)

As previously mentioned, newer antiepileptic medicines are generally unavailable in most developing countries. In addition to personal and governmental financial constraints, a further hindrance to medicine supply and use can be the natural profit-maximizing behaviour of pharmaceutical companies and distributors, which may discourage production and distribution of newer medicines that may not yet be commercially viable (77).

It is possible that a medicine may be included in a country's essential medicines list but might not be available on a regular basis and in the appropriate dosage in health care services. In some countries, government policy or legislation may be in place for prescription of antiepileptic medicines, but they may still be available over the counter (90).

Figure 3 gives information on the cost of antiepileptic medicines in the Eastern Mediterranean Region; Figure 4 shows the number of DALYs gained per year in the Middle East and North Africa through use of selected antiepileptic medicines.

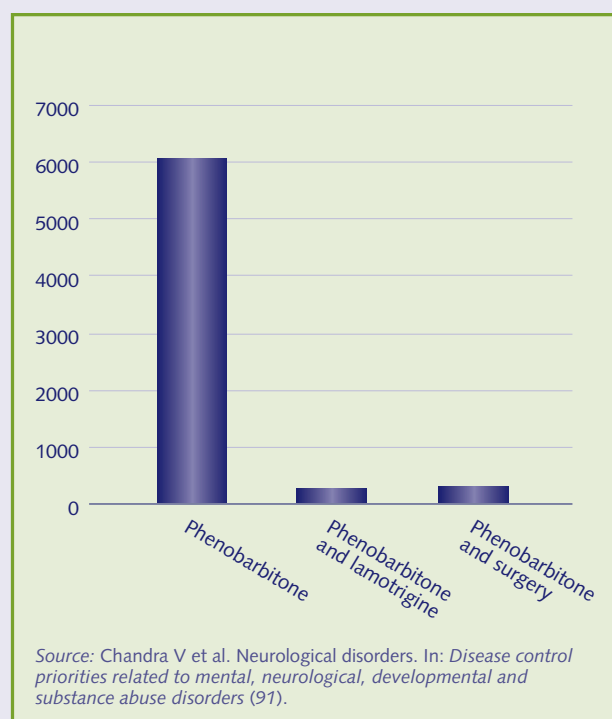


Figure 4. Number of DALYs gained per US\$ 1 million per year in the Middle East and North Africa through use of selected antiepileptic medicines

Epilepsy surgery

Despite the old and new generations of antiepileptic medicines, about 20–40% people with epilepsy have seizures that are medically intractable. One quarter to half of these patients are potential candidates for specific surgical therapy (5). In developing countries, social and economic deprivation introduce an additional factor. Surgery in selected people with clinically intractable epilepsy provides the means of avoiding more expensive, lifelong pharmacotherapy (92–96).

In their survey regarding epilepsy surgery in developing countries, based on the proceedings of the 19th–23rd International Epilepsy Congresses and Medline reports from 1991 to November 1999, Wieser and Silfvenius (97) reported that at least 26 (18.3%) of 142 developing countries (including Egypt and the Islamic Republic of Iran) perform epilepsy surgery. The surgical outcomes achieved were similar to those in the developed world, but at a fraction of the cost. To internationalize epilepsy surgery, they recommend that assessment

methodology on the outcome, cost and savings are needed, as well as general support from developed countries.

In some areas in the Eastern Mediterranean Region, vagus nerve stimulation is used to treat patients with epilepsy, as it is a well-established device to treat selected patients with medically refractory seizures (94,98).

It is of note to mention that successful results, especially for patients with mesial temporal lobe epilepsy and hippocampal sclerosis (MTLE-HS) and lesion-related epilepsies, can be obtained at centres with limited resources if the diagnoses and evaluation procedures are performed carefully (99). In *Atlas: epilepsy care in the world 2005* (10), epilepsy surgery was reported available in only half of the responding countries of the Region and in none of the low-income countries. However, there is little existing information regarding the range of surgical interventions available within the countries, or the type, quality and estimated numbers of such facilities and their distribution within each country.

Team approach to the management of epilepsy

As epilepsy has an impact on multiple medical and non-medical aspects of a patient's life, a multidisciplinary approach is needed. Epilepsy usually starts in patients in their formative years, and thus can distort the development of a favourable self-image. Low self-esteem will equip the patient poorly for the vocational and social challenges of life. Active participation in patient care by a multidisciplinary team maximizes the effectiveness of each professional and minimizes the avoidable consequences of this chronic disorder (100).

Primary health care. The use of primary health care workers and key community informants to identify and follow patients under treatment with either phenobarbital or phenytoin appears to be the most effective intervention for reducing the treatment gap for epilepsy in developing countries. In addition to administering and monitoring medicine treatments, trained primary health care workers can help to identify individuals with epilepsy in their communities and encourage them to seek medical attention. They can play an equally important role as

health educators by providing accurate information about prevention, causes and available treatments of epilepsy. Greater understanding of epilepsy has been shown to improve attitudes towards treatment and reduce stigma (7,101–104).

Services provided by primary health care centres in different parts of the world often suffer from lack of public policies and linkages between medical personnel. Primary health care workers are often not sufficiently trained to care for the neurological disorders in their population, though such disorders are relatively common. Geographical, financial and cultural barriers substantially limit physicians' referral practices (105–107). In a study on the quality of care of children with chronic diseases in Egypt, investigators noted that compliance can only be achieved if health care providers are involved in the education of the patient and the family, which further stresses the need for training of primary health care workers, who are in a unique position to ensure at least a minimum quality of care for patients with chronic illness (108). Integration of mental health into primary health care, including the components of epilepsy screening and management, is being carried out in several countries, including, for example, Islamic Republic of Iran and Pakistan (109).

Specialist care. Specialist medical professionals, when available, are important members of the team providing comprehensive care for people with epilepsy, especially at tertiary level. They are also essential for training and providing support and supervision to primary health care providers in epilepsy care. Specialists may be more alert to the long-term side-effects of antiepileptic medicines, possible medicine interactions, the impact of epilepsy on the patient's lifestyle and complications of epilepsy.

Psychiatric complications of epilepsy are neither rare nor benign. Interictal disturbances of memory, cognition and personality may interfere with relationships and professional performance, thus being potentially more disabling than the ictal events. Psychiatric symptoms, especially anxiety and depression, are frequent comorbidities in people with epilepsy, with a prevalence of up to 50%. Pre-existing vulnerability factors, neurobiological factors,

iatrogenic influences (antiepileptic medicines, epilepsy surgery) and psychosocial factors are all likely to play a role, but with considerable individual differences (110–114). A study in Egypt found that as many as one quarter of patients with epilepsy showed personality disorders that were considered by many to be the result of evil spirits (115).

The neurologist, psychiatrist and clinical psychologist perform an essential role in the assessment and management of patients with epilepsy, including helping them cope with stress and relationship problems (92,100). According to the atlas on epilepsy care in the world (10), there are no available epilepsy specialists in nearly one third of the respondent countries of the Region. Although paediatric neurological disorders are common in daily practice, a study in one country of the Region showed that most physicians (64%) did not receive a structured neurological rotation during their training and were not confident in diagnosing and treating affected children. Furthermore, they had no access to paediatric neurologists or epilepsy specialists for referral purposes (116–118). It should be noted, however, that strengthening specialized services without a strong link with primary health care cannot be recommended.

Social rehabilitation, special education, sheltered work and special equipment should also be available to patients with epilepsy, either free of charge or without special conditions through insurance coverage. Facilities for social rehabilitation are available in 42.9% of the countries of the Region that responded to the atlas survey, free of charge in one third of them. Facilities for special education are available in 35.7% of those countries. In 40%, those services are available to people with epilepsy free of charge or without any special conditions (10).

■ 2.4 Psychosocial consequences and stigmatization of epilepsy

Research confirms that epilepsy is associated with increased levels of psychological morbidity, including anxiety and depression, low self-esteem, and reduced sense of mastery (119,120). Psychosocial variables may also explain the social withdrawal and isolation that is often reported among people with

epilepsy and may be the consequence of anxiety about the negative reactions of others if a seizure occurs in public. Such fear can lead to self-denial of opportunities and can be reflected in lower rates of marriage and fertility (121).

In studies of the psychosocial consequences of epilepsy, one major recurring theme is that epilepsy is a stigmatizing condition. It is important to differentiate between perceived and enacted stigma. Perceived stigma refers to an individual's perception of being stigmatized, whereas enacted stigma refers to the actual event of being stigmatized. The evidence to date is that, in both developed and developing countries, epilepsy is perceived as a stigmatizing condition. The "burden of the diagnosis" may also have significant consequences in the way individuals appraise or reappraise themselves and the world; consequently some individuals will see themselves as defined by their diagnosis (121).

In a study conducted to assess stigmatization and psychosocial problems of people with epilepsy in Pakistan, it was concluded that although patients did not appear to be highly stigmatized, their education and grades were affected by the disorder. They had difficulty performing the activities of daily life and found it hard to make decisions about whether to marry or to have children (20). A study in 2007 suggested that the gap in community knowledge about epilepsy may explain the prevalence of negative attitudes (120). A study performed in 10 countries, including countries of the Region, found that only 11% felt highly stigmatized by their illness, but more than one third of the respondents reported that their condition negatively affected their overall health, future plans and ambitions, and their feelings about themselves (122). Similarly, in a retrospective analysis of 55 people with chronic epilepsy admitted for psychiatric treatment in Kuwait, adverse effects on marriage, education and occupation were reported to be common. People with epilepsy were more prone to have social difficulties, and their marital status and fertility were far from satisfactory (123). In Tikrit, Iraq, the overall underemployment for patients with epilepsy was 33%, which was higher in those with uncontrolled epilepsy (124). In Oman, a study investigating the attitude of physicians towards people with epilepsy

demonstrated that negative views still persist in matters related to cognitive and behavioural domains (110). In a study in Tunisia, the health-related quality of life of people with epilepsy was related to seizure frequency, time since last seizure and the side-effects of antiepileptic medicines. Seizure-free adults had a quality of life comparable to those of the control group (125).

A recent study in the Islamic Republic of Iran on attitudes towards epilepsy among five major ethnic groups – Persian, Azeri, Kurd, Lur and Arab – found that while the level of awareness and understanding of epilepsy among respondents was generally good, and their attitude towards the employment, childbearing and social integration of people with epilepsy was positive, the response to the prospect of their children marrying someone with epilepsy was

highly negative, as it is in other parts of the world (126). A study in Turkey found that knowledge about epilepsy is associated with less perceived stigmatization and social isolation, as well as fewer depressive symptoms and misperceptions (127).

Another study in Turkey, and studies in Kuwait, including one among university students, found a vague knowledge of the causes of epilepsy. Misconceptions about, and negative attitudes toward epilepsy were unexpectedly high among university students (128–130).

Poor community knowledge and awareness, cultural beliefs and stigma were considered the major problems facing about two thirds of health professionals and people with epilepsy in the atlas survey (10).

3. Challenges

- Epilepsy is a major public health concern, with an estimated 4.7 million people in the Eastern Mediterranean Region having the disorder (5). It can have serious medical, psychological, social and economic consequences for people with epilepsy and their families (10).
- Many of the risk factors for epilepsy described are preventable or modifiable. There is a very high incidence of marriages within the family in the countries of the Region, which is a risk factor for epilepsy (19,55–57).
- There are few published studies addressing the magnitude of the problem of epilepsy in the Region, and little information about the availability of diagnostic services and their national and regional distribution (18–22).
- Although an effective treatment exists for most people with epilepsy, service utilization is limited and the majority of these people are inadequately and inappropriately treated because of limited health resources, lack of prioritization, gaps in national health policies and distance from health care facilities (77).
- Community perceptions and cultural beliefs have been identified as barriers to proper provision of epilepsy care. In many countries of the Region, traditional healers do not consider epilepsy as a medical illness but attribute it to devils or spirits. There are also many challenges related to legislation or regulations, such as driving restrictions and limitations to employment (20,122–124).
- In most countries, out-of-pocket payment is the major source of financing for epilepsy care, especially in the absence of social insurance or government-funded health care. In many countries, few people actually receive disability benefits for epilepsy even when they are available, because of lack of public information about such benefits and the procedure for claiming them, which is sometimes very complicated (77).

4. Existing initiatives

4.1 Global Campaign Against Epilepsy

Epilepsy is a global problem affecting all ages, races, social classes and countries. Epilepsy imposes enormous physical, psychological, social and economic burdens on individuals and families, compounded by misunderstanding, fear and stigma. In response to these challenges WHO and its regional offices joined forces with two leading international epilepsy organizations, the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE), for a campaign of concerted action to address the common but neglected global problem of epilepsy. 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. The Campaign's mission statement is to improve the acceptability, diagnosis and treatment, services and prevention of epilepsy worldwide. The Campaign's strategy has two parallel tracks:

- raising general awareness and understanding of epilepsy, for instance by organizing regional conferences on public health;
- supporting departments of health in identifying needs and promoting education, training, treatment, services, research and prevention nationally, by initiating demonstration projects.

The Campaign's objectives are to:

- reduce the burden of epilepsy by decreasing the treatment gap and promoting the inclusion of epilepsy care in national health care plans;
- improve understanding of epilepsy;
- promote primary and secondary prevention of epilepsy;
- improve medical, social and psychological care for people with epilepsy;
- reduce the limitations encountered by people with epilepsy and their families.

The Campaign's ultimate objective is to ensure that governments and health care providers place epilepsy on the health and development agenda in order to formulate and implement cost-effective responses to epilepsy. The indicators of its success will be the proportion of targeted countries that have implemented reforms in epilepsy care and

the number of countries that have increased their budget for epilepsy care.

The strategic approach of the Campaign is dissemination of information on the magnitude, burden, diagnosis and treatment of epilepsy as well as information on available resources; support to governments and health care providers in formulating and implementing comprehensive services by offering successful models of epilepsy care; support to countries in fighting stigma and discrimination; and support for research capacity-building in developing countries.

The Campaign was launched at WHO headquarters in Geneva, Switzerland, in June 1997 and in Dublin, Ireland, in July of the same year during the 22nd International Epilepsy Congress. During the first three years, the Campaign concentrated mainly on increasing awareness, creating acceptance and improving education, including within ILAE, IBE and WHO. The most important achievement during that period was the acceptance of the Cabinet Paper on the Global Campaign in December 1999, which raised its status to one of the highest priorities of WHO.

Regional conferences on the public health aspects of epilepsy have been organized in the African Region, the Region of the Americas, the South-East Asia Region and the Western Pacific Region jointly, the Eastern Mediterranean Region and the European Region. The aims of these conferences were to:

- adopt regional declarations on epilepsy, calling on governments and health care providers to take strong, decisive action to meet the objectives of the Campaign;
- promote the creation of regional white papers on epilepsy as detailed public health statements with appropriate recommendations for political action.

More than 1200 representatives from IBE, ILAE and WHO, other United Nations agencies, and nongovernmental organizations, governments, universities and health care providers from over 130 countries, representing millions of people with epilepsy, participated in these conferences, where the concept of regional declarations aimed at identifying problems and proposing solutions was elaborated. The second phase of the Campaign, aimed at

improving health care services for treatment, prevention and social acceptance of epilepsy worldwide was launched in Geneva on 12 February 2001 in the presence of Dr Brundtland (then Director-General of WHO), advisers from all six WHO regions and representatives of 13 WHO Member States, 24 national member organizations of IBE and ILAE, four nongovernmental organizations for neuroscience or neurology and 17 representatives of the private sector.

An important strategy for achieving the aims of the Campaign is the use of demonstration projects. These have been designed to identify people with epilepsy and offer them appropriate treatment. The specific objectives are to:

- develop models for the promotion of epilepsy control worldwide
- reduce the treatment gap and social and physical burden
- educate health personnel
- dispel stigma
- eradicate preventable causes of epilepsy
- integrate epilepsy care into national health systems.

Other Campaign activities include data collection on country resources for epilepsy, development of regional reports on epilepsy, organization of sessions during international congresses and other meetings, drawing up evidence-based guidelines, projects on stigma and a project on epilepsy and legislation.

■ 4.2 Regional efforts

Integration of mental health into primary health care, which has been one of the main strategies of the WHO Regional Office for the Eastern Mediterranean, has always included epilepsy, as reflected in many strategic documents (109). This decision was made because of the similarities that epilepsy has with mental disorders with regard to stigma and neglect, chronicity and need for long-term follow-up, in addition to epilepsy's high comorbidity with mental retardation and its shared pathology as a brain disease. In almost all the Region's countries, mental health units in ministries of health are also planning and implementing for

epilepsy. In the Islamic Republic of Iran the health information system, which includes mental disorders, also encompasses epilepsy.

In March 2003, under the aegis of the Global Campaign Against Epilepsy, the Inter-country Meeting on Epilepsy as a Public Health Concern was held in Cairo, Egypt, bringing together professionals from the health and social science sectors and academia, policy-makers and experts in the area of epilepsy from across the Region. During the meeting the Eastern Mediterranean Declaration on Epilepsy was formulated, calling upon governments, various organizations, health care providers and the general public to participate in "taking strong and decisive action to meet the objectives of the Global Campaign Against Epilepsy" (see Annex 1). They were specifically urged to:

- address the needs with respect to epilepsy in terms of prevention, access to trained personnel, modern diagnostic equipment, antiepileptic medication, surgical treatment where necessary, and social integration;
- include antiepileptic medicines in the list of essential medicines in all countries, and make them constantly available to avoid the serious consequences of treatment interruptions;
- educate and train health care and other relevant professionals and volunteers at all levels of health care about epilepsy;
- educate those affected by epilepsy, their families and the general public about epilepsy as a universal neurological condition, to eradicate misconceptions, and empower those affected to seek appropriate treatment and improve their quality of life;
- eliminate discrimination in all spheres of life, particularly concerning school and employment;
- encourage the public and private sectors and nongovernmental organizations to get involved in the local activities of the Global Campaign Against Epilepsy;
- encourage basic and applied research on epilepsy as an integral part of epilepsy services at all levels;
- proclaim a National Epilepsy Day;
- encourage regional and international cooperation.

5. Future directions

Integration of epilepsy prevention and care within primary health care is the most appropriate strategy. In countries where a mental health programme is functional within primary health care, epilepsy should be an important component. In addition, support should be extended to the recommendations of the Global Campaign Against Epilepsy launched by WHO, ILAE and IBE.

Specifically, governments in the Region are urged to address the following points.

5.1 Information and data

Implementation of nationwide projects for reliable data collection on epilepsy, its magnitude and other related health problems is encouraged. This should be done in collaboration with the leading epilepsy organizations to help set unified criteria for definitions (12).

5.2 Advocacy for political commitment

Epilepsy has to compete for resources with many other conditions and illnesses. Such competition is even harsher where there are low health budgets. A commitment to resources for epilepsy treatment must be gained from governments and international health organizations. Political patronage must ensure that epilepsy remains on the agenda and that essential medicine supplies are assured.

5.3 Prevention and control

Preventive measures could significantly reduce the incidence and prevalence of epilepsy in developing countries in several ways, including enhancement of prenatal and perinatal care (for example by improving mothers' nutritional status and detection of high-risk pregnancies), reduction of the causes of brain injury (for example by promotion and enforcement of traffic regulations and speed limits and ensuring safety regulations at work), and providing specific protection (for example immunization against communicable diseases) (12).

A decrease in poor maternal and fetal outcomes, both in epileptic and non-epileptic pregnant women, is required. Women with epilepsy are not at increased risk for obstetric and neonatal complications, provided there is a combined team management approach by a neurologist and an obstetrician (131).

5.4 Provision of appropriate care

Although an effective treatment often exists for more than two thirds of people with epilepsy, the majority of them are inadequately and inappropriately treated. An important cause is limited health resources.

Health care providers

Primary health workers are the most appropriate choice for providing information and education to patients, caregivers and the community as a whole about the disorder, the medication and its side-effects, and the implications and social issues involved (101–104).

Regular courses for training of involved personnel and encouraging better liaison and referral network between primary and secondary health care services are required to ensure the best care for patients (92).

Emphasis is needed to give nurses appropriate training and facilities for providing care to people with epilepsy. In countries with no formal training facilities for neurological nursing, general nurses can be trained to provide specific nursing care (77).

Specialist training in epileptology is needed on multiple levels to reach all those concerned in epilepsy management (109, 116–118).

Service delivery

Services should be available at different levels of the health care system from primary health care to secondary and tertiary levels. Specialized services should be made available at the tertiary level, where referrals from more peripheral levels will be received.

Existence of strong referral and back-referral systems at different levels of health care is a prerequisite for efficient and sustainable management of epilepsy (10).

Efforts need to be made to introduce some form of public financing into the national health infrastructure to cover epilepsy services. The availability of at least first-line antiepileptic medicines should be specifically ensured to all people in need, whether free of charge or through an insurance policy (77).

Efforts should be made to advocate for better provision of benefits for people with functional disability who suffer from epilepsy, especially in resource-poor countries where such benefits are most needed (10).

■ *Advocacy and rights promotion*

There is an urgent need to establish more patient groups, especially in low-income countries, to improve consumer participation in health care and promote self-management.

■ *Cultural issues*

Despite the limitations of the available dataset for this survey (10), it is clear that the number of social workers engaged in the field of epilepsy is grossly inadequate. Efforts need to be made to improve the situation. Awareness-raising campaigns about epilepsy with the aim of reducing the associated stigma are imperative (132).

To reduce the stigma effect in patients with epilepsy, this issue should not only be addressed primarily in specialized journals such as *Epilepsia*, *Epilepsy and Behavior*, *Seizure*, and *Social Science and Medicine*, but also in journals targeting readers of different specialties and interests (133).

■ **5.5 Research**

There is a compelling need to carry out multi-site epidemiological studies using standardized definitions and case ascertainment methods (134).

Studies are needed to identify the causes of epilepsy and the risk factors in different population groups and in different regions. Definitions need to be standardized to be able to compare different studies. The observed large rural–urban differences call for more efforts to identify such risk factors as infection, stigma, ignorance, inadequate obstetric care and lack of health facilities. Identifying correct etiologies will help to set priorities for prevention and early diagnosis of epilepsy, especially in vulnerable populations (10).

It should be mentioned, however, that in resource-poor countries implementation of epilepsy care is a higher priority than epidemiological research, and data derived from countries with similar conditions may help in estimating the magnitude of the problem (77).

■ **5.6 Monitoring and evaluation**

Programmes on the prevention and management of epilepsy need to be regularly monitored and evaluated. Indicators may include the availability of medicines, number of people in the population covered by services, proportion of primary health care centres in which epilepsy is integrated and proportion of people with epilepsy whose disorder has been controlled (77).

6. Conclusion

Epilepsy is a major public health concern and at least 4.7 million people in the Eastern Mediterranean Region suffer from it. The disorder can have serious medical, psychological, social and economic consequences for people with epilepsy and their families. The impact is even heavier for children and adolescents.

With modern advances in medicine, epilepsy has become a treatable condition, and most people with epilepsy can live productively as a result of relatively inexpensive, cost-effective treatment. Many of the risk factors for epilepsy described are preventable or modifiable. Yet epilepsy does not receive adequate attention commensurate with its magnitude, toll and preventability in existing national health plans in many countries.

A number of challenges face the efforts to address the issue of epilepsy in the Eastern Mediterranean Region. The efforts to finalize this report made apparent the inadequacy of regional data on the magnitude of the problem, the availability and distribution of diagnostic services, and the proportion of services available and affordable for those who need them.

Information on epilepsy, trained human resources, diagnostic aids and antiepileptic treatment may not be available to, or affordable by, many people with epilepsy, due to a myriad of causes – geographical, financial, cultural or social. Hence, many people in parts of the Region, more so in rural areas, may have

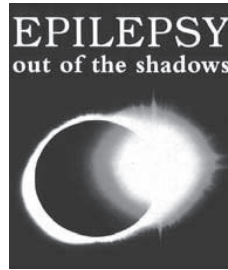
no access to proper health care and treatment or may not be able to utilize the available services. The resulting treatment gap needs to be addressed at all levels, taking into account the wider sociocultural landscape and its interactive relationship with the disorder.

There is a dire need for capacity-building and working towards making universal access to uninterrupted treatment a reality. Education of people with epilepsy, their families and the communities in which they live, about epilepsy as a universal brain condition cannot be overlooked. Such efforts must be made in order to eliminate prevalent misconceptions, and empower those affected to seek appropriate treatment and improve their quality of life.

In the attempt to relieve the heavy implications of epilepsy, available opportunities need to be utilized at local, regional and global levels. The Global Campaign Against Epilepsy is but one platform for collective efforts to achieve better, more humane and respectful services and improved lives for people who have epilepsy and who suffer subsequent stigma and discrimination. Through concrete actions, the Campaign can facilitate the transformation of hopes into realities where people with epilepsy are no longer marginalized, but are given an equal chance to become active members in an inclusive society.

Annex 1.

Eastern Mediterranean Declaration on Epilepsy



EASTERN MEDITERRANEAN DECLARATION ON EPILEPSY

Under the aegis of the Global Campaign Against Epilepsy of the World Health Organization (WHO), International League against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE), a meeting "Epilepsy as A Public Health Concern in the Eastern Mediterranean Region" was held in Cairo, Egypt, on 3 and 4 March 2003. Professionals from Health and Social Sciences sectors and representatives from universities coming from the member states of the Eastern Mediterranean Region unanimously agreed to the following Declaration:

CONSIDERING THAT:

- epilepsy is the most common serious chronic brain disorder, estimated to affect at least 50 million people in the world of which at least 4 million live in the Eastern Mediterranean Region,
- contrary to many misconceptions, epilepsy is a brain disorder with natural causes and requiring medical treatment,
- it is often not realised that epilepsy is treatable, and that most people with epilepsy can lead productive lives as a result of relatively inexpensive, cost-effective treatment,
- in parts of the Eastern Mediterranean Region many people, especially in rural areas, have no access to appropriate healthcare provisions and treatment,
- general information about epilepsy, trained expertise, diagnostic facilities, antiepileptic drugs and surgery are not available for or affordable by many people with epilepsy, for geographic, financial, cultural or communication reasons,
- epilepsy has serious physical, psychological and social consequences for the afflicted and their families,
- the impact of epilepsy is most severe in children and adolescents,
- epilepsy does not receive adequate attention in existing national health plans in many countries,

We call on the governments of the member states of the Eastern Mediterranean Region, national and regional, public and private organisations, all health care providers, and the general public to join us in taking strong and decisive action to meet the objectives of the Global Campaign Against Epilepsy of the WHO/ILAE/IBE "Epilepsy: Out of the Shadows".

Specifically we urge action to:

- address the needs with respect to epilepsy in terms of prevention, access to trained personnel, modern diagnostic equipment, antiepileptic medication, surgical treatment where necessary, and social integration,
- include antiepileptic drugs in the list of essential drugs in all countries, and make them constantly available to avoid the serious consequences of treatment interruptions,
- educate and train health care and other relevant professionals and volunteers on all levels of health care about epilepsy,
- educate those affected by epilepsy, their families and the general public about epilepsy as a universal neurological condition, to eradicate misconceptions, and empower the affected to seek appropriate treatment and improve their quality of life,
- eliminate discrimination in all spheres of life, particularly concerning school and employment,
- encourage the public and private sectors and NGO's to get involved in the local activities of the Global Campaign against Epilepsy,
- encourage basic and applied research on epilepsy as an integral part of epilepsy services on all levels,
- proclaim a National Epilepsy Day,
- encourage regional and international co-operation.

CAIRO, March 04, 2003

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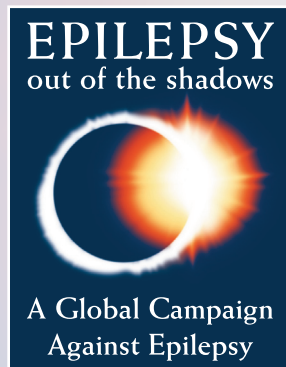
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EPILEPSY, a common neurological disorder, is a target of enduring myths which have shaped social and cultural attitudes and practices. Such myths continue to survive, and contribute in no small measure to the stigma and discrimination faced by people affected by epilepsy and their families. This, in turn, feeds into a vicious circle, where affected individuals and their families do not access treatment, even if it is available. Epilepsy affects an estimated 4.7 million people in the Eastern Mediterranean Region. Despite the fact that low-cost treatments are available, up to 98% of individuals in some countries are not able to benefit. This report brings together, for the first time, all the available evidence on epidemiology, etiology and management available from the Region and suggests the directions that need to be pursued to bridge the gap between the resources needed and those available, in order to make treatment of epilepsy accessible and affordable to the community. The report is the result of collaborative efforts between WHO, ILEA and IBE and will be of interest not only to health professionals but also to the public.



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