Epilepsy: the public health aspects
Introduction

The respondents were asked about the presence of a separate budget for epilepsy care and services in the health budget and the primary method of financing epilepsy services in the country.

Salient findings

- A separate budget for epilepsy care and services is present in only 6.4% of the responding countries.
- Out-of-pocket payments, tax-based funding and social insurance are the primary methods of financing epilepsy care, each method in about one third of the responding countries. Private insurance and private foundations constitute only 1.9% and 1%, respectively, of the primary method of financing.
- Out-of-pocket expenses are the primary source of financing epilepsy care in Africa (62.5% of the responding countries), South-East Asia (66.7%) and the Eastern Mediterranean (50%), while tax-based funding is the most important source of financing epilepsy care in the Western Pacific (57.1%).
- Social insurance is the most important source of financing in Europe (58.8% of the responding countries) and the Americas (43.8%), while none of the responding countries in South-East Asia and only 4.2% in Africa use social insurance as the primary method of financing.
- Out-of-pocket expenditure is the primary method of financing epilepsy care in 72.7% of low-income countries, compared with 4% of high-income countries.
- While social insurance is the primary method of financing in 55.6% and 56% of higher middle-income and high-income countries, respectively, none of the low-income countries employs it as the primary method of financing.
- Of the responding countries, 37.6% have private insurance as a method of financing epilepsy care. Only 11.1% and 17.7% of the countries in South-East Asia and Africa, respectively, have private insurance, compared with the Americas where private insurance is available as a method of financing in 70.8% of the countries. Social insurance as one of the methods of financing is present in 25% of low-income countries, compared with 66.7% of high-income countries.
- Although definitions were provided with the questionnaire, it is possible that they may not have been used accurately.

Limitations

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

Conclusions

- Although a separate budget for epilepsy care is not essential, when present it assists in earmarking the resources and in planning the services effectively. In many countries, the budget for epilepsy care is included in that for mental health.
- In most low-income countries, out-of-pocket payment is the major source of financing. Epilepsy services are scarce in low-income countries; in addition, patients are required to pay, so further inequity results in the utilization of these services. Efforts need to be made to introduce some form of public financing into the health infrastructure of these countries to cover epilepsy services.
23.1 Primary method of financing Epilepsy care in WHO regions and the world
N=106

- Africa: 29.1% Out-of-pocket, 4.2% Tax-based, 62.5% Insurance
- Americas: 4.2% Out-of-pocket, 66.7% Tax-based, 33.3% Insurance
- Eastern Mediterranean: 37.5% Out-of-pocket, 12.5% Tax-based, 50% Insurance
- Europe: 43.8% Out-of-pocket, 6.2% Tax-based, 25% Insurance
- South East Asia: 11.8% Out-of-pocket, 29.4% Tax-based, 58.8% Insurance
- Western Pacific: 28.6% Out-of-pocket, 14.3% Tax-based, 57.1% Insurance

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

- Low: 35.8% Out-of-pocket, 132.1% Tax-based, 32.1% Insurance
- Lower middle: 0% Out-of-pocket, 0% Tax-based, 100% Insurance
- Middle: 72.7% Out-of-pocket, 24.2% Tax-based, 3.1% Insurance
- Higher middle: 0% Out-of-pocket, 0% Tax-based, 100% Insurance
- High: 0% Out-of-pocket, 0% Tax-based, 100% Insurance

- Out-of-pocket: 31.1%
- Tax-based: 1.9%
- Social Insurance: 1%
- Private Insurance: 33%
- Private Foundation: 33%
Introduction

- Disability benefits are payable from public funds as part of a legal right in cases of epilepsy that cause physical, mental or intellectual impairment leading to functional limitations.

Salient findings

- Disability benefits in some form are available for people with epilepsy in 46.5% of the responding countries.
- Disability benefits are available in only 14.6% of low-income countries compared with 82.4% of high-income countries.
- Availability of disability benefits for people with epilepsy varies across regions. While 11.1% of the responding countries in South-East Asia, 13.3% in the Eastern Mediterranean, and 21.1% in Africa reported availability of some form of disability benefits for people with epilepsy, such benefits are available in 36.4% of responding countries in the Western Pacific, 54.2% in the Americas, and 86.4% in Europe.
- Of the types of disability benefits reported by countries, monetary benefits (82.5%) and rehabilitation and health benefits (54.8%) are the most commonly reported, followed by other benefits including housing, transport, education and special discounts (42.5%) and benefits at the workplace (34.2%). Specific benefits for caregivers are reported to be available in 12.3% of the countries.

Limitations

- Information on the exact type of disability benefit for people with epilepsy was not obtained in a structured format. The figures might therefore be underestimated.
- Data regarding coverage within the countries were not available.

Conclusions

- In many countries, despite the availability of disability benefits for many conditions, people with epilepsy are not covered. The situation must be assessed and action must be taken.
- In many countries, few people actually receive disability benefits for epilepsy even when they are available, because of a lack of public information about such benefits and the procedure for claiming them, which is sometimes very complicated.
- For enhanced social and professional integration of people with epilepsy, drafting of appropriate legislation in countries is vital. Efforts should be made to advocate better provision of benefits for functionally disabled people with epilepsy, especially in resource-poor countries where such benefits are most needed.
24.1 Presence of disability benefits for people with epilepsy in the world
N=157

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

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

Presence of disability benefits for people with epilepsy in WHO regions and the world

- Africa: 21.1%
- Americas: 54.2%
- South-East Asia: 11.1%
- Eastern Mediterranean: 86.4%
- Europe: 13.3%
- Western Pacific: 36.4%

World: 46.5%

Presence: Absent:

Information not available:

Presence of disability benefits for people with epilepsy in different income groups of countries

- Low: 48.9%
- Lower middle: 52%
- Higher middle: 14.6%
- High: 82.4%

Ethics, Atlas © WHO 2005

Presence: Absent:

Information not available:
People with disabilities are among the most vulnerable in any society; this is even more true of people with hidden disabilities such as epilepsy and other neurological conditions and intellectual disabilities. While the vulnerability of people living with epilepsy may be partly attributed to the disorder itself, as Ann Jacoby remarked, “all chronic medical conditions have an impact on daily life, but the impact of epilepsy is greater” (90), the particular stigma associated with epilepsy brings a susceptibility of its own. Stigmatization leads to discrimination and people with epilepsy experience prejudicial behaviour in many spheres of life, throughout many centuries and across many cultures. It is as Rajendra Kale said: “the history of epilepsy can be summarised as 4,000 years of ignorance, superstition and stigma, followed by 100 years of knowledge, superstition and stigma”.

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

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

Failure to secure insurance protection leaves people with epilepsy unnecessarily exposed to risks which largely have no bearing at all on their epilepsy, and refusals and restrictions to obtaining insurance are not limited to developing countries. As many as 36% of people with epilepsy were refused one or more types of insurance in the United Kingdom (91). This discriminatory behaviour translates as a restriction to the right to make adequate financial provision in guarding against risks to the individual and his or her family. People with developmental disabilities, including epilepsy, experience a heightened risk of becoming victims of violence and abuse, according to Petersilia (92), who reported on a study by Sobsey & Doe which found that 70% women with developmental disabilities are sexually assaulted in their lifetime – not in South Africa or another country where sexual assaults are among the highest in the world, but in the United States in 1991.

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

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

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

Unemployment and underemployment exists worldwide. In the U.S. the first law that prohibited discrimination against people with physical handicaps passed in 1973, however this law only had a limited scope and it was not until 1990 with the passage of the Americans with Disabilities Act, that provided a more uniform remedy to persistent discrimination (98). Until the 1970’s for instance it was still legal in the U.S. to deny persons with seizures access to restaurants, theatres, recreational centres and other public accommodations. These employment and legal devaluations further authenticated the stigma attached to epilepsy in the modern western, eastern and southern culture (99).
The recent reports on epilepsy in the African Region (68) and the Western Pacific Region (100) provide numerous accounts of civil and human rights violations against people with epilepsy across these regions, which comprise mainly developing countries. However, examples of legislation based on centuries of stigmatisation are found in many countries all over the world. From reading the accounts it becomes clear that, while specific practices may vary from country to country, discriminatory attitudes and prejudicial behaviour towards people with epilepsy are common across the globe.

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

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

While the epilepsy movement has made great advances in the physiological understanding of the condition and improving drug therapy, progress in creating a more understanding and accommodating world for people with epilepsy has sadly not kept pace. It would seem appropriate that people with epilepsy themselves should be at the forefront of this battle, and that all those involved in managing the condition should lend their support to ensure that the gap between medical and social advances is bridged rather than broadened.
Introduction
◆ The respondents were asked about the inclusion of epilepsy in the country’s annual health reporting system and the presence of an epidemiological data collection system for epilepsy.

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

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

Conclusions
◆ An organized health reporting system is essential in order to assess the situation and thus enable health planners to decide how to use their various resources.
◆ There is a need to establish standard guidelines for the health reporting system to enable comparison across countries and over time.
◆ Epidemiological data facilitate the gathering of information regarding the disease burden and trends and help to identify the high priority issues. This information is highly useful for planning health services and monitoring trends over time.
Presence of epilepsy in the health reporting system in different income groups of countries
N=154

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

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

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

Presence of data collection system for people with epilepsy in WHO regions and the world
N=153