EPILEPSY: SOCIAL CONSEQUENCES AND ECONOMIC ASPECTS

SOCIAL IMPLICATIONS

Fear, misunderstanding and the resulting social stigma and discrimination surrounding epilepsy often force people with this disorder "into the shadows". The social effects may vary from country to country and culture to culture, but it is clear that all over the world the social consequences of epilepsy are often more difficult to overcome than the seizures themselves.

Significant problems are often experienced by people with epilepsy in the areas of personal relationships and, sometimes, legislation. These problems may in turn undermine the treatment of epilepsy.

Misunderstanding and Social Stigma

Some examples of misunderstandings about epilepsy from around the world:

* In Cameroon it is believed that people with epilepsy are inhabited by the devil. This does not mean that they are seen as evil, but that evil invades them and causes them to convulse from time to time.

* In China, epilepsy diminishes the prospect of marriage, especially for women. A survey of public awareness in 1992 revealed that 72% of parents objected to their children marrying someone with epilepsy.

* In some rural areas of India, attempts are made to exorcise evil spirits from people with epilepsy by tying them to trees, beating them, cutting a portion of hair from their head, squeezing lemon and other juices onto their head and starving them.

* In Indonesia, epilepsy is often considered as a punishment from unknown dark forces.

* In Liberia, as in other African countries, the cause of epilepsy is perceived as related to witchcraft or evil spirits.

* In Nepal, epilepsy is associated with weakness, possession by an evil spirit or the reflection of a red colour. Bystanders who witness a seizure will often spray water on the forehead of the person experiencing the seizure of make him or her smell a leather shoe.

* In the Netherlands in 1996, a person was whipped and put into isolation because her seizures were thought to result from magic.
* In Swaziland, many traditional healers mention sorcery as the cause of epilepsy.

* In Uganda, as in many other countries, epilepsy is thought to be contagious and so people with epilepsy are not allowed to join the communal foodpot for fear of others contracting epilepsy through that person’s saliva.

Legislation

In many countries legislation affecting people with epilepsy has reflected centuries of suspicion and misunderstanding about epilepsy. For example, people with epilepsy are often prevented from marrying or having children:

* In both China and India, epilepsy is commonly viewed as a reason for prohibiting or annulling marriages.

* In the United Kingdom, a law forbidding people with epilepsy to marry was repealed only in 1970.

* In the United States of America (USA), many individual States prohibited people with epilepsy from marrying. The last State to repeal this law did so in 1980.

* In the United States of America (USA), 18 States provided eugenic sterilisation of people with epilepsy until 1956. Until the 1970s, it was also legal to deny people with seizures access to restaurants, theatres, recreational centres and other public buildings.

Employment

Unemployment and underemployment exist worldwide, but more so with people with epilepsy. The misunderstandings and stigma mentioned previously are usually to blame for this. For instance:

* A survey in China showed that 31% of respondents believed that people with epilepsy should not be employed.

* Data from Germany, Italy and USA indicate that people with epilepsy of working age, 40%-60% are employed (although these jobs are often below their potential), 15%-20% are unemployed and about 20% retire early.

* In rural areas of India, people with epilepsy are generally looked after by their families and they usually help with their family’s trade, although this will be with fewer responsibilities and less strenuous roles than “normal” people.

* In a recent research survey, nearly a quarter of Nepalese people with epilepsy took the view that they were unable to work. As in many countries, these people with epilepsy had been culturally conditioned to underrate themselves.

Treatment

Misunderstandings about epilepsy, combined with the economic and financial barriers to availability of treatment in developing countries, play an important role in preventing treatment becoming available to millions of people in developing countries. For example, culturally informed health-seeking strategies often lead the majority of people with epilepsy in developing countries to turn to traditional healers for treatment.
Economic Aspects

* In 1990, WHO, identified that, on average, the cost of the anti-epileptic drug phenobarbitone (which alone could be used to control seizures in a substantial proportion of those with epilepsy and which is on the WHO list of essential drugs) could be as low as US$ 5 per person per annum.

* The World Bank report "Investing in Health" (1993) states that, in 1990 epilepsy accounted for nearly 1% of the world’s disease burden. Epilepsy commonly affects young people in the most productive years of their lives, often leading to avoidable unemployment.

KEY POINTS

* The cost and burden of epilepsy varies between countries.

* The anti-epileptic drug phenobarbitone can cost as little as US $5/person/annum and can be used to treat many people with epilepsy.

* People with epilepsy continually face social stigma and exclusion. A fundamental part of ridding the world of this stigma is to raise public and professional awareness.

* Legislation which reinforces fear and discrimination must also be changed.