September is National Epilepsy Awareness month. I have seen epilepsy described as the ‘forgotten disease’ by those involved in its management, and certainly all the literature around the subject appears to back this up. In the developing world, epilepsy is probably the leading brain disorder and it is estimated that 80% of all people suffering from epilepsy live in developing countries. Obviously the heavy burden of infectious diseases that can lead to epilepsy must play a part, but there are also many perinatal and postnatal stressors in people suffering from malnutrition and the other consequences of poor socioeconomic conditions.

According to a report put out by the World Health Organisation (WHO) in 2000, epilepsy affects 34 million Africans, 80% of whom have no access to epilepsy services. However, the reasons for this are not simply economic, but social, with stigma, myths and superstition playing an enormous role. On their website (www.who.int) WHO gives some examples of misunderstandings about epilepsy around the world:

- In Cameroon, people with epilepsy are believed to be inhabited by the devil — not evil within themselves, but invaded by evil at the time of a fit.
- In China, people with epilepsy are less likely to get married, particularly women.
- 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 some hair, squeezing lemon and other juices over their heads and starving them. (A primitive attempt at a ketogenic diet perhaps?)
- In Indonesia, epilepsy is considered as punishment from dark, unknown forces.
- In Liberia and other African countries, epilepsy is believed to be caused by witchcraft or evil spirits.
- In Uganda, as in many other countries, epilepsy is thought to be contagious and people with epilepsy are not allowed to eat from the communal food pot for fear of others contracting the condition.

And this level of superstition is not confined to the developing world. As recently at 1996 a woman in the Netherlands was whipped and put into isolation because her seizures were thought to result from magic.

Legislation in some countries actually reflects misunderstandings about the disease. In both China and India epilepsy is still viewed as a common reason for prohibiting or annulling marriages. In Britain, the law forbidding people with epilepsy to marry was only repealed in 1970, and in the USA, the last state to repeal a similar law did so in 1980. People with epilepsy suffer when it comes to employment as well. Information from Germany, Italy and the USA shows that only 40 - 60% of working-age people with epilepsy are employed (often below their potential), 15 - 20% are unemployed and about 20% retire early.

In 2000 WHO and its partners launched the ‘Out of the shadows’ campaign in Africa to improve health care services, treatment and social acceptance of epilepsy in the region. Treatment can be provided for as little as US$5 per person per annum and most epileptic people, if correctly treated, can live a normal life. Unfortunately, because of the superstition surrounding the disease in Africa, many people consult traditional healers rather than conventional doctors, and the myths are perpetuated.

However, as was pointed out by correspondents to The Lancet a couple of years ago, the myths about epilepsy seem particularly difficult to dispel. Although epilepsy is classified as a disease of the nervous system in the International Statistical Classification of Diseases and Related Health Problems (ICD-10), the WHO also presented epilepsy as one of many other mental diseases in their World Health Report in 2001, listing it under the heading ‘Burden of mental and behavioural disorders’. It seems that old attitudes are difficult to break, although the most recent World Health Report has no such obvious faux pas. It also appears that the WHO global collaboration launched in 2000 has had some success in many regions. Under the WHO’s new Director-general, Lee Jong Wook, it is to be hoped that this important and potentially debilitating disease does not once again slip unnoticed into the shadows.

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