

# Australia's involvement in epilepsy care in East Timor

Ernest R SOMERVILLE

Prince of Wales Hospital and University of NSW, Sydney, Australia

## Abstract

East Timor is a young country with high treatment gap. The East Timor National Epilepsy Training Program was established to improve epilepsy care in the country. There are many challenges in establishing a training program to improve the care of epilepsy in a developing country. This paper describes some of these challenges.

Epilepsy is rarely treated in East Timor due to a shortage of doctors and traditional beliefs that epilepsy is supernatural.<sup>1</sup> The East Timor National Epilepsy Training Program (ETNETP) is a joint effort of the East Timor Ministry of Health (MoH), the Epilepsy Society of Australia, Epilepsy Action (Australia) and AusAID (the Australian Government's overseas aid program).<sup>2</sup> The ETNETP has two aims: Firstly, to train nurses delivering primary health care throughout East Timor to diagnose and treat generalised tonic-clonic seizures; secondly, to improve community awareness that effective treatment is available in their community. This is achieved through training nurses to take a standardized history and use diagnostic and treatment algorithms. Australian neurologists train groups of 5-10 nurses over a 2-day period, using a small number of real patients. Two months later, two groups come together for a 1-day review session, at which they present cases they have seen since the training. Workshops with community leaders were also conducted. These were held in the same districts as the nurse training at around the same time. The aim is to create demand for epilepsy treatment and match it to the newly acquired capacity of the general nurses.

## CHALLENGES

There are many challenges in establishing a training program to improve the care of epilepsy in a developing country. The challenges for ETNETP include the following.

*Geography and transportation:* Many clinics are remote and inaccessible, especially in the wet season. This also impacts on drug supply. Training is held in district centres to improve accessibility.

*Security:* Recent violence interrupted the program for 6 months. Some project staff are unwilling to go to certain districts where they feel threatened and some nurses were forced to flee their posts.

*Language:* There are many indigenous languages, the most prevalent being Tetum. Training materials were initially in Bahasa Indonesia, as this was the language that had been used at the nursing schools. However, the nurses preferred Tetum and because precision of the wording in diagnostic and treatment algorithms is essential to avoid errors, the documents have been translated into Tetum. However, the simplicity and limited vocabulary of this language have created other challenges.

*Literacy:* Community education materials rely heavily on visual rather than written material. Seizure diaries are impractical.

*Lack of medical records:* Medical records do not exist and histories are often inaccurate.

*Lack of investigations:* EEG and neuroimaging are not available. Simple blood tests are possible only in a few centres. While this may disadvantage patients, it makes clinical diagnosis by nurses more acceptable.

*Lack of doctors:* The country had few doctors. But after the program was started, over 300 Cuban doctors were employed in East Timor. The impact of this on epilepsy care is unclear. There is still no neurologist, so training is provided by neurologists from Australia. The diagnostic and treatment algorithms have been translated into Spanish and epilepsy training will be provided to the Cuban doctors. The lack of neurosurgical

facilities actually simplifies management by eliminating the need to detect epileptogenic lesions that would benefit from surgery.

*Drug supply:* The East Timor MoH provides antiepileptic drugs (AEDs) free of charge, distributed to general nurses via the Mental Health nurse in each of the 13 districts. Drug became unavailable when some mental health nurses fled during the recent violence and a shipment of drug from overseas was delayed, resulting in an urgent shipment donated by an Australian supplier.

*Competition from other health priorities:* Malaria, tuberculosis and other infectious diseases affect many more people than epilepsy and may be seen as more important.

*Cultural beliefs and practices:* The East Timorese community generally believes that epilepsy is a supernatural condition but although traditional medicine is almost always tried, it is rarely considered effective. It is generally not known that epilepsy is a medically treatable disorder and patients do not seek medical treatment even when it is available. Equipping nurses with the skills to treat epilepsy will be effective only if people with epilepsy come to them for treatment. The program therefore includes workshops for community leaders, emphasizing that epilepsy is not contagious and that treatment is now available in their communities and encouraging referral. Nurses trained by the program are also encouraged to recruit patients from their communities.

*Bureaucracy:* Administrative systems tend to be inflexible, inconsistently applied and sometimes obstructive. This is partly overcome by having the Program Co-ordinator located within the Ministry of Health.

*Funding:* East Timor is the poorest country in Asia and is dependent on foreign aid. However, the MoH supports the program in many ways, including provision of venues, travel and living expenses for nurse trainees, office space for the Program Co-ordinator and antiepileptic drugs. The program has multiple sources of funding, including the Epilepsy Society of Australia, Epilepsy Action, AusAID and pharmaceutical companies.

*Fertility:* East Timor's birth rate of 8 children per woman is the world's highest. Obstetric ultrasound is not available. As the teratogenic risk

of AEDs is cumulative with multiple pregnancies, this becomes an important factor in AED choice. Carbamazepine is used in all patients except those with juvenile myoclonic epilepsy, in whom valproate is used. This strategy also reduces cost. Doses are small and titrated against seizures.

*No effective community support group:* The East Timor Epilepsy Association has ceased to function due to lack of funding and the recent security crisis.

## PROGRESS

The program was started in March 2005 and in its first 18 months, 9 of 15 mental health nurses and more than 200 primary care nurses from 7 of 13 districts have been trained. Community leader education workshops have been held in the same districts. A formal evaluation is under way, collecting data on numbers of patients receiving treatment, diagnostic accuracy and the views of the MoH and health workers.

## ACKNOWLEDGEMENTS

The program is funded by the Epilepsy Society of Australia, Epilepsy Action, AusAID (Australian government), East Timor Ministry of Health, Pfizer, Sanofi Aventis, UCB, GSK and Novartis.

## REFERENCES

1. Somerville E. The needs in East Timor. *Neurol Asia* 2004; 9 (Suppl 1): 73.
2. Somerville E, Black A, Pelekanos J, et al. The diagnostic and treatment algorithms in the East Timor National Epilepsy Training Program. *Neurol Asia* 2007; 12 (Suppl 1):