

The Lao initiative on access to treatment for epilepsy

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Abstract

In Lao PDR research conducted over the last 7 years has highlighted the difficult challenges that the 52,000 patients living with epilepsy (PWE) have to face. Mortality and morbidity is high among untreated patients. The treatment gap is 90% or more. The highly traditional and poor knowledge of the disease and its treatment, low trust in modern treatment, restricted access to anti-epileptic drugs (phenobarbital is the first line drug), and ignorance of requirement for long term treatment explain the high treatment gap. Stigma, misconceptions, and fear of the disease are common. Knowledge of medical staffs regarding epilepsy diagnosis and treatment is poor. The neurology investigational facilities are basic and mainly concentrated in the capital city. Using lessons from program of neighboring countries, the authors have been developing a step-by-step treatment intervention project since 2009. The intervention was adapted to the local constraints and a limited budget, which demanded regular feedbacks, analysis and reorientation of the activities.

INTRODUCTION

Lao PDR, a low income multi-ethnic landlocked country of 6 million inhabitants, research conducted over the last 7 years by the Francophone Institute for Tropical Medicine and its partners has highlighted the difficult challenges that patients with epilepsy (PWE) have to face. A total of 10 papers have described the situation of patients living with epilepsy.¹⁻¹⁰

It is estimated that about 52,000 people are living with epilepsy in Laos in 2010.^{1,6} Misconceptions, false beliefs of the disease, fear and stigmatisation of patients are common.⁷ The treatment gap is over 90%. A pilot project provided treatment with phenobarbital to 46 PWE in a rural area north of capital Vientiane from 2005 to 2007.¹⁰ From the project, we learnt the following lessons: (1). Few patients (n=10, 21%) fully adhered to treatment, 9 (19.6%) had a low compliance; (2). Among the PWE compliant to phenobarbital, efficacy was good with 69% being seizure free or had seizure frequency decreased from 3.5 to 0.3/month; (3). Mortality was high among the patients not adhering to treatment (6/28, 21%); (4). The mortality was particularly high among the young males (median age 18 years) and PWE with mental disorders (5/6).

In view of these findings, it was decided to move from research to implement an access to

treatment of epilepsy project.¹ In this paper, we present the main components and activities of this initiative. The project was started in 2009, after obtaining a grant from the Sanofi “Access To Treatment” program, which allowed a Lao physician to enroll and start building a team in September of 2009. As there was little efforts of intervention treatment on epilepsy in Laos previously, the project had to be approached “top down” as well as “bottom up”.

RESULTS

The epilepsy team was formed in September 2009, and has progressively expanded its activities resulting in gradual improvement of epilepsy treatment. The followings were the activities undertaken.

- 1) Advocacy of epilepsy to the Lao health authorities and public awareness campaign

We conducted two scientific conferences to launch the project in 2008-2009 in Laos and also presented the situation of epilepsy in Laos during various other local medical conferences. A working group on epilepsy was set up and the group met every month. Meetings were organised with the health authorities at the central level and in all provinces. As a result, there is an

increasing awareness of the burden of epilepsy by the health authorities, though there is to date no official commitment for further action. Information on epilepsy was also disseminated to all non-government organizations (NGO) working in Laos with the objective of integrating epilepsy into the other NGO works. It is hoped that more NGOs will participate in the screening of epilepsy patients in the remote areas of Laos in 2011. A daily broadcast time slot was also obtained from the local radio station since June 2010 to inform the public on epilepsy, with a phone-in hot-line being set up.

2) Training of health care personnels

Every two months, a 3-days training involving 12-14 participants is being conducted in various provinces. The program comprises of theory for one day, practical with screening of patients in the villages for the next day, and case discussion for the third day. Phenobarbital is distributed to the hospitals where physicians have been trained. The fees collected from selling phenobarbital are expected to allow the hospitals to order for more drugs. Phenobarbital is subsidised for poor PWE, and may be given free for the first 3 months of treatment. To-date, training on epilepsy has been held in 5 provinces, involving 3 provincial hospitals, 27 district hospitals and 13 health centres, involving a total of 68 physicians. After the training, the physicians are being followed up monthly using phone calls. These monitorings show a slow increase in new patients. Of the 167 patients treated by the trained physicians in our program, 103 patients are attending regular follow up. This project also involves further training of the key personnel in Neurology institutions in the neighboring countries. One Lao physician was trained in Neurology for one year at the University of Malaya, Kuala Lumpur. She is now in charge of clinical diagnoses of the patients. Three other Lao physicians are currently undergoing long term training in Malaysia and Thailand.

3) Opening of a new outpatient department

It is our hope that there will be a new outpatient department in capital Vientiane to serve the patients in the capital and the provinces. Currently the Psychiatry ward in Hospital Mahosot, Vientiane provides care to about 300 patients annually, who are often referred to the Department from the Emergency Unit after being attended for initial seizures. Currently two other

organizations besides ours (Basic Needs and Handicap International) are attending to a total of about 160 PWE in Laos. It is encouraging that majority of PWE who are being treated with AEDs (93% with phenobarbital) reported a decrease in seizures, with a global satisfaction rate of 80% versus 20% of patients not receiving AED treatment.

4) Guidelines to management

Information leaflets on epilepsy and management guideline are being produced in the Lao language, and are being widely distributed. Posters are under press.

5) Ensure the availability of antiepileptic drug

A previous survey has shown that phenobarbital was available only in a small number of higher categories pharmacies, and not allowed to be sold in the lower category pharmacies, which are the pharmacies in virtually all of the rural Lao PDR at the district and health centre level.^{1,4} Investigations showed that the import of phenobarbital is controlled by International Narcotic Board Committee in Vienna which approves a yearly quota of 25kg. This is adequate to treat a maximum of 650 patients, which is far less than the estimated 52,000 epilepsy patients in the whole country. The amount of phenobarbital ordered by the Food and Drugs Department of the Ministry of Health is based on the requests from the hospitals where only few epilepsy patients are being seen, to avoid drug spoilage. This partly explains the recurrent shortage of phenobarbital in the pharmacies.

6) Research to improve care and access to treatment

Three researches were conducted since 2008.³ A two stage sampling national survey in 2009 showed a poor knowledge of the disease among the health care professionals. A mean of one new patient a month attends the provincial, district and health facilities. Another national survey highlighted the difficulties managing epilepsy at a rural level in 2010. Follow up of PWE by phone proved very difficult in rural areas. A third survey explored the compliance of PWE according to the PWE care (hospital based or community based) and found an unexpected better compliance rate than expected with the compliance being marginally better in hospital based care.

CONCLUSION

The initiative to improve access for AED treatment in Laos faces many constraints and challenges which are gradually being overcome by our team. The preliminary results from these efforts are encouraging. For our future direction, we have identified six major goals: To improve PWE detection; to increase the number of PWE receiving AED treatment long term, and attending follow-up; to improve networks of the health care personals involved in treatment of epilepsy by recruiting more medically qualified physicians and the existing NGO networks; to overcome the problem of poor availability of AEDs; to work towards greater commitment of the Lao health authorities to epilepsy care; and to initiate a patient based epilepsy association; with overall aim to ensure the long term sustainability of this project.

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