

# Epilepsy in Lao PDR: From research to treatment intervention

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## Abstract

Epilepsy in Lao Peoples' Democratic Republic (Lao PDR) is a neglected condition. After 5 years of research, we established some baseline information for people living with epilepsy in Lao PDR. Prevalence was 7.7 per thousand population. Stigma and misconceptions were common. Traditional beliefs and practices were prevalent. The treatment gap was 90% or more. Phenobarbital was available in less than 55% of pharmacies in the capital city of Vientiane and not available in many rural areas. There are two neurologists in the country. The neurology investigational facilities are basic, mainly concentrated in the capital city. The studies demonstrate that epilepsy is a public health concern in Lao PDR. The authors proposed a treatment intervention project involving multiple partners and a step-by-step approach.

## INTRODUCTION

Although epilepsy is one of the most common neurological disorders, in many countries with limited resources, people with epilepsy (PWE) are an under-served patient group. Epilepsy patients often do not receive modern antiepileptic drug treatment and may have a higher mortality rate than the normal population. Epilepsy not only affects the patients' life, but also the lives of the household members. In countries with scarce resources, it is a great challenge to integrate the control and management of epilepsy in the health care delivery system, and overcome the high treatment gap.

Since 2003, the Francophone Institute of Tropical Medicine (IFMT)<sup>1</sup> and the Institut d'Epidémiologie Neurologique et de Neurologie Tropicale (IENT), in close collaboration with Lao Institutions such as the National Institute of Public Health (NIOPH), Ministry of Health (MOH), and provincial and district health authorities have carried out several studies on epilepsy and PWE in Lao Peoples' Democratic Republic (Lao PDR). The aim was to establish epidemiological, socio-cultural and public health base-line information for treatment intervention in this country.

In January 2008, a workshop brought together researchers and health care professionals from Lao PDR and abroad to raise awareness on

epilepsy in Lao PDR, to discuss the results of the research and the next interventional strategy. This article aims to summarize the current state of the discussion.

## SOME BASIC FACTS ON LAO PDR

Lao PDR is a landlocked country, sharing borders with Vietnam, Cambodia, Thailand, China, and Myanmar. The multi-ethnic population of 5.6 million people (2005) is mostly rural (87.8%), living in a country with many hills and mountains with low population density (24 inhabitants/km<sup>2</sup>). The GDP is 490 USD per capita. It ranks 133 out of 177 nations on the Human Development Index (2004). The health indicators are among the lowest in South East Asia. For example, maternal mortality is 530 per 100,000 births; life expectancy at birth is 61 years (National Census 2005). Per capita health expenditure is estimated to be 12 USD; about 60% are covered by out-of-pocket of household budget, 30% from international donors and 10% from the Lao Government.

## PREVALENCE AND RISK FACTORS OF EPILEPSY IN LAO PDR

In 2004, the prevalence of epilepsy was studied in Hinheub, a mountainous rural district 120 km north of the capital, Vientiane. Three of the

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villages with a population of 4,310 inhabitants were selected for the study. The prevalence of epilepsy was estimated to be 7.7 per thousand population (95% CI, 5.3-10.7 per thousand).<sup>2</sup> This is the first study on the prevalence of epilepsy in Lao PDR. The prevalence corresponds to the prevalence rates of the neighboring countries.<sup>3</sup> Table 1 lists the estimated number of PWE in 2 main regions of Lao PDR based on this prevalence rate. The total number of PWE in the country is estimated to be approximately 50,000.

A preliminary case-control study to determine the risk factors for epilepsy in Lao PDR was also performed in Hinheub, a rice farming rural district with pig rearing as subsistence activity. Family history of epilepsy was the strongest risk factor (O.R. 12.8), and head injury (OR 4.7) as other significant risk factors.<sup>4</sup> Despite taeniasis being a common diagnosis in Lao PDR, cysticercosis serology was not found to be significantly associated with epilepsy. None of the subjects in the epilepsy group and 4.8% in the control group had positive cysticercosis serology. This may be due to small number of study subjects, or difference in strain of taeniasis endemic in Lao PDR. Also, pork consumption is a strict taboo for PWE in Lao PDR, as epilepsy is known as *sak pa moo*, “mad-pig-disease” in the local Lao language; thus, reducing the rate of positive cysticercosis serology once seizures develop.

#### TREATMENT GAP AND AVAILABILITY OF PHENOBARBITAL

Of the 33 PWE identified in the prevalence study in Hinheub district<sup>2</sup>, only one was receiving antiepileptic drug, indicating a high epilepsy treatment gap. A similar situation exists in the capital Vientiane, where only 12 out of approximately 2,350 PWE regularly visits the pharmacies to obtain the antiepileptic drugs.<sup>5</sup> The epilepsy treatment gap in Lao PDR is thus high,

estimated to be 90% or more. A high treatment gap is known to be able to deeply affect the quality of life of the PWE.<sup>6</sup>

As phenobarbital is an effective antiepileptic drug most affordable in countries of limited resources, a study was also done to determine the availability and cost of antiepileptic drugs and quality of phenobarbital in Vientiane municipality, Lao PDR.<sup>5</sup> Despite being on the national essential drugs list, phenobarbital was available only in a small number of pharmacies. Only 53% of urban higher categories pharmacies surveyed in Vientiane municipality had the drug, and diazepam was more widely available in 88% of the pharmacies. A short course of diazepam was the most commonly used regime in the treatment of seizures.<sup>5</sup> Also, phenobarbital is not allowed to be sold in the lower category pharmacies, which are the pharmacies in virtually all of the rural Lao PDR, a major limitation for the accessibility of phenobarbital in the rural part of the country. The direct cost of a yearly treatment with phenobarbital was estimated to be at least 25.2 USD, which imposed a heavy financial burden for a population with GNP of USD 490. On the other hand, the quality of phenobarbital was rather satisfactory.<sup>5</sup> Currently, there are no national guidelines for the treatment of epilepsy.

#### TRADITIONAL BELIEFS, MISCONCEPTIONS AND STIGMA

Misconceptions and stigma on epilepsy among patients, relatives and the general population are common in Lao PDR.<sup>7</sup> In a study in 3 rural districts of Vientiane province, epilepsy was viewed as having a supernatural origin in 25-42%, a disease transmissible by saliva in 26% of family and 44% of villagers. Sixty three percent of family members reported that they would restrict a PWE from sharing meals with them, or from marrying someone from their households (61.4%).

**Table 1: Estimation of the number of people with epilepsy in Vientiane Capital and Luang Pra Bang regions of Lao PDR**

	Population (2005)	People with epilepsy 7.7 per thousand	Minimum 5.3 per thousand	Maximum 10.7 per thousand
Vientiane	700,000	5,390	3,710	7,490
Luang Pra Bang	410,000	3,157	2,173	4,387
<b>Total</b>	<b>1,110,000</b>	<b>8,547</b>	<b>5,883</b>	<b>11,877</b>

In 2008, we conducted a qualitative survey in 16 villages belonging to 7 out of the 17 provinces in Lao PDR (Barennes, unpublished observations). Eighty three subjects were selected to reflect the diversity of the Lao PDR population. Preliminary results confirmed the widespread misconception and stigma towards PWE. Traditional treatments are widely practiced, although they are often considered to be ineffective. There is greater awareness of the need for acute treatment of seizure attacks, as compare to the needs for long-term treatment to prevent recurrent seizures.

## MORTALITY

PWE have a shorter life expectancy and subject to many fatal accidents.<sup>8</sup> A small-scale intervention study was carried out from 2004 to 2006 in a rural area north of Vientiane involving 53 PWE.<sup>9</sup> Phenobarbital was provided free of charge by the district hospital after an initial consultation by a neurologist from France. Compliance with treatment was low; only 10 patients (21.6%) were fully compliant. A high mortality (6/53, 11%) was observed over the 2 years period, all among those who were not fully compliant. Of the 6 mortalities, the causes were drowning (2), burns (1), fall (1), and unspecified cause (2). Five of these were mentally retarded young males.

## HEALTH CARE INFRASTRUCTURE AND HUMAN RESOURCES

The health care services in Lao PDR are characterized by predominance of the public health care services, and low numbers of skilled staff. The main network for health care service provision is the public system, although private health care services are growing. All the hospital beds are from the public health system with 0.9 hospital beds per 1,000 inhabitants. The private health care services consist of around 254 clinics, and 1,865 pharmacies, mainly in urban areas.<sup>10</sup>

There is general shortage of qualified health workers. High- and mid-level medical staff under the Ministry of Health, defined as physicians (high-level), nursing staffs and midwives (mid-level) with more than two years of formal training, account for only 23% of the workforce in the health sector (4,123, i.e. 0.74 workers per 1,000 inhabitants). There are only 2,992 high- and mid-level medical staff working at health care facility, at the provincial and district hospitals and health centers. This translate to 0.53 workers per 1,000 inhabitants; far below the recommended WHO target of 2.5. They tend to be concentrated in regions that are socio-economically better-off.<sup>11,12</sup> Table 2 summarizes the health facilities and human resources in the 2 main regions in Lao PDR.

The bulk of the medical staffs work in the district health care services, which are mainly manned by mid- and low- level staffs. Health centers are almost totally manned by low- and mid-level staff. Nationwide, there are only 6 doctors working in health centers.

## ACCESS TO AND USAGE OF HEALTH SERVICES

The State's mainly curative health services are tremendously underutilized, especially outside the urban areas. The general public's concept and belief system on health, high illiteracy rate, and difficulties in access to the health services are some of the reasons. Recently introduced health village volunteers and village revolving drug funds are measures to overcome this.

Only one in 7 sick people receives modern health care treatment. Most people rely on self-medication, traditional plants, sauna, massage and acupuncture<sup>12,13</sup>, natural physiological healing<sup>14</sup> and/or religious ceremonies for treatment.<sup>15</sup> A majority (77%) justified their preference of traditional treatment as they believed it to be more effective.<sup>16</sup>

**Table 2: Population and health facilities in Vientiane Capital and Luang Pra Bang regions, Lao PDR**

	Population (2005)	Provincial hospital	District hospital	Health center	Medical staff* (2001)
Vientiane	700,000	1	10	27	1,499
Luang Pra Bang	410,000	1	11	44	1,197
<b>Total</b>	<b>1,110,000</b>	<b>2</b>	<b>21</b>	<b>71</b>	<b>2,696</b>

\*Medical staff, including doctors and nurses

Many ethnic groups still consider health and well-being as a consequence of spiritual balance rather than as a result of a sufficient food intake, hygiene, health care practices.<sup>17,18</sup> Many patients stopped seeking modern health care services when the disease relapse or become chronic.<sup>14</sup>

On the other hand, the public health care services, especially at district level has grossly inadequate resources, is poorly maintained, and the cost of medicine is often high for the villagers. In the remote uplands, health services are also often difficult to access. The distance to health centers increased from 10.7 km in 1992/3 to 11.7 km in 2002/3 for the poor people, while it fell from 7.4 km to 6.5 km for the non-poor people.<sup>11</sup>

### NEUROLOGICAL FACILITIES

There is currently one neurologist and one neurosurgeon in the whole country practicing in the capital, Vientiane. One additional physician completed the training in Neurology in April 2008, and will be working in the neurological unit in Mitthapap Hospital, one of 4 main hospitals of Vientiane. Two young doctors have been offered a grant to enroll in a two years-neurology training program in Khon Kaen University, neighboring Thailand. Outside Vientiane, one medical team has been trained for managing patients with neurological and mental disorders. Some 1-2 weeks training in neurology is being conducted once or twice a year by specialists from overseas.

There are currently 5 CT Scans in Lao PDR, 3 in Vientiane. There is an electroencephalography machine in Mitthapap hospital, though still not operational.

### PROPOSED TREATMENT INTERVENTION PROJECT

The authors would like to propose a treatment intervention project to improve the access to treatment for PWE in Lao PDR. The project will initially be carried out in two main regions of Lao PDR, capital Vientiane and Luang Pra Bang, covering 1.1 million inhabitants, about 20% of the national population (Table 1). A comprehensive and step-wise approach involving all aspects of epilepsy care will be addressed: (i) epilepsy awareness by patient, families, and general public; (ii) epilepsy diagnosis and management among health care personnel; (iii) availability of antiepileptic drugs; (iv) accessibility of drugs in urban and rural pharmacies; (v) costs of

treatment (affordability); (vi) patient – health care workers communication; and (vii) acceptability of treatment by the patient.

The project will involve multiple partner organizations, including institutions and non-governmental organizations already involved in training and direct health care in Lao PDR. These include the Faculty of Medicine, National University of Laos that already revised their curriculum for medical students to include epilepsy management; the Ministry of Health and the nursing training centers. The non-governmental organizations involved in training are Health Frontier<sup>19</sup>, IFMT, and Family Medicine Specialty Program.<sup>20</sup> Over the years, these bodies have managed to train 26 pediatricians, 60 family physicians and 90 physicians with postgraduate training such as Master in Tropical Medicine. Basic Needs and Handicap International have been involved in caring of PWE in Lao PDR. Handicap International has started a community based project in 2006 in Savannakhet province in central Lao, cumulating valuable experience in managing epilepsy in the community. INGO group, an association of all non-government organizations working on health in Lao PDR can help in networking of the various partners.

Sustainability is the main challenge for the project. Antiepileptic drugs will be made available at basic costs through the public health system. Sustainability will also be based on integration of the activities in the current health system. High awareness of the Ministry of Health and involvement of Lao physicians and authorities will be of high priority. Other aspects include training of Lao neurologists who can be future leaders of epilepsy development in the country long term, increasing the number of local physicians skilled in the diagnosis and management of epilepsy, raise the profile of epilepsy in various levels of medical education, increase the awareness of epilepsy among the general public.

The current efforts include a survey to determine the interest of local physicians to be involved in the project, and the number of PWE currently under follow up. The potential new patients can then be identified, and the human resource required.

In conclusion, the research on epilepsy in the last 5 years has shown that epilepsy is a public health concern in Lao PDR. The research has provided a firm foundation for a treatment intervention program to improve epilepsy care in this country.

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