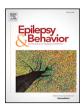


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Explanatory factors of adherence to community-based management of epilepsy in Lao PDR



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ABSTRACT

Relevance: A low level of knowledge about epilepsy among health workers, a context of stigmatizing sociocultural beliefs, and a low availability of antiepileptic drugs in Lao People's Democratic Republic (PDR) are major gaps in the medical management of people with epilepsy in this country.

Objectives: The principal objective of the study was to identify the associated factors of adherence to community healthcare structures in Lao PDR. Specific objectives were to evaluate patients' adherence status, practices and knowledge about epilepsy and its care, and factors influencing decision-making on therapeutic interventions. *Materials and methods:* The study was an observational cross-sectional survey about knowledge, attitudes, and practices, handled from February to May 2016. Eighty-seven people with epilepsy were identified in two areas in the periphery of Vientiane Capital through an active screening in villages and homes. Semidirective questionnaires were conducted to collect quantitative and qualitative data. Quantitative analysis included a comparison of adherent vs. nonadherent people with epilepsy, using Chi-square or Fisher's test. Advanced qualitative lexical analysis was carried out on the open-ended questions.

Results: Sixty-two people with epilepsy were included and the adherence rate to community care was 67.7%. The only sociodemographic variable that differed significantly between adherent and nonadherent members was the income level (p=0.015): the wealthiest class of people with epilepsy did not adhere to community healthcare. Eleven percent of people with epilepsy thought that epilepsy was contagious, 80.6% that medication may reduce epilepsy seizure rates, and 33.9% that it was possible to cure epilepsy permanently. Physicians informed about the disease in 69.0% of adherent people with epilepsy and in 40.0% of nonadherent ones (p=0.029), whereas villagers were involved in 29.0% and 50.0% of cases, respectively. There was a significant difference between the two groups for the prescribed antiepileptic drugs (p=0.012): phenobarbital covered 73.8% of adherent people with epilepsy but only 40% of nonadherent ones. Half of nonadherent people with epilepsy went regularly to a central hospital in the Vientiane Capital, 15.0% went to Thailand, and 10.0% practiced self-medication in occasional mobilities. *Conclusion:* A wider range of antiepileptic drugs at a reduced cost and the promotion of adherence to community healthcare would allow a better management of people with epilepsy in Lao PDR.

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1. Introduction

Epilepsy is a common chronic neurological disorder that affects people regardless of gender, age, or social class. Around 70 million people are living with epilepsy worldwide, 80% of whom live in low- and middle-income countries [1].

In 2010, a World Health Organization (WHO) program of action (Mental Health Gap Action Programme [mhGAP]) supported recommendations in a guide to community care (including epilepsy) specifically for

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low and middle-income countries [2]. These recommendations rely mainly on health workers in decentralized care structures at the primary (e.g., local healthcare clinics) and secondary (e.g., district hospital) levels. This well-supported recommendation for community-based epilepsy management is particularly well-suited to this disease. The diagnosis can be clinically done by general practitioners, and there are inexpensive antiepileptic drugs (AEDs) available [3] to respond to this chronic condition and its long-term treatment. Complementary examinations (electroencephalography and medical imaging) are used to determine the classification of epilepsy and/or its etiology [4], and these examinations are generally accessible in major cities and provincial capitals. It is considered that about 70% of epilepsy cases could be treated properly with a first-generation AED and handled correctly at the community level.

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There is no doubt that the community-based management of people with epilepsy (PWE) promulgated by the mhGAP guide would significantly reduce the treatment gap and improve the quality of care for epilepsy [5]. This optimistic vision of a general practice for epilepsy improving the accessibility to healthcare in rural areas is however clearly conditioned by the adherence of PWE to their local structures, rather than the availability of a specialized medicine at the central level. The challenge is even more difficult when we consider the high stigma associated with epilepsy in low- and middle-income countries. This social perception does not facilitate the detection and management of PWE at the community level [6].

The Lao People's Democratic Republic (Lao PDR, known also as LAOS), landlocked in the heart of the peninsula of South-East Asia, is particularly suited for community-based medical management of epilepsy. The healthcare delivery system in Lao PDR is historically owned by the government and highly centralized. Coverage of the population by the governmental health insurance is very low and outof-pocket expenses can become too high for those with low or modest incomes. There are officially four levels of service providers in Lao PDR: large central-level hospitals, province hospitals, district-level hospitals, and community-level health centers. Patients prefer to use central and provincial hospitals because of higher quality service but the availability of medical personnel is limited in this predominantly rural country (6.7 million inhabitants living in 236,800 km²) [7]. As an example, the number of neurologists rose from two in 2011 to only nine in 2018, and most of them are based in the capital. As a consequence, healthcare services cannot respond to demands and expectations of the local population and, for those who can afford to travel, seeking care in neighboring countries is common.

The prevalence of epilepsy in Lao PDR is 7.7/1000 inhabitants [8], the treatment gap is higher than 90% [9], and there is no national guideline for epilepsy treatment. This finding is understandable because of a low level of knowledge about epilepsy among health workers [10], a context of stigmatizing sociocultural beliefs [11,12], and low availability of AEDs [13].

This study aimed to identify the associated factors of adherence to the country's community healthcare structures, particularly at the district and local health center levels. We defined adherence of PWE to community healthcare by the following: 1) diagnosis of epilepsy done at the district hospital by a general practitioner based on the history of the disease and confirmed by a neurologist; 2) follow-up of PWE consisting in a monthly visit conducted by health volunteers for monitoring seizures, verification of treatment compliance, and renewal of AEDs; and 3) access to AEDs provided at the primary health center or at home. This study also took into consideration patients' personal research into alternative (or complementary) care, as well as complementary factors influencing decision-making on therapeutic pathways.

2. Method

2.1. Identification of PWE through the DHeVELoP program

In 2014 and 2015, the Domestic health visitors for improving access to care for people with epilepsy in the Lao PDR (DHeVELOP) program carried out a quasi-experimental study to evaluate an intervention strategy based on active screening in villages and homes and a follow-up of identified PWE [14]. The villages were selected according to the size of the population (expected number of PWE) and the distance to the first healthcare center in order to be representative of the different situations in the district. The interviewers received 3 types of training on epilepsy: about 20 h of general training on epilepsy, two weeks of clinical training on epilepsy in the outpatient department of Setthathirath Hospital in Vientiane Capital, and practical training for the completion of questionnaires in 10 villages out of the study area (practical training module before the survey) in order to validate the screening of PWE and the completion of questionnaires. This intervention program enabled us to have a list of 87

PWE confirmed by a neurologist in November 2015. Diagnosis criteria followed the International League Against Epilepsy (ILAE) definition: two or more unprovoked seizures occurring at least 24 h apart [15]. The status "adherent" or "nonadherent" to community healthcare was determined by the domestic health volunteers: 51 PWE were nonadherent and 36 were adherent. The 87 PWE had been identified in two areas on the periphery of Vientiane Capital (Fig. 1): 50 km on the national road leading to the south of the country (Pakgnum District, 53,434 inhabitants) and 50 km on the national road leading to the north of the country (Sangthong and Naxaythong Districts, 94,653 inhabitants). This presence of PWE in two different areas allowed the observation of diversified therapeutic pathways.

2.2. Selection criteria and data collection

From February to May 2016, based on the list of PWE in the DHeVELoP program, we were able to interview 58 PWE in 38 villages. Twenty-nine patients were not included because they were lost to follow-up, dead, refused to participate, or had moved to other areas. Four news cases were included during our survey. The total number of participants in our study was 62 (Fig. 2). We included all people with a diagnosis of epilepsy in our study area. People with epilepsy with disabilities and mental health disorders were also included. We excluded people who refused to participate.

The interviews were conducted by the first author (bilingual, Lao native), using a general question to initiate the discussion. Individual interviews were conducted at the place that best satisfied participants.

The semidirective questionnaire consisted of four items: sociodemographic characteristics, knowledge and perception of the disease, therapeutic itinerary (consultation and supply sites for treatment), and practices with respect to conventional and traditional medicines. This face-to-face process consisted of 18 questions: 10 close- and 8 open-ended questions that allowed free expression on a given topic. More specific questions were subsequently asked based on the information provided in response to the general question. The researcher allowed participants to share their ideas without influencing the responses. The discussion lasted between 50 to 60 min. The interviews were recorded in Lao on paper but were tape-recorded only if participants agreed. Both the taped and paper records were translated into English.

Written consent was systematically obtained prior to the interview. For children under 18 years of age, written permission was obtained from parents. If a patient with epilepsy could not respond directly because of disability or mental health disorders, caregivers were interviewed.

2.3. Quantitative and qualitative data analysis

The analysis focused on the composite response to the descriptive objectives of the cross-sectional survey and analyses were performed by the first, second, and last author. The overall analyses also included a comparative analysis of adherent vs. nonadherent PWE to reveal significant differences (depending on the adherence status at the time of the survey). For the dichotomous and closed questions, proportions were reported, and the tests used were Chi² or Fisher's test. Quantitative variables were expressed by their mean and standard deviation, and the Student Test was used. The significance threshold for all analyses was set at 0.05.

For open-ended questions, the feedback translation and transcripts were done by the bilingual interviewer, a native of the Lao PDR (1st author of the article). The lexical analysis was based on the semantic occurrences, which allowed a coding according to the most frequently cited methods. These questions were then analyzed as closed, multiple-choice questions through proportional analysis. We presented some of the most significant lexical segments in the main body of this article. The transcripts and coding of the lexical segments of interest were carried out using the functionalities of Word software, and the

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