

EPILEPSY EDUCATION AND TREATMENT PROGRAM IN TIBET



A PROMISING STRATEGIES PROJECT

Set up in 2006, as a way of supporting IBE chapters through the provision of financial support for projects aimed at improving the quality of life of people with epilepsy, to date, 81 projects in 38 countries have received a total of US\$330,000 in support.

For centuries Kangding has served as the last outpost before the wild Tibetan mountains and passes of the Chengdu-Lhasa highway. It has been acting as the bridge between Han and Tibetan cultures and as a major trading port on the Tea Horse Road.

Our team members are from Chengdu and Kangding and, once again, we want to act as a bridge of knowledge exchange, and proper epilepsy management, with the help of IBE.





The Tibet region is on the Qinghai-Tibetan plateau, which is about 4,000 metres above sea level. Over 3 million Tibetan people live in an extremely harsh natural environment on this high plateau. Few qualified neurologists work in the area. Our previous study showed the prevalence rate of active epilepsy to be 2.4 (95% CI = 1.7–3.3) per 1,000 in the Tibet Autonomous Region. And 97% of patients with active epilepsy did not receive antiepileptic therapy [1,2]. As a result, medical, educational and financial support is urgently needed to bridge the treatment gap in Tibet.

The Ganzi Tibetan Autonomous Prefecture is part of the Tibet area and Kham Tibetan dialect is the primary language.

ORGANIZATION

Ganzi People's Hospital is located in the city of Kangding, Sichuan Province, in a valley of the Tibetan Plateau, about 210 kilometers west-southwest of Chengdu.

Since 2014, each year West China Hospital has sent a neurologist to Kangding, to live and work with the local doctors for twelve months. A neurologist, nurse and Kham Tibetan dialect translator from West China Hospital and Ganzi People's Hospital work together on the project. With the staff, we plan an epilepsy education and treatment program in Kangding city. We have already provided services such as:

1. Continuous training for local primary

medical workers.

2. Education in local communities.
3. Treatment, data collection and analysis, and follow-up.

With the help of CDC and the government, a network for education, control, and screening of Hydatidosis (Echinococcosis) and other chronic diseases has already been built and has worked well in Ganzi's villages and counties [3]. By using the already existing network, after the start of the project, we want to provide those services and epilepsy screening in all 18 counties of Ganzi.

Members of our team have helped in setting up a management network, based on the primary health care system in rural areas of Sichuan Province, and have carried out door to door epilepsy screening in Tibet[1,4]. We believe those experiences will be helpful in this Tibetan project.

Medical resources are very insufficient in the Ganzi Tibetan Autonomous Prefecture. At county-level, hospitals have only 3 to 5 doctors, and only one with a practitioner's license. People living in Tibet have the shortest life expectancy and highest

illiteracy rate in China. Our previous study showed the epilepsy treatment gap to be as high as 97%. And 60% of people will choose traditional Tibetan medicine [1,2].

TARGETED POPULATION

General doctors and patients are the targeted population. There is an urgent need to train the local general doctors in proper epilepsy control; to educate people with epilepsy to adhere to appropriate treatment; and increase public awareness of epilepsy.

One million people live in Ganzi. Our previous study showed the prevalence rate of active epilepsy to be 2.4 (95% CI = 1.7–3.3) per 1,000 in Tibet Autonomous Region. So there would be 2,400 people with epilepsy and 90 (18x5) general doctors in county hospitals.



Photo of our staff in front of Ganzi People's Hospital with the project manager, Jiani Chen (back row, second from left), The road in the background is part of the ancient Tea Horse Road, and the mountain in this photo is the gateway to Tibet.



ANTICIPATED IMPACT OF THE PROGRAM

1. Provide information on prevalence, knowledge level, and treatment gap of epilepsy in the population of Ganzi for further studies.
2. Through the training program, improve diagnosis and treatment in county-level hospitals of Ganzi.
3. Promote better understanding and management of epilepsy in people with epilepsy for long-term epilepsy control.

POTENTIAL OBSTACLES

1. Transportation: driving on the highest plateau on earth could be a challenge, but Ganzi hospital would assist our team with their experienced local drivers.
2. Cooperation of the local hospital, CDC and the government: a network for education, control and screening of hydatidosis and other chronic diseases has already been built and worked well in Ganzi[3]. Doctors from Ganzi People's Hospital regularly go to counties and villages to undertake chronic illness control. Thus we could use this network.
3. Continuous participation of local doctors: In our previous rural area project in Sichuan province, we found that it would be a problem to make the local doctors perform continuous recording and follow-up of people with epilepsy, thus in this project. We plan to offer them a small bonus as an incentive.

OBJECTIVES AND BUDGET

The objectives of this project are three-fold.

1. Continuous training for local primary medical workers to enhance diagnosis. During 2017, the doctors from West China Hospital and Ganzi People's Hospital will visit regularly all 18 counties in Ganzi to provide training

in epilepsy screening, diagnosis and treatment for local primary health workers.

2. Treatment, follow-up, and patient education for better epilepsy control. As Ganzi People's Hospital is the only hospital has neurologists, MRI and EEG in this area, a referral system between local hospitals and Ganzi People's Hospital will be set up. Follow-up will be carried out by local health workers. They help patients learn more about epilepsy and explain the rationale and potential benefits of treatment, which might enhance compliance. Epilepsy patient data will be recorded using our online database.
3. Providing education in local communities to promote a better understanding of epilepsy. We will translate epilepsy handbooks into Kham Tibetan dialect and promote general awareness of epilepsy in local communities.

ASSESSING EFFECTIVENESS

The effectiveness of this education and control program would be measured by pre-post knowledge changes.

The questionnaire used to measure education effectiveness is the KAP questionnaire [5] for PWEs and locales, and the epilepsy knowledge questionnaire for doctors[6]. All these questionnaires were translated into Chinese.

The questionnaire would be gathered before and after lectures to see the changes in epilepsy knowledge.

OUTCOME MEASURES

The project will be measured by

1. The numbers of local health care physicians trained.
2. The numbers of epilepsy patients screened and educated.
3. Prevalence of epilepsy in Ganzi Tibet area. Calculation formula: number of PWE/population size × 100%

4. Treatment Gap. Calculation formula: proper management rate = proper management of the number of PWEs / the number of PWE × 100%. Treatment Gap=1- proper management rate

PROJECT SUSTAINABILITY

There is a rural areas education and control project for epilepsy in Sichuan province. Each year that project will provide support to 7-8 counties in Sichuan and will last for 2-3 years then shift support to other counties.

This project will be continued by support from the project for rural areas after it finishes supporting other counties[4].

References

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