

Global Campaign Against Epilepsy: An update on the China Demonstration Project and Crest Study

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Abstract

Global Campaign Against Epilepsy conducted the Demonstration Project to improve epilepsy care in rural China from 2000 to 2004. The project involved 5 provinces and 2,455 patients with convulsive epilepsy using phenobarbital monotherapy. Forty percent of the patients were seizure free in one year and another 30% had their seizures decreased by over half. With the support of the central government, the project has currently been extended to cover 12 provinces with 11,000 patients. The long-term plan is to integrate epilepsy management into the existing primary health delivery system of China.

During the second phase of the Global Campaign Against Epilepsy in People's Republic of China, a demonstration project was conducted in the rural area from 2000 to 2004.¹ This project tested the feasibility of diagnosis and treatment of convulsive forms of epilepsy at the primary health care level using phenobarbital as monotherapy. Among a population of 3,185,067 individuals, 2,455 convulsive epilepsy patients were treated with phenobarbital. Forty percent of the patients were seizure free in one year, 30% in 2 years and another 30% had their seizures decreased by over half. No obvious side effects were reported from the patients. The results are shown in Table 1. The long-term plan of the project was to integrate epilepsy management into the existing primary health delivery system of the People's Republic of China, mainly in rural area.

After 3 years of intervention, which included antiepileptic drugs and education, the treatment gap in the project area of the 5 provinces decreased by 12.8% from 62.6% to 49.8%. Two epidemiological surveys showed that the prevalence of active epilepsy in rural China was about 4.5/1,000. Thus, there were around 4 million active epilepsy patients in the rural area of China. It would be very beneficial to the people with epilepsy if the project could be extended to the whole rural area of the nation.

With the support of the central government of China, this project has been extended to 10 provinces in 2005. Thirty four counties which covered 19 million inhabitants participated in the project. More than 1,500 doctors working in the county level and village medical workers have been trained to manage the treatment of

Table 1. China Demonstration Project: The effect of treatment in patients by the end of 6, 12, 24 follow-up months

Change in seizure frequency from baseline	6 months		12 months		24 months	
	N	%	N	%	N	%
Seizure free	919	41	644	34	347	26
Reduced by > 75%	305	14	415	22	415	31
Reduced by 51-74%	245	11	230	12	185	14
Reduced by 26-50%	162	7	146	8	99	8
Reduced less than 25%	217	10	156	8	91	7
Increased \geq 25%	369	17	306	16	187	14
Total	2217	100	1897	100	1324	100

Table 2: 2006 National project in 12 Provinces in China

Province	Screened patients	On phenobarbital
Anhui	1,514	828
Gansu	1,253	1,202
Heilongjiang	700	465
Henan	1,550	984
Hunan	2,745	1,563
Jiangsu	1,854	1,329
Ningxia	1,371	1,060
Shandong	1,635	1,220
Shanxi	1,234	Nil
Shaanxi	2,114	436
Sichuan	2,427	1,074
Yunnan	1,436	592
Total	19,833	10,753

9,498 convulsive epilepsy patients. After one year of observation, similar to the experience during the demonstration stage, 40% convulsive epilepsy patients were seizure free, another 30% had decreased seizures. In 2006, the project was further extended to 2 other provinces and 36 “new” counties. To-date, 11,000 new convulsive epilepsy patients were screened and started phenobarbital treatment.

The aims of the extended National project are as follows: (1) To promote public and professional education on epilepsy; (2) To improve diagnosis, treatment, and services of epilepsy in rural area; (3) To develop local advocacy and support groups for people with epilepsy; (4) To reduce economic and social burden of epilepsy in rural area; (5) To set up and test the model that using public health workers to control general convulsive forms epilepsy.

The methods of the extended National project are: (1) To identify and establish the project team which consists of the government officials and experts in different levels; (2) Training of local physicians and public health workers; (3) To improve the public education and public awareness of epilepsy by distribution of educational material and leaflets; radio and television broadcast, news paper reports; (4) Screening of generalized convulsive epilepsy patients by township physicians with the diagnosis being confirmed by neurologists at county level and above; (5) Using protocols of the Demonstration Project to follow up patients with phenobarbital monotherapy; (6) Data collection and analysis. The number of the generalized convulsive patients who were screened and taking phenobarbital are shown in Table 2.

In collaboration with the Liverpool University, UK, a CREST (Collaborative Research on Epilepsy Stigma) study was also conducted in China in 2005 to examine the nature of epilepsy stigma. Ethnographic approaches were used to collect evidence of the nature of stigma. The study involved conducting in-depth interviews and focus group discussions with relevant target groups. One hundred and forty three interviews and 12 focus group discussions were implemented. The data collected are presently under analysis.

REFERENCES

1. Wang WZ, Wu JZ, Wang DS, *et al.* The prevalence and treatment gap in epilepsy in China. *Neurology* 2003; 60: 1544-5.