

The Mongolian plan to overcome epilepsy treatment gap and improve epilepsy care

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Abstract

Mongolia has a population of 2.5 million, with large territory and low population density, and estimated 7,433 epilepsy patients in 2005. The Mongolian Epilepsy Society, a chapter of ILAE was founded in 2002; and Mongolian Epilepsy Association, a chapter of IBE, in 2004. A study by the Society and Association on the epilepsy care in Ulaanbaatar in 2004 showed that most of the patients were young, with long duration of seizures, and no EEG or CT brain scan. Among the many plans to overcome the treatment gap and improve the epilepsy care with measures is an enhanced educational workshop for the public and professionals at district level, to be repeated in all parts of the country.

INTRODUCTION

Mongolia is the 17th largest country in the world with its territory of 1,564 thousand square kilometers. As of the end of 2004, the population of Mongolia reached 2.5 million with 50.4% living in urban settings and the remaining 49.4% residing in rural areas. Males comprise 48.8%, and females 51.2% of the total population. Children under 15 years, adults aged 15-64 years and those above 65 years account for 30.3%, 65.7% and 4.0% of the population, respectively. The country is one of the most sparsely populated countries in the world with a population density of 1.4 persons per sq km. Mongolia is divided into 22 major administrative units, including 21 provinces and the capital city of Ulaanbaatar. Geography, topography and demographics play a critical role in Mongolia's human development. Great distances, extreme weather conditions and a sparse isolated population have all contributed to the striking spatial inequalities across the country. It is difficult and expensive to reach many of the poor in Mongolia with health care and other services because they are spread over vast distances and many are nomadic.^{1,2} Mongolia started the transition into market oriented economy in 1990.

EPIDEMIOLOGY OF EPILEPSY IN MONGOLIA

Only few epidemiological studies of epilepsy have been carried out in Mongolia. One survey done in 1993 showed that the prevalence rate was 3.9 per 1,000; 4.3 in males and 3.6 in females in the capital city Ulaanbaatar, and 4.5 per 1,000; 5.4 in males and 3.6 in females in rural areas.³

According to the national health statistical data of 2003 and 2004, the number of patients with epilepsy increased by over 800 in 2003, and in 2004 by 779 patients respectively, making the total of 7,433 patients with epilepsy in 2005. This means an annual increase by more than 10% in Mongolia.²

EPILEPSY CARE IN MONGOLIA

Neurologists, neuro-pediatricians and psychiatrists are the main professionals managing epilepsy care in Mongolia. Currently there are 130 neurologists, 8 EEGs, 8 CT scans, 1 MRI in the country. The Mongolian Epilepsy Association, a member of the International Bureau of Epilepsy since 2005, was established in 2004 following establishment of the Mongolian Epilepsy Society in 2002. Mongolian Epilepsy Society became a chapter of International League Against Epilepsy in 2003. Thanks to efforts of both Mongolian Epilepsy Society and Mongolian Epilepsy Association, the Mongolian Epilepsy Center was established in 2005 by the permission from the Ministry of Health of Mongolia. Currently, the Center is only providing outpatient care and is aiming to expand its activities in the future.

Factors that hinder epilepsy care in Mongolia are: 1) Few medical professionals specializing in epilepsy care; 2) Lack of the equipment necessary for diagnosis of epilepsy, in particular EEG facilities in a country with vast geographical spread; 3) Inadequate supply of antiepileptic drugs (AEDs); and 4) Long distance travel of patients seeking consultations in the centralized facilities in Ulaanbaatar. This leads to frequent discontinuation of AEDs which in turn causes

worsening of seizures. The number of AEDs used in Mongolia is limited. There are a significant proportion of patients who are resistant to the AEDs.^{4,5}

EPILEPSY CARE FOR PATIENTS IN ULAANBAATAR

A study on the care of people with epilepsy in Ulaanbaatar City was conducted with the participation of Health Sciences University of Mongolia, Centre for Mental health and Narcology and Mongolian Epilepsy Society between January and October 2004, with financial support from WHO. The aim was to assess the current trends of care of people with epilepsy in the city. Table 1 shows the age and sex composition of patients involved in the study. As shown, the vast majority of patients were young. Most of the patients were of low income group and low education level, with the seizures lasting for more than 10 years. Carbamazepine was the most common AED used. In the majority of patients, there was no EEG or CT scan performed.

Based on this study, the following recommendations were made: 1) There is pressing need for Mongolian health authority to formulate policies and action programmes to improve care of people with epilepsy; 2) Whereas epilepsy is regarded as neurological disease in the medical community internationally, it is still regarded as a psychiatric illness in Mongolia. This aggravates the stigma that the patients face. Administrative change is required to address this; 3) There is a pressing need to establish an epilepsy center with expertise in epilepsy care.⁶

As a follow up of the recommendations, in 2006, the Mongolian Ministry of Health included epilepsy in the list of diseases that is treated free. Whereas previous to the study, the AEDs were given free only to patients under the care of psychiatric hospitals, the neurologists in provincial and district hospitals are also allowed to prescribe the free AEDs to patients with long

history of seizures. An outpatient epilepsy center was established in 2005 next to the Mongolian Epilepsy Society, with permission from the Ministry of Health.

FURTHER PLANS TO OVERCOME EPILEPSY TREATMENT GAP AND IMPROVE EPILEPSY CARE

In 2006, the Mongolian Epilepsy Society, with the Epilepsy Center and Mongolian Epilepsy Association started an enhanced health education workshop on epilepsy among the general public and the professionals who looked after epilepsy in the district levels (“Quality of Life”). The workshop involved 3-4 lectures with drama and video presentations. It is hoped that similar program can be repeated in all parts of the country. The Organizers welcome international partnership in this venture.

Other plans to overcome epilepsy treatment gap and improve epilepsy care include continuing to encourage the Government to place epilepsy care on higher priority; to recommend to the Mongolian Ministry of Health to register the new AEDs and make the drugs available to the public; to work with neighbor epilepsy organizations and pharmaceutical manufacturers on better supply of AEDs; to further study the epidemiology of epilepsy in Mongolia; to continue to develop the Epilepsy Centre; to enhance the training of epileptologists and social workers; to establish epilepsy treatment guidelines; to improve diagnosis of epilepsy in the rural areas by using mobile EEG; to expose the public and patients to the valuable experiences of epilepsy sufferers in other countries; and to have a demonstration project in Mongolia under the Global Campaign Against Epilepsy.

It is hoped that with all the above measures, we can rapidly reduce the stigma, and improve the quality of life of people with epilepsy in Mongolia.

Table 1: Age and sex structure of epilepsy patients in Ulaanbaatar

	Age								Total	
	<15 years		15-34 years		35-64 years		≥ 65 years			
	n	%	n	%	n	%	n	%	n	%
Male	71	4.5	409	26.1	408	26.1	8	0.5	896	57.3
Female	64	4.1	308	19.7	290	18.5	7	0.4	669	42.7
Total	135	8.6	717	45.8	698	44.6	15	1.0	1,565	100.0

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