

NEUROLOGY IN PRACTICE

Epilepsy care in Mongolia: Current problems and future prospects

Yasumichi Koide, Yushi Inoue, *Borgil Bayasgalan

National Epilepsy Center, Shizuoka Institute of Epilepsy and Neurological Disorders, Shizuoka, Japan;
*Second General Hospital, Ulaanbaatar, Mongolia

Abstract

Current problems of epilepsy care in Mongolia consist of shortage of health care personnel, limited diagnostic facilities, insufficient supply of the antiepileptic drugs, and difficulty in access to medical services. There is also lack of epilepsy knowledge among the professionals, patients, families as well as the public. There are many patients with epilepsy caused by preventable head trauma. Several initiatives to improve epilepsy care took place in Mongolia in recent years, including educational seminars for physicians in corporation with international organizations, workshops for professionals, patients and families, and training of Mongolian physicians overseas. Although epilepsy care in Mongolia has been improving steadily in the recent years, continuing international cooperation will further improve the quality of care.

INTRODUCTION AND CAUSES OF EPILEPSY

Mongolia has the 17th biggest area (1,564,100 km²) in the world. Its population is approximately 2.64 million with one million living in the capital city of Ulaanbaatar. The population is relatively young with 5.4% over 60 years of age. It has one of the lowest population densities (about 2 persons/km²) in the world. The GNP in 2008 was USD 3,096 billion, with per capita income of USD 1,288.¹ In recent years, there has been rapid growth of mining industry, with remarkable economic development generally.

In Mongolia, medical services have been basically provided free of charge under socialism since 1924. The market economy was introduced in 1990 and the medical insurance system in 1994. Nowadays, medical treatment is not equally distributed. The quality of care depends on the geographical location and the economic affordability of the patients.

According to the national health statistics in 2005, 7,433 people were diagnosed as epilepsy and it was reported that the number of patients has been increasing by 10% every year.^{2,3} However, there are reservations on the accuracy of such surveys, as expressed by the International Bureau for Epilepsy (IBE).³

Uuriintuya *et al.* reported on 210 epilepsy patients who underwent medical examination at Mongolian National University Hospital in 2003 and 2004.⁴ There were 128 males and 82 females. Their ages were between 3 and 70 years, about half were from the 15 - 34 years age group. The cause of epilepsy was, in order of frequency, head trauma 39%, birth trauma 21%, central nervous system infection 9.5%, cerebrovascular disease 5.2% and brain tumor 4.3%. There were 21% cryptogenic cases which probably includes idiopathic epilepsy.

The proportion from head trauma is remarkably high when compared with 5% reported from neighboring China. This might be due to motor vehicle accidents in the urban areas where motor vehicle traffics have been increasing rapidly in the recent years, and accidental falls from the horses in the rural area where traditional nomadic life style is common. Dr. Lai of IBE reported that head trauma due to falling from the horses accounted for more than 50% of epilepsy in the rural hospital of Zuun Mod.⁵

CURRENT PROBLEMS OF EPILEPSY CARE

Tovuudorj in 2007² highlighted the main problems of epilepsy care in Mongolia to be: 1) Lack of

specialists for epilepsy; 2) Lack of diagnostic facilities especially EEG; 3) Inadequate supply of antiepileptic drugs; and 4) Difficulty of access to health care facilities. These are further elaborated as below:

1) Personnel

There are about 200 neurologists in Mongolia, but only few in Ulaanbaatar are interested in epilepsy. Pediatric neurologists and psychiatrists show even less interest, though they are also responsible for managing epilepsy patients. Physicians often have inadequate knowledge on use of antiepileptic drug. Many physicians, including neurologists, prescribe antiepileptic drugs in insufficient doses, which may have contributed to poor control of seizures. Other than Ulaanbaatar the capital, there are virtually no epileptologist in practice. It is also very difficult to obtain the service of neuroradiologist to assist in the diagnostic work up of the patients.

Epilepsy surgery was first performed in 1970s, and there were 10 cases of epilepsy surgery done. However, there was no surgery for the following 30 years, with only a few richer patients able to seek surgical treatment in neighboring China, Korea and Japan.

It is even more difficult to have allied health care personnel involved in epilepsy care. This is partly because it is difficult for co-medical professionals to obtain training in epilepsy management in Mongolia.

Textbooks or journals on epilepsy are in short supply, reflecting generally a poor resource for knowledge in epilepsy. It is generally observed that many physicians who participated in epilepsy workshops were keen to receive further training abroad, and to receive other assistance from overseas. The same interest is also seen among the co-medical professionals.

2) Diagnostic facilities

Electroencephalography (EEG) and neuroimaging technologies such as CT and MRI are very important modern diagnostic tools for epilepsy. In 2009, there were about 10 EEGs, 13 CTs, and 2 MRIs in Mongolia. The MRIs were installed only recently. Most of these facilities are based in the hospitals in Ulaanbaatar the capital. These facilities are not only unevenly distributed, they are also difficult to access due to high cost, as these tests are not covered by the health insurance. For example, a CT examination costs USD 50, which is equivalent to the monthly salary of a

newly graduated physician in Mongolia. The MRI examination may cost up to about USD 200. Therapeutic monitoring with serum concentration of antiepileptic drugs was only recently available in Ulaanbaatar.

3) Supply of the antiepileptic drugs

There are currently about 30 drugs available for treatment of epilepsy worldwide. In Mongolia presently, only carbamazepine, sodium valproate, phenobarbital and recently lamotrigine are available. Of these, only carbamazepine and phenobarbital are manufactured locally.

Nimaga *et al* reported the effectiveness of phenobarbital in rural Mali.⁸ Phenobarbital is also available at low cost in Mongolia. However, there are concerns by physicians of the quality of phenobarbital as well as other drugs made locally. Although it is not difficult to have drugs imported from overseas, the cost is high relative to the income of the patients. As the cost of antiepileptic drug is not covered by public insurance, there are many cases where the treatment was discontinued due to economic reasons.

4) Access to medical services

In Mongolia, the medical service is categorized into three levels. The first level deals with mainly primary care and is provided by family physicians. Medical services of this level are termed "Soum", meaning "village" in Mongolian. The second level consists of hospitals with some equipment called "Aimag", which are located according to administrative districts. The third level consists of three regional centers and 17 specialized hospitals.

Although there are multiple levels of hospital including primary care services and district level hospitals distributed all over the country, epilepsy patients often have to travel to hospitals in Ulaanbaatar, which is the main center of medical resources, to seek diagnosis and treatment. This is due to inadequate personals and facilities outside the capital as described above. Some patients have to travel for more than 1,000 km to reach Ulaanbaatar. As the public transportation system is still not well developed, the travel can be harsh, and the cost high.

One of the problems peculiar to medical care in Mongolia is related to the nomadic life style of a large segment of the population. These populations move in this country with vast land in search of pastures according to the seasons. As such, the epilepsy patients may have to travel hundreds of

kilometers by horse to reach the medical center. This hampers stable long-term compliance to treatment.

The lack of general knowledge of epilepsy is another problem. Epilepsy is frequently regarded by the public as spiritual and as mysterious reaction, resulting in serious stigmatization to the patients. The traditional treatment including shamanistic therapy may conflict with modern treatment, resulting in poor compliance to antiepileptic drugs. IBE report⁵ indicated that epilepsy patients are apt to avoid or restrain from going out in public, for fear of the public seeing their seizures and thus more stigma and prejudice. The people with epilepsy can rarely get jobs even if they are qualified or trainable.

Patients themselves also lack knowledge of epilepsy. This contributes to irregular intake of antiepileptic drugs. Some patients continue to drive motor vehicles despite having frequent seizures.

ACTIVITIES FOR EPILEPSY CARE

WHO, International League against Epilepsy (ILAE) and IBE have cosponsored first phase of the Global Campaign Against Epilepsy “Bring epilepsy out of the shadows” since 1997.⁶ The first phase was primarily devoted to increase public and professional awareness of epilepsy as a treatable brain disorder, and raise public acceptance of epilepsy. The second phase of the Global Campaign was launched in 2001. It is devoted to promoting public and professional education on epilepsy, identify the needs of people with epilepsy on a national and regional basis, and encourage governments and departments of health to address these needs. Accordingly, many activities have been carried out in Asian countries. Activities in Mongolia began in 2002 with the organization of training seminar.⁷

1) Educational activities

In 2002, in cooperation with Health Sciences University of Mongolia (HSUM), a two-days seminar on diagnosis and treatment of epilepsy was held. There were about 50 participants consisting of neurologists, psychiatrists and pediatricians. There was also case discussion presented by physicians from HSUM. This seminar resulted in the formation of Mongolian chapters of ILAE and IBE in 2004.

Since then, several other seminars and workshops were organized by the Mongolian ILAE and IBE chapters, some of which were

also participated by international expert in epileptology. One of the highlights was the Seminar in 2007 in Ulaanbaatar, organized jointly by HSUM; First, Second, and Third Clinical Hospitals of Mongolia; Mongolian Epilepsy Society, Mongolian Association of Neurologists and National Epilepsy Center of Japan. About 150 physicians from Ulaanbaatar as well as nationwide participated in this clinical conference, consisting of lectures and discussions. The news of the Seminar was also announced and reported in the local newspaper. This helped to enhance the interest of epilepsy among the general public.

These activities certainly helped to improve the knowledge on epilepsy and attitude toward epilepsy among the physicians in Mongolia, even though the diagnostic facilities and antiepileptic drugs remained limited.

2) Training of physicians abroad

Commission on Asian & Oceanian Affairs of ILAE has been offering fellowships to young Asian physicians for training in epilepsy overseas since 2003. The Commission has also accepted applicants from Mongolia. This provided opportunities for Mongolian physicians to have training abroad. Through the fellowships, the physicians improved their skill on EEG and imaging, use of antiepileptic drugs, and comprehensive management of epilepsy. Upon return to Mongolia, the physicians also helped to initiate better epilepsy care system for their patients. Long term, the improvement in the epilepsy care system may be just as important as skills on management of individual patients. All these should be important learning objectives of future fellowships.

3) Educational activities to other health care personals, patients and families

The Mongolian Epilepsy Association has organized a very unique and important activity in 2006. This “Quality of Life Program” was organized with the First Clinical Hospital and Neurology Trainee Club.⁵ The Program involves workshops on epilepsy care for family physicians, nurses, patients, the patients’ families and administrators from the district health care units. This educational activity was epoch-making in improving the general knowledge of epilepsy. The program was carried out in two suburbs of Ulaanbaatar. Regrettably it has not been continued due to inadequate financial resources.

In November 2008, the first meeting for patients

with epilepsy and their families was organized in Ulaanbaatar by the local physicians with the Mongolian Ministry of Health. It was also broadcasted by radio. Many among the public were impressed that patients with epilepsy were for the first time able to express their feelings and experiences to the public.

FUTURE PROSPECTS

In the report on epilepsy care in rural Africa, Nimaga *et al* stressed the importance of overcoming the shortage of physicians and accessibility to health care facilities at the local level. At the national level, epilepsy should be placed at the same level of priority as leprosy and tuberculosis. At the international level, epilepsy control program providing free treatment, similar to the programs developed by WHO for the eradication of leprosy and onchocerciasis, should also be organized.⁸ These comments are probably also relevant to Mongolia, which shares many common problems similar to other developing countries.

In Mongolia, one of the most serious problems is lack of adequately trained health care personal in epilepsy care. Regional or international epilepsy organizations can help by providing opportunities in training to empower the physicians and co-medical professionals.

The availability of modern diagnostic facilities for epilepsy is usually dependent on the economic development and healthcare policies of the government authorities. As for EEG, being less costly compared to CT scan and MRI, may be acquired with the help of neighboring countries. In fact, there are currently two EEG machines in Mongolia that were donated from Japan, which are running well. In Mongolia, mobile EEG machine may be more practical in the rural area.

A stable supply of antiepileptic drugs is essential in good epilepsy care. It is thus crucial to expand the insurance coverage to facilitate an uninterrupted supply of antiepileptic drugs. International cooperative effort may also be helpful to improve the supply of antiepileptic drugs.

In view of the Mongolia's large geographical expanse, a good network that facilitates exchanges of the patient's information is essential. An epilepsy centre with facilities for diagnosis and care integrated with the network may also be beneficial. As in elsewhere, such a centre should also be involved in training and research, as well as direct clinical care, supplementing the role of

the University. Development of regional centers in different parts of the country may also be helpful.

Public education to reduce head trauma is essential in overall management of epilepsy, as post-traumatic epilepsy accounts for a significant proportion of epilepsy in Mongolia. The reduction of head trauma will of course have many other benefits.

As in other countries, public education on epilepsy is essential to reduce the stigma and discrimination towards epilepsy patients. The authors believe that the international community can also assist the many local initiatives by the Mongolian Epilepsy Society.

In conclusion, we described the development of epilepsy care in Mongolia in the recent years, its current situation and future prospects. We believe there are many areas where international cooperation can help to improve epilepsy care in Mongolia.

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