

Changing name of epilepsy in Korea; cerebroelectric disorder (*noi-jeon-jeung*, 뇌전증, 腦電症)

My Epilepsy Story

*Heung Dong Kim, *Hoon-Chul Kang, †Sang Ahm Lee, ‡Kyun Huh, and §Byung-In Lee

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SUMMARY

Public misconception of epilepsy may lead to significant stigma to the disease itself, thereby causing impaired quality of life in people with epilepsy. Traditionally, epilepsy has been considered to be the consequence of evanescent spiritual forces, and even demonic possession (in many countries). The names of epilepsy in some East Asian countries originated from China, and include madness in their meaning. We recently changed the Korean name of epilepsy, *gan-jil* (간질, 癲疾: a crazy, convulsive disease having meaning similar to 癲癇), to a neutral and scientifically explainable name: *noi-jeon-jeung* (뇌전증; 腦電症; cerebroelectric disorder). We expect that changing the stigmatized name of epilepsy to a neutral and scientific term with the meaning of cerebroelectric disorder will reduce the social stigma by understanding of epilepsy as one of the neurologic disorders.

KEY WORDS: Cerebroelectric disorder, Renaming.

Epilepsy is not limited to a medical condition, but it extends to difficulty with various aspects in daily social life in people with epilepsy (PWE). The magnitude of discrimination against PWE, or stigma, is the most important factor affecting the quality of life of PWE,¹ which may vary in different countries.² Misconceptions about epilepsy lead to a negative attitude from the public, which creates barriers to friendships, job search, marriage, and many other social relationships.

NAMES OF EPILEPSY AND NEEDS OF NEW NAMES IN ASIAN COUNTRIES

The word epilepsy is derived from the ancient Greek ἐπιληψία *epilēpsía*, which was from ἐπιλαμβάνειν *ēpilambánein* “to take hold of, to seize.” However, in the past, epilepsy has been associated with religious experiences and

even demonic possession, and in most cultures, persons with epilepsy have been stigmatized, shunned, or even imprisoned. Stigma continues to this day, in both the public and private spheres.^{3,4}

The story of the Chinese history of epilepsy has its debut approximately in the eighth century medical texts. These clearly described epileptic semiology under two terms: 癲, *dianji* and 癇, *xian*, which were eventually joined together as 癲癇, *dian-xian*. Unfortunately after many years, the meaning of the prefix word *dian* became corrupted and associated with madness. Furthermore, the Chinese name became transformed to have proximity to animals. Subsequent names described the disease as the bizarre movements of goats or pigs. The names of animals suggested links to animals, and the word *dian* carried the strong implication of psychiatric illnesses.

In the various regions in North East Asia, that is, China, Hong Kong, Taiwan, and Japan, as well as in some Southeast Asian languages, that is, Burmese, Khmer (Cambodia), Lao, Malay, and Thai, the naming of diseases has been influenced by the ancient Chinese medical literature and concepts, as shown in Table 1.³ This may partly contribute to the observations that despite wide adoption of modern scientific medicine, the misconceptions about epilepsy as a psychiatric disorder persist in the Asian countries; up to 24–57% of the Asian population think that epilepsy is a mental illness.

In Malay language, the term “gila babi” means pig madness, which has negative connotations both socially and in

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*Department of Pediatrics, Pediatric Epilepsy Clinic, Severance Children’s Hospital, Epilepsy Research Institute, Yonsei University College of Medicine, Seoul, Korea; †Department of Neurology, Ulsan University College of Medicine, Seoul Asan Hospital, Seoul, Korea; ‡Department of Neurology, Ajou University School of Medicine, Suwon, Korea; and §Department of Neurology, Severance Hospital, Epilepsy Research Institute, Yonsei University College of Medicine, Seoul, Korea

Address correspondence to Heung Dong Kim, Department of Pediatrics, Pediatric Epilepsy Clinic, Severance Children’s Hospital, Epilepsy Research Institute, Yonsei University College of Medicine, Seoul, Korea. E-mail: hdkimmd@yuhs.ac

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Table 1. Epilepsy in the various Asian languages

Language (Country)	Name	Meaning	Stigmatizing	Change
Chinese (China)	癲癇 (癲癇)(dien xien) or 洋癲風 (yang dian feng)	Madness or goat madness	++	
Chinese (Taiwan)	癲癇 (dian xian)	Madness	++	
Chinese (Hong Kong)	癲癇 (dian xian)	Madness	++	腦癇症 (nao xian zhen)
Japanese	Tenkan (てんかん; 癲癇)	Madness	++	
Korean	Gan-jil (간질; 癲疾)	Mad sickness	++	Noi-jeon-jeung (뇌전증; 腦電症; cerebroelectric disorder)
Mongolian	Unalt - tatalt	Madness, convulsion	++	
Malay (Malaysia/Indonesia)	Gila babi	Mad pig; mad pig disease	++++	Penyakit sawan or epilepsi
Lao	Sak pa moo	Sickness mad pig; mad pig disease	++	
Thai	Sok lom bai	Sickness mad pig; mad pig disease	++	
Burmese (Myanmar)	Wet you pyan yawga	Mad pig disease	++	
Khmer (Cambodia)	Chhkourt chrouk	Mad pig disease	+++	
Tagalog (Philippines)	Kumbulsyon	Convulsion	○	
Cebuano (Philippines)	Baboyon	Pig that has gone mad	++	
Tetum (Timor Leste)	Bibi maten	Dead goat	++	
Tamil	Valippu	Tremor, jerk	○	

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religion. The name of epilepsy in Malay has therefore been changed from “gila babi” to “penyakit sawan” (seizure disorder) or “epilepsi” (epilepsy). *Penyakit sawan* has been well accepted by the professionals as well as the public, and is currently used widely in Malaysia.

Because of the influence of traditional Chinese medicine in Korea, and the sharing of the original idiographic-based written scripts, the name of epilepsy in the Korean language *gan-jil*, 간질, 癲疾, is similar to the name for epilepsy in Chinese. That is, “*gan*” in Korean is same as the word *xian*, 癲, in the written Chinese script, although the pronunciation and the phonetic-based script are different. Therefore, the association with insanity is also present in the Korean terminology. In Korea, the word “*gan*” remains a common term to describe a crazy or mad person.

Apparently, there have been attempts to change the name of epilepsy in various countries in Asia. In 1980, Japanese epileptologists conducted a survey for “the action for epilepsy renaming,” but 50.1% of respondents were against the proposal. In 2009, the Chinese Chapter Against Epilepsy (CAAE) conducted a campaign to have the public choose a new name, but the attempt was not successful due to differences in opinions among board members. The Hospital Authority of Hong Kong, China, successfully changed the name from “Dian xian (癲癇)” to “Nau xian zheng (腦癇症)” in 2010, which was same name proposed by the Korean Epilepsy Society (KES).

Therefore, “Epilepsy Renaming” has been a hot target for epilepsy campaigns in many countries of Asia; *gan-jil* (간질, 癲疾: a crazy, convulsive disease having a meaning similar to 癲癇) was the previous name for epilepsy in Korea,

which was replaced by a new name, *noi-jeon-jeung* (뇌전증; 腦電症; cerebroelectric disorder).

PROJECT OF “EPILEPSY RENAMING IN KOREA”

The project of Epilepsy Renaming was officially launched on June 8, 2007, and it was successfully completed on June 19, 2011.⁵ The background and the progress of “Epilepsy Renaming” were introduced with brief remarks on future plans of the KES and Korean Epilepsy Association (KEA).

This project was initiated by a proposal from Professor Kyun Huh, the president of KEA, with the “Epilepsy Renaming Joint Task Force” of KES and KEA, which was organized in August 2008. “Cerebroelectric disorder” (*noi-jeon-jeung*, 뇌전증, 腦電症) was finally chosen as the new name, and it was approved by the Korean Medical Association in May 2010. It subsequently became a “Legal Language” replacing the old term (*gan-jil*, 간질, 癲疾), with the approval from the National Assembly in June 2011 (Table 2).

The new name, “cerebroelectric disorder; *noi-jeon-jeung*,” was chosen on the basis of satisfying the criteria for (1) terminology at neutral position, (2) terminology implying a scientific basis, (3) terminology being easily differentiated from words of resemblance (e.g., convulsion, fits, spasm, and so on), (4) terminology easy to use as both a noun and an adjective, and (5) terminology being more likely to be acceptable in global epilepsy communities affected by cerebrovascular disease, neuromuscular disorder, and so on. Although this adopted term can help avoid

Table 2. Progress of the project of “Epilepsy Renaming”

2007.06.08	Korean Epilepsy Association (KEA) proposed the Project of “Epilepsy Renaming”
2008.08.28	Organize “Epilepsy Renaming Task Force”
2008.09.01	Appeal to members and patients for submission of New Names to replace 癇疾 (<i>gan-jil</i>) through newspapers, mails, home pages, and internet website of NGOs
2009.06.04	A ballot at the General Assembly of Korean Epilepsy Society (KES): “Cerebro-electric disorder” (<i>noi-jeon-jeung</i> , 뇌전증, 腦電症) was chosen as the new name of epilepsy
2009.10	Official request of opinions about the “New name of Epilepsy: “Cerebro-electric disorder” (<i>noi-jeon-jeung</i> , 뇌전증, 腦電症) to seven relevant Academic Societies
2010.05.03	Korean Medical Association officially approved “cerebro-electric disorder” (<i>noi-jeon-jeung</i> , 뇌전증, 腦電症) as the new name replacing <i>gan-jil</i> (간질, 癇疾)
2011.06.24	Officially changed the Korean name of KES and KEA with <i>noi-jeon-jeung</i>
2011.06.29	“Cerebro-electric disorder” (<i>noi-jeon-jeung</i> , 뇌전증, 腦電症) become a “Legal Language” by the approval at the National Assembly

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misperceptions about epilepsy related to insanity or spirit possession, it would be more ideal to select a name that is also able to reflect the modern scientific understanding of the disease, such as a “brain electrical storm,” or “brain electrical disorder.” Such a term will lead the user to understand the disease as a neurologic disorder affecting the brain, with a physiologic abnormality in the brain electrical activity. One example of changing the name of a disease to reflect modern scientific understanding is cerebrovascular disease, which replaced “stroke” and “cerebrovascular accident.”

FURTHER PLANNING OF EPILEPSY RENAMING

KES and KEA held a ceremony celebrating the epilepsy renaming event “Declaration of New Name, *noi-jeon-jeung*,” on June 7, 2012, with attendance of both presidents from the International League Against Epilepsy (ILAE) and International Bureau of Epilepsy (IBE); the presidents of regional chapters of Japan, China, Taiwan, Singapore, Philippines, and Thailand; the president of the Korean Medical Association; and many other representatives from related academic societies and nongovernmental organizations (NGOs). It was the first announcement of changing the Korean name of epilepsy to the public through the ceremony, press conference, and academic activities in the 17th Annual Congress of KES and KEA. This event was introduced on nationwide TV, in daily newspapers, and in many medical news magazines.

KES is planning public educational programs to reduce the stigma through media and social campaigns. Lectures and educational videos are other important ways for school children and teachers to become more knowledgeable and familiar with the disease of epilepsy at an early age, prior to stigmatization.

More active educational programs for patients and families should be promoted through workshops, courses, and camps by enhancing activities from patient support groups and NGOs.

CURRENT PROGRESS

PWE prefer to use the new name for epilepsy “*noi-jeon-jeung*; cerebroelectric disorder,” in place of the old name, even though it is not yet well known to the public. There are increasing numbers of activities that help PWE to reduce the stigma through media and social programs with the new name of epilepsy in Korea.

CONCLUSIONS

Names of epilepsy often reflect perceptions of the language speakers, which may have resulted in stigma that had significant impacts on the life of PWE. It is obvious that there may be significant benefit to changing the names of epilepsy that contribute to stigma in the local culture, to a nonstigmatized neutral name without implications of mental illness or association with animals. Although such change may be difficult to implement, and some may feel that it is ineffective without a change in the public attitude toward epilepsy, the Project for Epilepsy Renaming can be accomplished with strong support from professionals and intimate collaboration with regional and international epilepsy communities.

DISCLOSURE

None of the authors has any conflict of interest to disclose. We confirm that we have read the journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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