

## VIEWS AND REVIEW

# Name of epilepsy, does it matter?

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### Abstract

Names of epilepsy may reflect misconception and contribute to stigma in epilepsy. Epilepsy in Chinese (*dian xian*, madness; *yang dian feng*, goat madness) is associated with insanity and animals. Because of the influence of Traditional Chinese Medicine, the names of epilepsy in certain East and Southeast Asian languages also convey the image of insanity and associated with animals. In the case of Malay who are mainly Muslim, it is also religiously unclean (*gila babi*, mad pig disease), contributing to stigma of the epilepsy patients. Of the East and South East Asian languages, epilepsy in Chinese, Japanese, Korean, Malay, Lao, Thai, Burmese, and Khmer (Cambodia) has the connotation of madness. The names of epilepsy have been replaced by a neutral terminology in Malay in Malaysia, and recently also for Chinese in Hong Kong, and Korean in South Korea.

### INTRODUCTION

People with epilepsy are burdened by a multitude of social, psychological and economic consequences of stigmatization which leads to poor quality of life.<sup>1,2</sup> The effect of stigma is nicely summarized by Boer as follows: children with epilepsy may be banned from school, adults may be barred from marriage, and employment is often denied, even when seizures would not render the work unsuitable or unsafe.<sup>2</sup> This results in marginalization of the people with epilepsy in the society.

In medical anthropology, the Western Civilization is viewed as depending mostly on a naturalistic explanation of illness. There is also strong emphasis on basic human rights. This probably minimizes the misconception and stigma in epilepsy, which may lead to better attitudes by the public. In contrast, in many parts of Asia and Africa, the non-scientific explanation is still prevalent. Epilepsy may be viewed as spiritual, contagious or a form of insanity. It is not surprising that these areas also have poorer attitudes towards epilepsy.<sup>3</sup>

The misconceptions in epilepsy may have reflected in the name chosen for epilepsy in their languages. In turn, these names may reinforce the misconceptions in epilepsy and contribute to its stigmatization.

### NAMES OF DISEASES

Diseases are often named based on concepts of its essential nature, based on the main symptoms and attributed causations of the disease. For example, for diabetes mellitus, “Diabetes” originated from Greek which means ‘siphon’, indicating the emaciation of the body from flowing out of the body fluid. “Mellitus” is from Latin which means ‘honey’, from the sweet urine.

Epilepsy, which is a complex disease to understand prior to the era of electroencephalogram, was also given names that reflect its attributed causation and manifestation. In the Western world, though there was biological explanation, epilepsy was commonly accepted as spiritual or mental, as reflected by the names such as ‘caducus’ (the falling sickness), as well as ‘demoniacus’ and ‘lunaticus’.<sup>4</sup> The term ‘Epilepsy’, first used by Avenenna, a famous Persian physician, was coined from a Latin word meaning ‘being possessed by an outside force’.<sup>5,6</sup> However, with the development of modern medicine, the word ‘epilepsy’ was given a new definition based on scientific concepts, and no longer perceived as spiritual or mental.

### EPILEPSY IN CHINESE, THE ORIGINAL MEANING

In the various regions in North East Asia, i.e.,

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China, Hong Kong, Taiwan, Japan and Korea, the naming of diseases has been influenced by the ancient Chinese medical literatures and concepts, as shown in Table 1. Epilepsy was described in “the Medical Classic of the Yellow Emperor” (Huang Di Nei Jing 黄帝内经), published more than 2000 years ago as *dianji* (癡疾) and *xian* (癩).<sup>7</sup> The word *dian* was subsequently associated with madness. The terminology was further described in a Ming Dynasty dictionary (正字通) as a disorder of the internal organs secondary to wind and associated with different kinds of animals e.g. goat and pig (癩有風熱, 小兒有五癩, 五臟各有畜所屬).

Because of the influence of the Traditional Chinese Medicine (TCM) in Korea and Japan, and the sharing of the original idiographic based written scripts, the names of epilepsy in Korean and Japanese languages are similar to the name for epilepsy in Chinese. That is, ‘Gan’ in Korean is same as the word *xian* (癩) in the written Chinese script, and ‘tenkan’ in Japanese kanji is same as *dian xian* (癡癩) in Chinese script, though the pronunciation and the phonetic based scripts (tankan, ganjil) are different. Thus, the association with insanity is also present in the Korean and Japanese terminologies. Furthermore, the terminology for epilepsy in these regions continues to be used to describe insanity currently. In China, the word ‘dian’ remains a common term to describe a crazy or mad person. In Japan, ‘Ten’ of the word *tenkan* is also frequently used in psychiatry to indicate madness, e.g. an insane person is called ‘fu-ten-nin’.<sup>8</sup> This may partly contribute to the observations that in contrast to the West, despite wide adoption of the modern scientific medicine, the misconceptions of epilepsy in the Asian countries as a psychiatric disorder persists, with as high as 24-57% of the Asian population think that epilepsy is a mental illness.<sup>9</sup> The name epilepsy in Mongolian *unalt-tatal*, also has the connotation of madness. (Tovuudorj A, personal communication)

### NAMES OF EPILEPSY IN OTHER ASIAN LANGUAGES

In some Southeast Asian languages, i.e., Burmese, Khmer (Cambodia), Lao, Malay and Thai, the names for epilepsy are also associated with madness and animals, as shown in Table 1. This is likely to be due to the influence of the TCM concepts. In the Malay language, the term ‘gila babi’ means pig madness. As majority of the Malays are Muslims, besides the association

with insanity, the term also results in religious stigmatization because pig is perceived as religiously not “halal” or unclean. This name has resulted in both social and religious stigmatizations in the populations that adopt Malay language and practice Muslim religion. In the Philippines, most of the names used in the various dialects refer to convulsion. However, in the Cebuano dialect spoken in some parts of Visayas (central Philippines) and Mindanao (southern Philippines), “boboyon” refers to a pig that has gone mad, thus would be stigmatizing. Casanova-Gutierrez has summarized the language used in epilepsy in Philippines<sup>10</sup>, showing the rich varieties of language used in the country. In East Timor, where the most widely spoken language is Tetum, the usual term is *bibi maten*, which means dead goat.<sup>11</sup> It is either because they sound like a goat when having a seizure or that eating goat meat gives you epilepsy because goats convulse when they are slaughtered. *Manu maten*, which means dead chicken refers to people who have cerebral palsy and epilepsy. The official term is “Epilepsi” but *bibi maten* continues to be used. (Ernest Somerville, personal communication). It is interesting that the terms in Tectum still have some Chinese medicine concept of relating to different animals, but “madness” as a term and concept has been dropped, to be replaced by “dead”, which is probably also stigmatizing.

### HOW DOES NAME OF EPILEPSY CONTRIBUTE TO STIGMA

We believe these names convey concepts which are not only erroneous, but also contribute to stigma. Stigma (from stigmata, marks, or blemishes) means being negatively regarded because one is different from the norm. All societies develop norms, and those who are perceived as differing from them are stigmatized, or rejected as abnormal, and therefore marginalized (i.e., not admitted into normal social interaction). This is also related to the human need for predictability. Most people have no experience of epilepsy and do not know what causes it. The uncertainty caused by an inability to predict causes insecurity. Fear of the unknown arouses negative feelings, which we try to reduce by rejecting its cause - i.e. the people with epilepsy.<sup>12</sup> With names of epilepsy that convey the image of insanity and religiously unclean, it evoked from the public that the epilepsy patients are abnormal, and the emotion of insecurity from the unknown, thus contributing to stigma of the epilepsy patients, and their isolation from the society.

**Table 1: Epilepsy in the various Asian languages**

| Language (Country)          | Name                                       | Meaning                           | Stigmatizing | Change  |
|-----------------------------|--|-----------------------------------|--------------|---|
| Chinese (China)             | 癲癇 (癲癇)(dian xian) or 羊癲風 (yang dian feng) | Madness or goat madness           | ++           |   |
| Chinese (Taiwan)            | 癲癇 (dian xian)                             | Madness                           | ++           |   |
| Chinese (Hong Kong)         | 癲癇 (dian xian)                             | Madness                           | ++           | 腦癲症 (nao xian zhen)                                 |
| Japanese                    | Tenkan (てんかん; 癲癇)                          | Madness                           | ++           |   |
| Korean                      | Gan-zil (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                        | O            |   |
| Cebuano (Philippines)       | Baboyon                                    | Pig that has gone mad             | ++           |   |
| Tetum (Timor Leste)         | Bibi maten                                 | Dead goat                         | ++           |   |
| Tamil                       | Valippu (வலிப்பு)                          | Tremor, jerk                      | O            |   |

**SHOULD THE NAMES IN EPILEPSY BE CHANGED? THE RESPONSES FROM MALAYSIA, HONG KONG, KOREA, JAPAN AND CHINA**

As mentioned above, in Malay language, the term ‘gila babi’ means pig madness, which has

negative connotation both socially and in 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 widely used in Malaysia.

In Hong Kong, China, the name for epilepsy, *dian xian* (癲癇) was replaced by *nao xian zheng* (腦癲症, epilepsy), on 27<sup>th</sup> June 2010 by the Hospital Authority of Hong Kong, which is more consistent with modern scientific concept, value-free with no linkage to psychiatric disorders or animals.<sup>13</sup> The change was made to facilitate equal opportunity for people with epilepsy without discrimination. Being an open cosmopolitan city of relatively small population, it will be a challenge to have the general public adopt this in common usage.

In Korea, the name for epilepsy, *gan-zil* (간질, 癲疾, mad sickness) was replaced by a new name, *Noi-jeon-jeung* (뇌전증, 腦電症, cerebroelectric disorder) on 19<sup>th</sup> June 2011.<sup>14</sup> The epilepsy community in Korea felt that *gan-zil* represent a socially stigmatized concept of a 'forbidden disease', and therefore the most effective way of challenging the negative attitudes toward epilepsy is to rename epilepsy using a neutral terminology that has a modern scientific basis. The new term was subsequently approved by the Korean National Parliament and will be promoted into the public language through campaign and public education.

In Japan, in a survey of the attitudes of 349 Japanese epileptologists in 1980, 35.2% thought that it was necessary to change the term *tenkan*, and 32.7% agreed to use the term 'epilepsy' instead of *tenkan*. However, many of the respondents thought that a change in terminology without a corresponding change in public attitudes will be useless, and 50.1% did not think change of the term *tenkan* was necessary.<sup>8</sup> *Tenkan* continues to be the used as epilepsy in Japanese today.

In mainland China, efforts have been made in the past few years by the China Association Against Epilepsy (CAAE) to change the terminology of *dian xian* (癲癇). A nation-wide campaign among the public was carried out in 2009 to choose a new name. A few terminologies were selected as "candidates". However, because of differences in opinion within the CAAE Board, and complicated procedures for approving changing of medical terminology in China, a definitive decision is yet to be reached.

#### HOW SHOULD THE NAME BE CHANGES?

It is obvious that names of epilepsy, when contribute to stigma in the local culture, should be changed to a non-stigmatized name, though the change may be difficult to implement, and some may feel that it is ineffective without a change in the public attitudes toward epilepsy.

How should a new name be chosen? Based on the guideline used by the Korean epilepsy community<sup>12</sup>, the new name must be neutral without implication of a mental illness or association with animals. In Malay, the adopted name *penyakit sawan* (seizure disorder) is based on the symptom. Although this adopted term is able to avoid misperceptions of insanity or spirit possession, it would be more ideal to give 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'. These terms will lead the user to understand the disease as a neurological disorder affecting the brain, with physiological abnormality in the abnormal brain electrical activity. One of the examples of changing the name of the disease to reflect modern scientific understanding is cerebrovascular disease, replacing 'stroke' and 'cerebrovascular accident'.

Guidelines for new name used by the Korean epilepsy community<sup>14</sup> listed some useful general principles as follows. The new terminology must be (1) at neutral position, (2) implying a scientific basis, (3) easily differentiated from words of resemblance (e.g., convulsion, fits, spasm, etc.), (4) easy to use as both a noun and an adjective, and (5) more likely to be acceptable in global epilepsy communities.

#### CONCLUSION

Names of epilepsy often reflect the perceptions of the language speakers, which may resulted in stigma that had significant impacts on the life of people with epilepsy. Stigmatizing names should be changed based on modern scientific understanding of epilepsy.

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