

GUEST EDITORIAL

Renaming dementia – an East Asian perspective

Worldwide, the number of individuals with dementia is growing in an epidemic manner, with an estimated 35.6 million people affected in 2010 (Prince *et al.*, 2013). With the population aging in Asia, dementia care will become a major public health challenge in this region in the coming decades. Over half of the patients with dementia in the world will live in Asia by 2030. In China alone, a recent review of dementia studies showed that there were 9.2 million dementia patients in 2010 (Chan *et al.*, 2013). These figures are staggering. In many Asian countries, dementia is regarded as a shameful illness, and the local terms for dementia are derogatory. Dementia carries a stigma that may lead to patients' reluctance in seeking treatment and delay in diagnosis. In addition, local names for dementia frequently conjure up pictures of severe stage of dementia, and may lead to therapeutic nihilism, discouraging mental health professionals from working with elderly patients with dementia. As Asia faces the challenges of a rapidly aging population and provisions of care for growing number of dementia patients, change in local names for dementia has become an issue of attention.

The salience of language describing dementia in shaping our perceptions of dementia patients has been eloquently and poignantly discussed by George (2010). Some of the terms used evoke images of “total loss of self,” resulting in “living death” and “social death,” and it has been suggested that semantic choice in describing dementia is part of our moral challenge (George, 2010). It has been argued that the term “dementia” conspires against early diagnosis because of its negative connotations (Sachdev, 2010). In a review paper on the concept of dementia, the authors proposed that the term dementia should be replaced with a new term that could accommodate scientific advances as well as the needs of patients and carers (Kurz and Laughtenschlager, 2010). In 2013, the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) replaced the term “dementia” with “Major Neurocognitive Disorder.” This change in name partly reflects the current conceptual framework of the condition, as well as the perception that the term dementia is pejorative (Ganguli *et al.*, 2011).

In recent years, there have been movements to change the local names of schizophrenia and

dementia in some Asian countries. Part of the motivation to change the name lies in the fact that it is gradually becoming clear that services for mentally ill patients are improving much more slowly than expected in view of the increase of knowledge about them. The explanation for this gap between knowledge about mental illness and service improvement is probably the stigma of mental illness, including dementia. This leads mental health professionals to consider ways in which terms for mental disorders could be changed to avoid stigma, particularly in countries in which the terms for mental disorders are in local languages and are comprehensible to the public. This paper describes the situation on the change of local names for dementia in some Asian countries and cities. It is noteworthy that the local names for dementia in many East Asian countries are based on Chinese characters (kanji).

In China, the Chinese name for dementia is Chi Dai Zheng (癡呆症), which has negative connotations of “insane and idiotic.” In 2012, The Central Television Station, jointly with several academic organizations concerned with dementia, initiated a campaign to rename dementia. It asked people to select the most appropriate name replacing dementia from the following names: memory loss disorder, Alzheimer's disease, brain degenerative disorder, and intelligence loss disorder. Altogether, 1.2 million people voted via various means such as SMS from mobile phones, online survey, telephone, and letters. A majority of 70% voted for “brain degenerative disorder.” However, the campaign ceased without invoking further reactions from professionals. Nevertheless, great interest and attention has been aroused in this area, and it is hoped that there will be actions to take up the renaming process soon.

In Hong Kong, the Chinese name for dementia, “Chi Dai Zheng” (癡呆症), is used, and is pejorative. Many local professionals believe that the stigma attached to the Chinese term for dementia is a major factor leading to delay in the presentation of the condition as well as reluctance to seek treatment.

In late 2010, a campaign to change the Chinese term for dementia was initiated by a local dementia center, and the Chinese term meaning “brain degenerative disorder” was selected. However, the

medical professional community did not accept this term as it was thought that the term did not represent the core features of the condition accurately. The Hong Kong Psychogeriatric Association was the first professional association that wrote an open letter to the government and many agencies to express disagreement with the proposed term. Subsequently, a Working Group on New Chinese Terminology for Dementia and Cognitive Impairment comprising ten professional associations was formed to examine the matter further. In 2012, the Working Group proposed the term “Ren Zhi Zhang Ai Zheng” (認知障礙症), which meant “cognitive disorder,” to replace the old Chinese term, as this new Chinese term reflected the core deficits in dementia and was consistent with the term “major neurocognitive disorder” used in DSM-5. It was also believed that this new term would be much less stigmatizing (Chiu and Li, 2012). A recent survey of 466 patients with dementia and their carers in Hong Kong by the above-mentioned working group showed that the new term was more acceptable to the public than the old one. In fact, around half of the patients thought that they had been stigmatized because of the old Chinese term for dementia. The overwhelming majority of the patients (87%) supported replacing the old term with the new proposed term (認知障礙症). Indeed this new term is now gaining popularity and is widely used by the media as well as professionals. However, the Government has not yet officially adopted the proposed new Chinese term, and accepts both old and new local terms for dementia.

In Taiwan, the traditional and original Chinese term for dementia was based on the concept of “stupidity and slow-witted brain with psychosis-like feature,” which was translated as 癡呆症 (Chi Dai Zheng, i.e., disease with low mentality and psychosis). The traditional Chinese term for dementia was much stigmatized in Taiwan. A movement to rename this traditional Chinese term was initiated in 1998, and was led by healthcare and social work professionals, patients and their families as well as professional associations such as the Catholic Sanipax Socio-Medical Service & Education Foundation in Taiwan, Taiwan Catholic Foundation of Alzheimer’s Disease and Related Dementia, Dementia Care Association, Taiwan ROC, and Taiwan Alzheimer’s Disease Association (TADA), which is a member of Alzheimer’s Disease International since 2002. Currently, the new Chinese term for dementia (Shi Zhi Zheng (失智症), i.e., disorder with dysfunction of intelligence or loss of wisdom) is in use. The public and the media seldom use the old term after TADA advocated, appealed, and officially communicated with the National Communications Commission

to formally declare that the new Chinese term for dementia must be used by the media in Taiwan.

In Japan, the old local term for dementia was “Chiho” (癡呆), which implied that the person was foolish and absentminded. In 2004, two years after replacing the local term for schizophrenia, “Chiho” was replaced by a new term, “Ninchi-Sho” (認知症), which means “cognition disorder,” without any accompanying change of the concept. The change in name occurred under the auspices of a committee of government administration after widespread consultation with professional associations and the public. For instance, a survey was conducted at that time to solicit public opinion on appropriate name, which resulted in 6,333 responses, and finally the term “Ninchi-Sho” was chosen (Miyamoto *et al.*, 2011). In 2004, the government officially replaced the old name with the new term. The government declared 2005 as the year of understanding “Ninchi-Sho” to spread knowledge about dementia and its prevention, treatment, and care. The goal of the public awareness campaign was to promote early diagnosis and intervention for patients with dementia in the aging society of Japan.

The Japanese Society of Geriatric Psychiatry accepted the new name as an official medical term in 2005. The effect of renaming in psychiatric practice has not been evaluated. Nevertheless, it is noteworthy that after the change of name, more patients with dementia began to talk about their experiences in public (Miyamoto *et al.*, 2011). This suggests that there is a change in the attitude and perception of the condition by the public. Currently, the old term has been completely replaced with the new term. However, since DSM-5 has recently changed the name of dementia as major neurocognitive disorder, it is currently under discussion whether “Ninchi-Sho” would continue to be used or a new local term would be used in Japan.

In South Korea, the local term for dementia is “Chi-Mae” (癡呆). The two words, “Chi” and “Mae” mean stupidity. This term is still currently used in psychiatry and general medicine. The implication of the term “Chi-Mae” is that patients with dementia can be ridiculed due to their foolish thoughts and behaviors. The term “Chi-Mae” makes people think that patients with dementia are ridiculous old people, rather than patients who need psychiatric treatment (Cho, 2002). It seems however that readiness to find a new name for dementia is growing. In particular, after the change of name in DSM-5, there is much discussion about the change of local name for dementia in South Korea. It is likely that further discussion on this issue will be carried out by the Korean Neuropsychiatric

Association (KNPA) and the Korean Association for Geriatric Psychiatry (KAGP) in the near future.

In Singapore, the Chinese term for dementia is also “Chi Dai Zheng” (癡呆), which implies stupidity. Patients are fearful of the label, and families are embarrassed by their association with dementia patients. While talking to dementia patients or their families, psychiatrists often say it is a “disorder of memory.” This is a more acceptable diagnosis and also encourages patients to seek help from other community services such as day-care centers. A name change has been mooted during a recent public forum on healthcare of the elderly people.

In changing the local terms for dementia, Japan and Taiwan have led the way and set an example for other Asian countries and cities. Commitment from the government and involvement of professionals, consumers, and the public are crucial. Changes or proposal of changes of local names are taking place in several other East Asian countries and cities. It will be very useful to develop collaborative efforts among these Asian countries and cities to evaluate the impact of name change. If it is found that change in the local names for dementia will decrease stigma and lead to earlier diagnosis and service improvement, this will provide important insight to our fight against stigma of mental illness.

Conflict of interest

None.

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