

## REVIEW ARTICLE

# Epilepsy stigma in Asia: the meaning and impact of stigma

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### Abstract

Stigma is conceptually broad and culturally variable. Understanding stigma from the conceptual theories, culturally application based on the word stigma in other languages, the definition of stigma and its synonyms, as well as the medical implications in other stigmatized disease such as AIDS, will help us to understand the complexity of stigma in epilepsy. This review investigated the meaning and types of stigma from different perspectives, leading to staging stigma into 5 levels, i.e. social identity, stereotype, prejudice, discrimination and social disability. In addition to the conventional categorization of stigma into social, felt, self-perceived or internalized stigma, new categories of stigma i.e. personal and general attitudes towards epilepsy based on a newly developed Public Attitudes Toward Epilepsy (PATE) scale was introduced. Courtesy stigma was further elaborated in related to Asian culture. Based on well-established and recently developed theories, the causation and impact of epilepsy stigma was discussed in an Asian context, especially from the aspects of language and society values which are culturally specific. Integrating these theories of causation, illness and stereotype perceptions were proposed to be the mediating mechanism of stigma, which led to the development of a practical and multi-dimensional stigmatization model, aiming to guide, widen and deepen the scope of future stigma research in epilepsy. Using the established model, together with review of related studies, research priorities in epilepsy stigma research especially in Asia focusing on five aspects, i.e. expanding population studies especially on significant others, understanding stigma from personal attitude perspective, investigating the cultural and social causation of stigma, and the impacts of stigma on patients as well as the family members, were proposed.

### STIGMA IN EPILEPSY: THE MEANING OF STIGMA

#### What is stigma?

Although stigma has a universal concept across culture, stigma is conceptually broad and variable, according to the condition it is attached with, as well as the history, social norms and even the language used to describe the condition.<sup>1,2</sup> In order to understand stigma comprehensively in the cultural context, we took a multi-disciplinary approach by defining stigma based on different perspectives, as shown in Table 1. This followed by characterising the concept of stigma and developing a model of stigmatization in epilepsy for future research, especially in understanding the causation and impact of epilepsy stigma among Asian population.

#### Characteristics of stigma in epilepsy

Conceptualized from the meanings of stigma described above, the characteristics of stigma can be viewed in five levels as follows.

- Stigma is a label, a spoiled social identity different from the actual social identity (*social identity*);
- Based on an inaccurate simplistic generalisation of a group of people, not only on their illness, but also on their attributes and personality (*stereotype*);
- With unfair judgement and unreasonable attitudes toward an undesired difference (*prejudice*);
- Resulting in discredit and rejection of the stigmatized by the society (*discrimination*);
- With restriction imposed by the society, without given a fair chance or a basic human right, and

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**Table 1: Definition of stigma**

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|---|
| <b>Dictionaries</b>   |
| <ul style="list-style-type: none"> <li>According to The American Heritage Dictionary of the English Language<sup>3</sup>, stigma is from Middle English stigma which means <i>brand</i>, from Latin <i>stigma</i>, <i>stigmat-</i>, <i>tattoo indicating slave or criminal status</i>, or from Greek, <i>tattoo mark</i>, from <i>stizein</i>, <i>stig-</i>. Stigma is a mark or token of infamy, disgrace, or reproach. In <i>Archaic</i> language, stigma is a mark burned into the skin of a criminal or slave; a brand.</li> <li>In Collins English Dictionary<sup>4</sup>, stigma is explained as a distinguishing mark of social disgrace.</li> </ul>   |
| <b>Theories</b>   |
| <ul style="list-style-type: none"> <li>In Goffman's stigma theory, stigma is defined as "<i>The phenomenon whereby an individual with an attribute is deeply discredited by his/her society is rejected as a result of the attribute. Stigma is a process by which the reaction of others spoils normal identity.</i>" Disorders that are discreditable, which are not immediately perceivable, are distinguished from those discrediting. This attribute is resulted from a discrepancy between the virtual and actual social identity, i.e. the person they might be and the person they are.<sup>5</sup></li> <li>Jones expanded the dimension of stigma into six dimensions, which include concealability, course, disruptive, aesthetics, origin and peril.<sup>6</sup></li> <li>Field described four categories of illness, of which chronic stigmatising illness is characterised by the illness becoming the central part of the identity and social consequences persist irrespective of the severity of the illness.<sup>7</sup></li> <li>Bruce Link and Jo Phelan<sup>8</sup> had proposed a four-component stigmatization model, inclusive of (1) Differentiation and labeling: Individuals differentiate and label human variations; (2) Linking to stereotypes: Prevailing cultural beliefs tie those labeled to adverse attributes; (3) Separation between us and them: Labeled individuals are placed in distinguished groups that serve to establish a sense of disconnection between "us" and "them"; and (4) Disadvantage: Labeled individuals experience "status loss and discrimination" that leads to unequal circumstances.</li> <li>Falk wrote: All societies will always stigmatize some conditions and some behaviours because doing so provides for group solidarity by delineating "outsiders" from "insiders".<sup>9</sup> He categorised stigma into <i>Existential Stigma</i>, stigma deriving from a condition which the target of the stigma either did not cause or over which he has little control, and <i>Achieved Stigma</i> as "stigma that is earned because of conduct and/or because they contributed heavily to attaining the stigma in question."</li> <li>Pryor described a dual-process model of reaction to perceived stigma, which consisted of a primarily reflexive or associative response (implicit stigma), and a rule based or reflective response (explicit stigma).<sup>10</sup> <i>Explicit attitudes</i> are those that people consciously acknowledge and are obtained using self-report measures. <i>Implicit attitudes</i> are assessed using performance-based measures, such as the Implicit Association Test.<sup>11</sup></li> </ul> |
| <b>Synonyms</b>   |
| <ul style="list-style-type: none"> <li>Stigmata, marks or blemishes (烙印感): defect, flaw, drawback, deficiency</li> <li>Prejudice: an adverse judgment or opinion formed beforehand or without knowledge or examination of the facts. The act or state of holding unreasonable preconceived judgments or convictions.<sup>3</sup> It is an intolerance of or dislike for people of a specific race, religion, etc.,<sup>4</sup> or an unreasonable feelings, opinions, or attitudes, esp. of a hostile nature.<sup>12</sup> In Shakespeare's social model of disability, it was reconceptualised that "<i>People with impairment are disabled, not just by material discrimination, but also by prejudice. This prejudice is not just interpersonal, it is also implicit in cultural representation, in language and in socialization.</i>"<sup>13</sup></li> <li>Discrimination: treatment or consideration based on class or category rather than individual merit; partiality or prejudice.<sup>3</sup></li> <li>Stereotype: a set of inaccurate, simplistic generalizations about a group that allows others to categorize them and treat them accordingly.<sup>4</sup> The main difference between stigma and stereotype is that it can also be positive or neutral.</li> </ul>   |
| <i>Stigma in other languages which add additional meaning to the word stigma in English</i>   |

- Chinese 羞耻感、耻辱感: shamefulness
- Japanese 汚名、偏见: dishonor, prejudice
- Korean 오명: stigma, pillory, opprobrium
- Hebrew יִלְעָל תִּאָ: mark of disgrace, stigma, brand
- Latin *ignominia*: disgrace, dishonor, humiliation, public degradation

#### *Disease specific stigma e.g. AIDS*

- AIDS-related stigma and discrimination refers to prejudice, negative attitudes, abuse and maltreatment directed at people living with HIV and AIDS. HIV stigma is socially shared knowledge about the devalued status of people living with HIV. It is manifested in prejudice, discounting, discrediting, and discrimination directed at people perceived to have HIV and the individuals, groups, and communities with which they are associated. Because the meanings attached to the disease are created through social interactions (e.g., experiencing discrimination or learning of other people being mistreated), the experience of HIV stigma can vary across cultures.<sup>14</sup>

#### *Epilepsy specific stigma*

- Stigma is precisely described 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>15</sup>
- Epilepsy has been considered as a disability under Americans with Disabilities Act (1990).<sup>16</sup> According to *social model of disability*, impairment exists in the real physical world and disability is a social construct that exists in a realm beyond language within a complex organisation of shared meanings, discourses and limitations imposed by the environment at a particular time and place. This is different from the medical model of disability, which stated that disability is due to the impairments of an individual.<sup>17</sup>

persists despite condition improves (*social model of disability*).

#### **Type of stigma**

Stigma can be viewed from different angles. *Social stigma* is the attitude of others towards people with epilepsy. *Enacted stigma* is the actual episodes of discrimination, both formal and informal, against people with epilepsy solely on the ground of their having epilepsy. When the stigmatization is experienced by a person with epilepsy, it is named *felt stigma*; whereas *self-perceived stigma* or *internalized stigma* is stigma perceived when having a painful inner struggle with having epilepsy, even without any encounter with actual stigmatization. Enacted stigma may be uncommon; whereas self-perceived stigma is much more prevalent which may lead to feeling of fear and shame, concealment of their condition, and be a self-fulfilling prophesy.

*Courtesy stigma* is a stigma acquired as a result of being related to a person with a stigma, as introduced by Goffman.<sup>5</sup> For example, siblings of those with epilepsy might suffer from courtesy stigma when people wonder if epilepsy is genetic. In China, stigma was felt by 76% of the family

members of people with epilepsy.<sup>18</sup> The moral weight attached to epilepsy not only applied to the affected person, but also threatened familial aspirations and life chances through a process of “courtesy stigma”: because of fear of family disgrace, people with epilepsy were typically kept at home and their diagnosis was kept secret.<sup>19</sup>

A newly developed Public Attitudes Toward Epilepsy (PATE) scale demonstrated a dichotomy in attitudes toward epilepsy, including general and personal attitudes. Items on *general attitude* require minimal or no consideration of respondents' involvement (for example, “people with epilepsy should not marry”), whereas items on *personal attitude* require a long-term personal commitment or involvement such as “I would marry someone with epilepsy, even though he/she has epilepsy” or “I feel uncomfortable working with someone who has epilepsy”.<sup>20</sup> Those with higher education level were shown to have a more positive general attitude but not the personal attitude.<sup>20</sup> Classifying into general and personal attitudes is conceptually similar to dichotomizing social stigma into explicit and implicit stigma, whereby *explicit stigma* is rule based and a deliberative processes is involved in validating activated knowledge for appropriateness and

consistency, and *implicit stigma* consisted of a primarily reflexive or associative response and can be assessed using performance-based measures, such as the Implicit Association Test.<sup>11</sup>

## STIGMA IN EPILEPSY: THE CAUSATION OF STIGMA

### Factors associated with stigma in epilepsy

Studies on different types of epilepsy stigma had identified a variety of factors associated with stigma. In related to *social stigma*, people from rural areas with lower educational level and socioeconomic status have been found to have more negative attitudes towards epilepsy.<sup>21-30</sup> Other factors include old age, female gender, being single, and not having heard or witnessed anyone having seizure.<sup>23,25,26,28,29,31</sup> The magnitude of the negative attitudes was also seemed to associate with misconception of epilepsy, which include the perception of epilepsy as a form of insanity, being untreatable, contagious, hereditary, or a form of mental retardation.<sup>22,23,25,32,33</sup>

*Perceived stigma* in people with epilepsy was associated with experience of actual discrimination, introverted personality, degree of problem solving control, and emotional subscale of QOLIE.<sup>34</sup> Seizure control was another important associated factor to self-perceived stigma. Two years after diagnosis, one tenth of those who remained seizure free as compared to 45% of those experiencing continuing seizures reported feeling stigmatized.<sup>35</sup> The percentage of people reporting feeling highly stigmatized rose from 10% of those who had been seizure free in the previous 12 months to 29% of those reporting ongoing seizures of more than once monthly.<sup>36</sup>

### Stigmatizer and stigmatized

#### Stigmatizer

Many studies in epilepsy focus on the stigmatized, but not on the stigmatizer. From the perspective of the stigmatizer, stigmatizing others can serve several functions for an individual, including self-esteem enhancement, control enhancement, and anxiety buffering, through *downward-comparison* — comparing oneself to less fortunate others.<sup>37</sup> However, this is not the only reason why people stigmatizing others.

Those related to a person with epilepsy can hold the same perception and stereotyping them similar to a non-related stigmatizer. As a result,

the people with epilepsy might be overprotected and restricted from many activities by their family members, friends or teachers.<sup>38</sup> Overprotection arising from stigmatization can have severe consequences.

In addition, stigmatization by the closely related can be a result of actual negative consequences experienced by the stigmatizer. For example, a sibling of a person with epilepsy can be deprived from parent's attention and love, resulting a negative perception and discrimination on them. Similarly, an employer or colleague of a person of epilepsy can suffer loss during a seizure, thus forming a negative stereotypic perception of those with epilepsy.

Stereotyping through natural selection can be a survival instinct based on the theory of natural selection. Those with no epilepsy are more likely to be selected by an employer during an interview who is trying to protect the benefit of a company. People are more likely not to marry a person with epilepsy, possibly to avoid negative impacts if seizures occurred, based on attitudes studies in epilepsy.<sup>39</sup>

#### Stigmatized

In traditional concept, the stigmatized are devalued and rejected by the society. However, the stigmatized can experience an *internalized stigma* when having an enormous and painful inner struggle<sup>40</sup>, which might be more intense than the actual stigma imposed by the society. In addition, those who perceive themselves to be part of a stigmatized group, though it might not be obvious to those around them, often experience psychological distress and view themselves contemptuously.<sup>37</sup> In contrary, many people with stigmatized attributes perform effectively and have good self-esteem despite the stigmatization.<sup>37</sup>

### Theories of causation

#### 1. Dimension of stigma

Jones divided stigma into six dimensions, which include concealability, course, disruptive, aesthetics, origin and peril, as shown in Table 2.<sup>6</sup> Concealability (visibility) and controllability (course) were the two dimensions which were thought to be more relevant to epilepsy.<sup>35</sup> However, in Asia, other dimensions might play a role in the development of stigma, as elaborated in Table 2.

**Table 2: Dimension of stigma and its relevance to epilepsy in Asia**

| Dimension                    | Definition and relevance to epilepsy   |
|------------------------------|--|
| Concealability or visibility | Extent to which the condition is visible to others: <i>For example, whether the seizures occur mostly during the daytime or night, and whether the seizures are accompanied with behavior changes or with secondarily generalization.</i>  |
| Course or controllability    | Whether the condition becomes more salient over time: <i>It depends on the degree to which the seizures can be controlled, whether there is presence of medication side effects, and whether the epilepsy is complicated with cognitive impairment.</i>  |
| Disruptiveness               | Degree to which it interferes with social interaction, ongoing life & activities: <i>Seizures are highly disruptive, causing those observing to be terrified.</i>  |
| Aesthetics                   | Subjective reactions of others to the unattractiveness of the condition: <i>Seizures may be aesthetically unpleasant to the observers especially presented with incontinence or with fall and injuries.</i>  |
| Origin                       | Whether seen as congenital, accidental or intentional: <i>People with epilepsy may be perceived to be morally culpable for their condition.</i>  |
| Peril                        | Perceived danger to others; <i>such as being contagious. Seizures may appear violent, or accompanied with behavioral changes and psychosis perceived to be harmful to those around. In broader context, seizures may be perceived to result negative consequences to the workplace and family.</i> |

## 2. Significance others

How one perceives himself/herself is dependent on the views of others, particularly these *significant others* such as parents, teachers, health care professionals, their views are in turn likely to be crucial in the development of self-perceived stigma among people with epilepsy.

*“My neighbor’s daughter found it difficult to relate to people and was extremely shy and withdrawn. It was clear that she had a profound sense of being different. There emanated from her an air of shame. I saw that there was a definite link between her parent’s inability to accept her condition and the way she coped with it.”* by Susan Usiskin, an epilepsy counsellor at the National Hospital, London.

## 3. Society values

The concepts related to the underlying values of the society are likely to be crucial in the development of epilepsy stigma. In both China and Vietnam, beliefs about the causes of epilepsy and triggers of seizures were a complex

interweaving of concepts. Seizures were more commonly described as having a psychological basis, being triggered by tiredness, nervousness, excitement, anger, low mood and “too much brainwork”.<sup>2</sup> *Too much brainwork* is an Asian quasi-physical concept of stress which is related to a stressful lifestyle, with heavy and over work, and compounded by stressful life events. Therefore, as a consequence, people with epilepsy should be confined to doing “simple”, “special” or “appropriate” work only, and be prevented from doing “strenuous” or “too tiring” because that might trigger seizure.<sup>2</sup> Similarly, as reflected in this paper, the lack of marriageability of people with epilepsy in Asia seemed to center on two main issues, i.e. (1) the inheritability of epilepsy and (2) the functional capacity of the people with epilepsy and their ability to contribute adequately to family economy. The findings by Jacoby *et al.* are particularly significant in the context of the work-orientated cultural values and emphasis on family honor in the Chinese and Vietnamese societies. This is contrasted with the individual fulfillment and happiness as core value in the Western society.

#### 4. Language

Language carries thoughts and concepts, and the names we use for epilepsy implies certain concepts which may contribute to stigmatization. The words we use can influence our perceptions and have consequences in terms of social stigma associated with epilepsy. A review of Lim et al.<sup>1</sup> showed that epilepsy in Chinese (*dian xian*, madness; *yang dian feng*, goat madness) is associated with insanity and animals. 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, possibly because of the influence of Traditional Chinese Medicine. In the case of Malay who are mainly Muslim, the name of epilepsy consisting the word “pig” that is religiously unclean (*gila babi*, mad pig disease), contributing further to stigma of the epilepsy patients. There are efforts to replace these name with a neutral terminology in Malay in Malaysia, and recently also for Chinese in Hong Kong, and Korean in South Korea, but the concepts carried with the old names may take some time to change.

When the word “epileptic” is used to refer to a person with epilepsy, a study by Fernandes showed that more high school students tended to think that people with epilepsy have difficulties in finding employment and at school, as compared with those who was given a questionnaire without the word “epileptic”.<sup>41</sup> This implies that language can influence our perceptions, with a significant consequence on stigma in epilepsy.

#### 5. Lack of appropriate contact / encounter with people with epilepsy

According to Hills<sup>42</sup>, the most important means of reducing the prejudice arising from stigma is by *contact*. In his view, for one’s prejudice toward another to be reduced, they must experience contact with them which is on an *equal status* footing, *repeated and consistent*, requires *interdependence*, is *socially approved, enjoyable, contradicts the stereotypes* held, and is with individuals seen as *representative* of the out-group as a whole. An epilepsy ambassador project in Taiwan, in which people with epilepsy was trained to promote a healthy image and the awareness of epilepsy, and the public attitudes were shown to improve over 20 years.<sup>43</sup> In contrary, a contact with a person with epilepsy or a seizure might have a negative influence on someone’s perception of epilepsy. The experience of encountering a seizure can be traumatic. Furthermore, an inappropriate contact

might result in misconceptions, which might be shared and magnified. Nonetheless, having contact with more people with epilepsy is more likely to improve understanding and possibly reducing the misconceptions and myths about epilepsy, if it is formally organized with supports from professionals.

#### Illness perception and stereotype perception

Stigmatization is built on a person’s perception on the illness (illness perception), and beyond that the perception of the attributes and personality of a person with the illness (stereotype perception). The five theories of causation stated above lead to the proposal of illness and stereotype perceptions being the mediating mechanism of stigma.

A systematic review showed that people with less knowledge about epilepsy, or without personal contact with someone with epilepsy, have poorer attitudes.<sup>39</sup> However, the knowledge assessed in previous studies is not the same as the medical facts about epilepsy. It comprised a person’s perception of what the illness is, which can be influenced by knowing a person with epilepsy or knowing epilepsy via the others or mass media. In fact, a study correlating epilepsy knowledge based on medical facts and attitudes toward epilepsy showed that only certain aspects of knowledge in the scale contributed to the correlation.<sup>44</sup> Illness perception were described by Leventhal as a cognitive response to a health threat and a scale, i.e. illness perception questionnaire, was developed to assess the perception of a patient.<sup>45</sup> Studies in illness perception showed good correlations with illness behaviour and clinical outcomes,<sup>46-50</sup> and thus should be considered to be applied in epilepsy stigma studies.

Besides perceiving what epilepsy is (illness perception), how a person perceives what people with epilepsy is like (stereotype perception, a simplistic generalization of people with epilepsy) will affect someone’s attitudes toward epilepsy. Previous studies on attitudes toward epilepsy had assess stereotype perception, such as “people with epilepsy are unreliable” or “people with epilepsy have low self-esteem”, but a standard and quantitative scale is yet to be developed.<sup>39</sup>

#### Stigmatization model

Based on the theories of stigmatization, the types and causation of stigma, a practical and multi-dimensional model as shown in Figure 1 was developed to ease subsequent discussion and future research. This model emphasizes

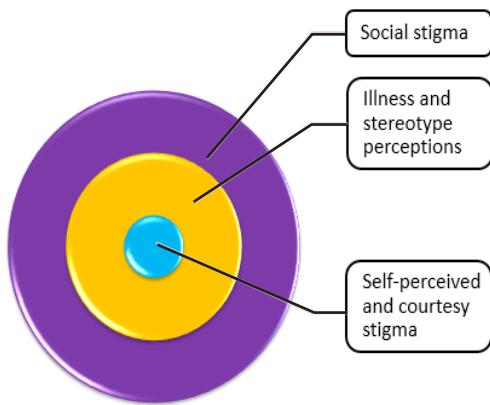


Figure 1: Stigmatization model

the relevance of patient's and public illness and stereotype perceptions on stigma, which can be classified to social, perceived and courtesy stigma depends on the population studied. This will enable us to understand the meaning, the causation and the impact of stigma in the patients, family and public.

## EPILEPSY STIGMA IN ASIA AND THE IMPACT OF STIGMA

### *Epilepsy stigma among Asian*

A cross-cultural comparison in Europe showed that there were significant differences in perceived stigma among people with epilepsy from various European countries.<sup>51</sup> It is expected to have a greater cross-cultural difference in stigma between the Western and the Asian countries. In the various studies on social stigma or public attitude towards epilepsy, there were as high as 56-57% of public respondents in epilepsy survey objected their children to play with people who sometimes had seizures, 86% thought that epilepsy patients cannot work as other people, and 71-86% objected to their children marry a person who sometimes has seizures.<sup>52-54</sup> In Malaysia, 20% of the children with epilepsy were not receiving any form of formal education although primary education is free.<sup>55</sup> In India, 25% of women with epilepsy had problems getting married as compared with 1% in controls, and 70% concealed their epilepsy from husbands.<sup>56</sup> The divorce rate among people with epilepsy in Korea is higher, 9% versus 0.7% in general population.<sup>57</sup> In a systematic review of public attitudes toward epilepsy, Asia and Africa were shown to be the two continents with the worst attitudes against employment in epilepsy,

where 50.0% (16/32) and 80.0% (8/10) of the published papers respectively reported more than 40% of participants with negative attitudes, as compared to none in North and South America, and Australia.<sup>39</sup>

### *Impact on quality of life*

Quality of life (QOL) is a reflection of general mental health and social functioning, and can be measured using a general measurement tool such as Short Form (SF-36) Health Survey or a disease specific measurement tool e.g. Quality of Life in Epilepsy Inventory (QOLIE-89 or QOLIE-31). Perceived stigma, as measured by Epilepsy Stigma Scale<sup>58</sup>, was shown to be correlated with quality of life as measured by SF-36, as well as worry and negative feelings about life.<sup>51</sup> In an analysis of factors contributing to overall quality of life, perceived stigma itself accounted for twice the amount of variance in scores as did seizure frequency and side-effects of AEDs, and is the 4<sup>th</sup> in importance in predicting the quality of life among people with epilepsy.<sup>59</sup> Perceived stigma is associated with impaired self-esteem, self-efficacy and sense of mastery, with greater perceived helplessness, rates of anxiety and depression, and somatic symptomatology, and reduced life satisfaction, which may explain a poorer quality of life among those with higher perceived stigma.<sup>35,60</sup> However, there is a lack of Asian studies relating stigma and QOL among Asians with epilepsy.

### *Socioeconomic impact*

Social stigma and workplace prejudice, which is prevalent in Asia<sup>39</sup> affected by the cultural misconception of epilepsy, often prevents a person with epilepsy from being employed. In Malaysia, epilepsy patients have high unemployment rate in Malaysia. Besides being unemployed, many were in part-time or low-income employment. As compared to their age-matched siblings, the patients were more likely to be unemployed (OR 13.1), single, have lower education level and lower monthly income.<sup>61</sup>

## RESEARCH PRIORITIES ON EPILEPSY IN ASIA

### *Population studies focusing on the public and significant others*

It is essential to determine and monitor the epilepsy stigma in various communities and cultures in

Asia, in order to identify the populations with greater epilepsy stigma.

The attitudes of the significant groups such as teachers, parents and media workers should be studied because of the influence of the attitudes of these significant others on the psychosocial achievement among the people with epilepsy in that community. In Malaysia, it was shown that teachers had more positive attitudes toward epilepsy as compared with the general population with tertiary education, suggesting that attitude to epilepsy may differ specific to types of work.<sup>62</sup>

#### *Assessing personal attitudes and implicit stigma*

Asian population culturally tends to answer survey in a socially desirable manner. Personal attitudes was shown to be significantly more negative in comparison with general attitudes, supporting that the respondents' social desirability was minimized.<sup>20</sup> Similarly, study on psychiatric disorder showed that the implicit stigma, which consisted of a primarily reflexive response, is significantly worse among the Asian.<sup>63</sup> Assessing personal attitudes or implicit stigma is therefore more likely to reflect the actual magnitude of social stigma in epilepsy.

#### *The cultural and social causation of epilepsy stigma*

Previous studies in Europe and Asia were supportive of cross-cultural variation in epilepsy stigma.<sup>39,51</sup> It is thus important to explore the perceptions on epilepsy in relationship with values of the various cultures in Asia, especially on the upbringing pattern of the various Asian cultures in the perspective of development of stigma in epilepsy. Therefore, understanding how different cultural groups perceive epilepsy (illness perception) and the people with epilepsy differently (stereotype perception) using a standardized questionnaire will allow us to compare and determine the cross-cultural influence on stigma, as shown in Figure 1.

Asian cultural values is work-orientated and with emphasis on family honor, as contrasted with the individual fulfillment and happiness as core value in the Western society. Determining how strong epilepsy stigma in epilepsy among Asian is related to low productivity of people with epilepsy and dishonor to family, will guide future intervention in reducing stigma in the Asian population. This will also guide social intervention and policy making in minimizing discrimination and improving the productivity of epilepsy patients.

#### *Impact of social stigma on the patients, using a community-based design*

It is technically difficult to determine the impact of public attitude or social stigma in a society on the felt stigma of the epilepsy patients staying in that society, because of multitude of social interaction in a community. However, using a multi-community design with each community as a unit, the impact of social stigma on people with epilepsy can be made possible. For example, in Malaysia, the attitudes toward epilepsy using PATE scale were less negative in Chinese with mean score of 2.16 versus 2.22 in Malay population<sup>62</sup>, and the employment rate of the Chinese and Malay epilepsy patients in Malaysia was 69.7% and 66.2% respectively.<sup>61</sup> This result suggested that population with less negative attitudes toward epilepsy might have better employment rate among people with epilepsy. Multi-centered study involving different communities with varying degrees of public attitudes (social stigma) and felt stigma, using a similar scales, may be able to demonstrate the relationship between social stigma and felt stigma.

#### *Others*

Family honour is an important core value in Asian countries. Impact of epilepsy and epilepsy stigma on the family members of the patients, and the upbringing patterns of the various Asian cultures in the perspective of development of stigma in epilepsy are two important areas requiring more research attention especially in Asia. Other research priorities include (1) determining the impact of stigma on QOL among Asians with epilepsy, (2) developing an epilepsy knowledge questionnaire relevant to epilepsy stigma in Asia, and (3) understanding the coping of people with epilepsy with a negative social label in various Asian cultures.

## **CONCLUSION**

This review explored a multi-directional approach to study the complexity of stigma. New categories of stigma i.e. personal and general attitudes towards epilepsy based on a newly developed Public Attitudes Toward Epilepsy (PATE) scale was introduced. Causation of stigma in Asia was updated based on studies on languages and society values. Detailed characterisation and categorization of stigma in epilepsy lead to development of a stigmatization model. Illness and stereotype perceptions were proposed to be

the mediating mechanism of stigma. Research priorities on epilepsy stigma based on the model were proposed.

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