

## Epilepsy research priorities in Asia: Psycho-social and cultural Issues

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### Abstract

Since the Asia and Oceania region has tremendous variety in cultural and religious background, the author would like to propose the formation of a research committee with representatives from different countries under the Commission on Asian & Oceanian Affairs to study the psychosocial and cultural aspects of epilepsy. A uniform study protocol can be designed to collect data on “public awareness, understanding and attitudes toward epilepsy” and “patients’ perception of having epilepsy.” The survey can be done among the general population, patients with epilepsy, family members, health providers, or school teachers.

In the 2002 Asian-Oceanian Epilepsy Congress (AOEC), a symposium entitled “Priority of Epilepsy Research in Asia” was held, and it was noted that the large population with epilepsy in the Asian and Pacific region provides a unique opportunity for quality research in various aspects of epilepsy.<sup>1</sup> Subsequently “religion and literature on epilepsy” were explored in the 2004 AOEC, and tremendously rich and colorful cultural backgrounds in Asia-Pacific areas were reviewed.<sup>2-5</sup> In fact, all three major religions - Buddhism, Islam, and Christianity - are heavily represented in these areas, and the two countries with the longest history and largest populations, China and India, both are part of this region. Consequently, the differences in traditional beliefs about epilepsy in this region are quite distinct, and it is believed that we should seriously look into the research priorities in studying the psycho-social and cultural issues of epilepsy in Asia-Pacific areas.

### SCOPE OF PSYCHO-SOCIAL AND CULTURAL ISSUES OF EPILEPSY

The definition of psychosocial is “pertaining to or concerning the mental factors or activities which determine the social relations of an individual.” (Webster, New Twentieth Century Dictionary, 1975). The definition of culture is, “The concepts, habit, skills, art, instruments, institutions, etc. of a given people in a given period; civilization” (Webster, New Twentieth Century Dictionary, 1975), or, “The social and religious structures and intellectual and artistic manifestation, etc., that characterize a society. (New Lexicon Webster’s Dictionary of the English Language, 1987.)

When one searches the literature for the link between “psychosocial” and “epilepsy”, it yields articles covering a varieties of areas, including psychiatric problems (mood disorders, anxiety, attention disorders); feelings of shame, fear, and worry; low self-esteem and self-mastery; education; employment; dating; marriage and child-bearing; family; impairment of cognitive function; poor quality of life; “treatment gap”; specific psychosocial issues in children including post-surgery follow-up; and legal concerns, such as drivers licensing. There are also literatures specifically concerning stigma such as the on-going multi-national *CREST* Study (Collaborative Research on Epilepsy Stigma) which has a goal of developing a culturally appropriate approach to stigma reduction and a long term goal of initiating stigma reduction interventions.<sup>6</sup>

When one searches the literature for the link between “cultural” and “epilepsy”, it yields articles covering a varieties of areas, including the believed etiology of epilepsy (“*Morbus sacer*” denoting either a sacred or demoniac condition); a divine punishment, witchcraft, poisoning, contagious; fear, shame, guilt and mysticism.

Publications on “public awareness, understanding and attitudes toward epilepsy” have been covered by both “psychosocial” and “cultural” aspects of epilepsy, and have been extensively studied in different countries in this region in the past few decades.<sup>7-11</sup>

### CHARACTERISTICS OF THESE ISSUES IN ASIA-PACIFIC REGION

There are wide varieties of cultural and religious backgrounds in the Asia-Pacific region, many of

which are significantly different from the western world. The studies from this region on the general belief in the etiology of epilepsy, understanding of epilepsy, and public attitudes toward patients with epilepsy indicate that many factors other than the degree of seizure control influence the quality of life for patients with epilepsy.<sup>7-11</sup> Some studies in this region have looked into some specific research topics. The following are a few examples.

The gender issue has been studied in Pakistan, showing that there are many more difficulties for female patients with epilepsy in coping with pressure from society and family, and female epileptic patients tend to internalize the prejudice and discrimination.<sup>12</sup>

Employment issues were studied in Korea which indicated that the employment rate for Korean patients with epilepsy (PWE) was as high as 31%, which was five times higher than that of the general population. Actual discriminatory practices in the employment of PWE were prevalent in Korea, and there were 24.5% who had been treated unfairly at work. More than half of those who disclosed their disease to employers reported that they had been refused a job because of epilepsy.<sup>13</sup>

Although public awareness, understanding and attitudes toward epilepsy have been studied in many countries, the studies were not done with the same questionnaire or conducted at the same period of time, and therefore, a sensible comparison between countries is difficult. Furthermore, in one of the surveys on Knowledge, Attitudes and Practice on Epilepsy (KAPE) conducted among Chinese living in China, Taiwan, Malaysia, Singapore, and Hong Kong, Lim commented that similarities as well as differences were found in certain aspects of KAPE, and he has thus suggested that knowledge, attitude and practice might not be uniform among other racial groups in the same or different regions of Asia.<sup>14</sup>

### **PROPOSAL OF RESEARCH PRIORITIES ON PSYCHOSOCIAL AND CULTURAL ISSUES IN EPILEPSY**

We would like to propose the formation of a research committee under the Commission on Asian & Oceanian Affairs (CAOA) to focus on psychosocial and cultural aspects of epilepsy with representatives from different member countries. The committee will discuss general issues, as well as idiosyncratic issues affecting their respective individual countries.

The committee members shall share the population characteristics of their countries, which include the following demographic data: country; composition of the population in ethnicity or race, gender (including the proportion of population); religion (including the proportion of population); education levels; language; employment; legal regulation concerning PWE's driving and status of employment; stigma; and degree of sophistication in medical care for PWE. An extensive collection of these data will have tremendous values on comparative study between countries. Furthermore, quality of life and perception of stigma can be incorporated into these studies.

The committee shall work together to design a uniform study protocol in collecting data on "public awareness, understanding and attitudes toward epilepsy" and "patients' perception of having epilepsy." The survey can be done among the general population, patients with epilepsy (PWE), family members of PWE, health providers, or school teachers. The questionnaire can either adopt Gallop's survey or KAPE, or be designed by the research committee. Since this region has tremendous variety in cultural and religious background, it is suggested that the Eight Questions from Arthur Kleinman (Table 1) cited by Ann Fadiman in her awarded book, "The Spirit Catches You and You Fall Down" should be incorporated into the survey.<sup>15</sup>

Further details of the survey methods as well as research protocol can be discussed in the meeting, and the committee members can continue to meet in the AOEC.

**Table 1: Eight questions by Arthur Kleinman<sup>15</sup> to elicit the concept of illness**

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1. "What do you call the problem?"
  2. "What do you think has caused the problem?"
  3. "Why do you think it started when it did?"
  4. "How do you think the sickness does? How does it work?"
  5. "How severe is the sickness? Will it have a short or long course?"
  6. "What kind of treatment do you think the patient should receive? What are the most important results you hope she receives from this treatment?"
  7. "What are the chief problems the sickness has caused?"
  8. "What do you fear most about the sickness?"
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With concerted effort, the study can be launched in the same period of time with the same standardized questionnaire in their own language. Such an ongoing concerted effort to study the cultural and psychosocial aspects of epilepsy will help members of our organization better appreciate how to learn from each other, and to delineate the influence of religion and culture upon the psychosocial aspect of epilepsy. We sincerely hope that we can all work together to effectively alleviate social discrimination against PWE, and improve the quality of life of PWE in the Asia-Pacific region.

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