

PSYCHO-SOCIAL ISSUES

Public awareness, understanding and attitude towards epilepsy in Bandung, Indonesia

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Background and Objective: Epilepsy is generally perceived negatively as a lifelong, incurable disorder and is frequently thought of as a punishment for evil deeds. Having a person in the family with epilepsy is a stigma. This problem is not only happening in Indonesia, but also in communities around the world.¹⁻⁴ The aim of this survey was to investigate the awareness, understanding and attitude towards epilepsy in a population of Indonesian public.

Methods: A face-to-face questionnaire interview survey was conducted by the author, 12 trained medical students and neurology residents at the Hasan Sadikin Hospital outpatient clinic from January to March 2004. The hospital was the regional referral hospital for West Java area. The words *ëayaní* or *ësakalorí* in Indonesian and Sundanese were used as substitutes for epilepsy if the respondent was not familiar with the word epilepsy. The list of questions asked were: 1. Are you an epilepsy patient? 2. Are there any of your family members suffering from epilepsy? 3. Have you ever heard the word *ëpilepsyí*? 4. Can you describe an epileptic seizure if you had ever witnessed one? 5. Do you think epilepsy is a contagious disease? 6. Do you think epilepsy is inherited? 7. Do you think epilepsy can be cured? 8. Should epilepsy patients take medication regularly, or only when seizures occur? 9. Do you think epilepsy patients can study as well as nonepilepsy ones? 10. Do you think epilepsy patients can work as well as nonepilepsy ones? 11. Do you think epilepsy patients can be married?

Results: One thousand subjects consisted of 463 men and 537 women; with mean age 39 years for men and 36 years for women were interviewed. Most subjects were secondary-school graduates (42%). Forty-one subjects were epilepsy patients, who were excluded from this analysis.

On awareness of epilepsy, 97% of the 959 respondents had heard of epilepsy. Of these, 84% had witnessed an epileptic seizure. On understanding of epilepsy, most of the respondents (91%) identified convulsions as epileptic attacks, either occurred spontaneously or triggered by fever or stimulus. Period of loss of consciousness was identified by 2%, and impaired consciousness by 0.8% only. Of those who heard of epilepsy, some identified epilepsy wrongly as a type of stroke, dizziness, heart attack, central nervous system infection, febrile convulsion, syncope, insanity, mental retardation or other psychiatric illnesses. Some thought epilepsy was triggered by seeing water or fire. Twelve percent of the respondents believed that epilepsy could be passed by patient's saliva, 4% was uncertain of the answer. Forty-nine percent believed that epilepsy was inherited, 5% was uncertain of the answer. Eighty-five percent thought that person with epilepsy should take antiepileptic drugs regularly, 82% agreed epilepsy could be cured. On attitude towards epilepsy, 92% agreed that a person with epilepsy could be married; 79% and 82% respectively agreed that epilepsy patients could work and study as can a person without epilepsy.

Conclusions: This study documented high awareness about epilepsy amongst the general public in Bandung, Indonesia, particularly convulsive form of seizures. There were however, a lot of misunderstanding about the nature of epilepsy.

References

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