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Self-perception of Stigma among Epilepsy Patients in Malaysia

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Abstract

Introduction: Epilepsy remains a stigmatised disease across geographical and temporal boundaries. Very little is known about epileptic stigma (ES) in cross-cultural settings. The aim of this study was to assess the prevalence of perceived stigma and factors associated with it, among patients with epilepsy (PWE) at a tertiary care referral hospital in East Coast of Malaysia. Methods: A cross sectional survey among 132 consenting PWE using pre-tested, semi-structured questionnaire in Malay/English language to assess their knowledge, attitude and practices (KAPs). Results: Among 132 respondents, 51.5% were male and 48.5 % were female. Their age ranged from 14 to 70 years (mean=31.6 +/- 13.41). Majority (53.8%) of them were aged 30 years or younger. The median number of years they had epilepsy was 8.0 (IQR 4.0-18.8) years and average duration of seizure prior to seeking medical attention was 1.0 (IQR 0.3-4.5) year. Most of them (90.9%) did not know the cause of epilepsy; however nearly all (91.7%) believed that it was a disease of the brain. Higher education level respondents possessed significantly higher KAP scores compared to lower education level respondents ($p < 0.001$). Respondents with good KAP scores believed that epilepsy was not contagious and they observed greater social tolerance. Conclusion: Our study suggests that there is an inverse relationship between knowledge and ES. Self-perceived stigma was more common among our PWE. The results suggest that there is a critical need to enhance epilepsy education amongst the PWE beyond mere seizure control.

Keywords

Author Keywords: Epilepsy; stigma; attitudes; prejudice; Malaysian population

KeyWords Plus: QUALITY-OF-LIFE; PUBLIC AWARENESS; ATTITUDES; KNOWLEDGE; POPULATION; PEOPLE; VIETNAM; ADULTS; ZAMBIA; IMPACT

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