Original article:

Assessment of Knowledge, attitude and practices of Epilepsy Patients' towards their illness and treatment in a tertiary care hospital in Kuantan Pahang Malaysia

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Abstruct:

***Objective**: Patients beliefs determine their response to an illness and its management especially if it is chronic. Studies assessing patient's knowledge of their epilepsy are scarce. We report the first objective study evaluating knowledge, attitude and practices of epilepsy patients referred to a tertiary care centre in East Coast of Malaysia. ***Materials and Methods**: A cross sectional study using pre-tested, semi-structured questionnaire among consenting epilepsy patients. ***Results**: The demographic details and responses to a questionnaire assessing their insight towards epilepsy were recorded. Among 132 respondents, 51.5% were male and 48.5 % were female. Their age ranged from 14 to 70 years (mean = 31.63 ± 13.41). Majority (53.8%) of them aged equal or less than 30 years. The median number of years they had epilepsy was 8.0 (4.0, 18.8) years and average duration of seizure prior to seeking medical attention was 1.0 (0.3, 4.5) years. The average number of years they were receiving treatment from a hospital was 5.50 ± 5.84. Most (90.9%) did not know the cause of epilepsy; however 93.9 % were aware that it can be treated with modern drugs. While only 22.7 % believed that faith healers can treat epilepsy, 74.2% had tried other forms of treatment. Negative attitude was reflected in the belief that epilepsy is due to supernatural powers (1.5%) and that epilepsy is contagious (17.4 %). Positive attitude included that PWE can take a job (66.7%), allowing a child with epilepsy to study (80%), not objecting children to play with a child with epilepsy (54.5%), marry (65.9%) and having children (58.3%). ***Conclusions**: Patients with epilepsy are not knowledgeable about their disorder. This is true regardless of age, educational background, or number of years with epilepsy. The results suggest that there is a critical need to enhance epilepsy education and improve attitudes towards epilepsy beyond seizure control.

Keywords: Attitude; Epilepsy; Knowledge; Practice; Seizure

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Introduction

Epilepsy is one of the most common neurological disorders affecting approximately 1% of people in the world.[1]It can affect any one at any age, in any race or social class, but is more prevalent in early years of life.[2]Worldwide more than 50 million people suffer from it, 80% of whom live in economically backward and developing countries. [3] Although around 70 % of them respond to anti-epileptic treatment and are seizure-free, up to 25% suffer from refractory forms

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of epilepsy which prevents them from living an independent life.[3-6]

Epilepsy is a major public health problem which provokes a variety of medical, social, psychological and economic burdens especially in developing countries where its incidence and prevalence are thought to be several-fold higher.[7,8]Despite scientific advances in its diagnosis and therapy, misconceptions about its cause and treatment still exist.[9] Although seizure control is the mainstay of epilepsy treatment, patient education is critical to improve attitudes andproper coping mechanisms.[10] In the West, several studies have reported thatpeople with epilepsy (PWE) knew only a little more, and in some cases even less, about their disorder than those without epilepsy.[11-17]Further recent studies have highlighted that PWE are dissatisfied with information provided to them by medical personnel.[10, 18-19]The other factors which influence the nature of treatment and care received by PWE include religious and socio-cultural beliefs and knowledge about its aetiology and curability. Therefore, it is important that they understand their illness and its management which is particularly important to enhance medication adherence.The present study was aimed to obtain information on knowledge, attitudes and practices (KAP) of epilepsy patients attending a tertiary care referral hospital in East coast of Malaysia and compare it with the published data from Malaysia.

Materials and Methods:

A cross-sectional descriptive and analytical study was carried out among 132 PWE attending out-patient department of the neurology clinic in Hospital Tengku Ampuan Afzan (HTAA) Kuantan, a tertiary care referral centre affiliated to faculty of Medicine, International Islamic university Malaysia (IIUM) from Dec 2014 to March 2015.

Ethics: The study protocol was approved by the ethical committees of both the HTAA and the faculty of Medicine, IIUM as well as National institute of health. Epilepsy patients of all ages (14 and above on treatment for >2 years) were included whereas those with secondary causes of epilepsy like stroke, brain tumour, and any co-morbid systemic or psychiatric illnesses were excluded. PWE who gave their consent were interviewed in the local language (Malay) or English, which ever they were proficient using pre-tested, semi-structured epilepsy Patient Knowledge Questionnaire. The questionnaire focused on collecting information regarding socio demographic characteristics, seizure characteristics, number of years with epilepsy, knowledge regarding cause of epilepsy, current medical treatment, alternative forms of treatment taken, and perceived stigma. The responses were recorded as 'yes', 'no' and 'Neutral/ not sure' where appropriate. In those patients who were not able to provide complete details, parents/ caregivers were also interviewed.

Statistical analyses were carried out using Statistical Package for Social Sciences (SPSS) for Windows version 22.0. Mean and standard deviation for each of the demographic, epilepsy data, and KAP were recorded. Statistical significance was evaluated by the use of Chi-square test. Kruskal-Wallis test was used to compare median of two groups. The p-value$\leq$0.05 was considered significant.

Table 1: Socio-demographic profile of respondents (n=132)

		Number (%)
Age (completed year) Median(25th, 75th centiles		28.5(21.0,37.8)
Gender	Male	68 (51.5)
	Female	64(48.5)
Race	1. Malay	98 (74.20)
	2. Chinese	27 (20.5)
	3. Indian	7 (5.3)
	4. Others	0 (0.0)
Religion	1. Islam	99 (75.0)
	2. Buddhism	11 (8.3)
	3. Christianity	4 (3.0)
	4. Hinduism	4 (3.0)
	5. Others	14 (16.0)
Marital status	1. Single	82 (62.1)
	2. Married	49 (37.1)
	3. Divorced	-
	4. widowed	1 (0.8)
Education level	1. No formal education	11 (8.3)
	2. Primary	20 (15.2)
	3. Secondary	81 (61.4)
	4. Tertiary level (College or University)	20 (15.2)
Occupation of patient	1. Unemployed	43 (32.6)
	2. employed	60 (45.5)
	3. Student	23 (17.4)
	4. House wife	6 (4.5)
	5.Dependent	-
	6. Others	-
Estimated average monthly total family income	(Ringgit Malaysia*)	
	<1,000	31 (23.5)
	1,000-5,000	94 (71.2)
	5,001 – 10, 000	6 (4.5)
	>10,000	1 (0.8)

Results: Out of 162 patients interviewed only 132 PWE were included who fulfilled our inclusion criteria. The demographic details of patients are shown in Table 1.

There were 132 patients of which 68 (51.5%) were male and 64 (48.5 %) were female. Majority of respondents were Malay (74.20%), Muslim (75.0%), and their age ranged from 14 to 70 years (mean = 31.63 ± 13.41). Majority (53.8%) of them aged equal or less than 30 years. A high proportion (62.1 %) were single, 37.1% were married, 0.8% widowed. Forty-five point five percent (45.5%) of respondents were currently in paid employment. In all, 9.1% of respondents said that patient with epilepsy cannot take up a job. The median number of years they had epilepsy was 8.0 (4.0, 18.8) years and average duration of seizure prior to seeking medical attention was 1.0 (0.3, 4.5) years. The average number of years they were receiving treatment from a hospital was 5.50 ± 5.84. Thirty seven point three percent (37.3%) were seizure free, 57.9% had between 1-5 epileptic attacks per month, and 4.8% had between 6-10 attacks per month. There were only 8.3% respondents who were illiterate while 61.4% had secondary education and 15.2% had tertiary level education. Majority of them (71.2%) belonged to the middle socioeconomic strata.

Table 2: Knowledge of respondents on causes of epilepsy and alternative forms of treatment

Questions		Number (%)
C1. Do you know the cause of your disease (epilepsy)?	1. No	120 (90.9)
	2. Yes	12 (9.1)
C1. If yes,	1. Disease of the brain	121 (91.7)
	2. Due to supernatural powers/evil spirits	2 (1.5
	3. Familial	2 (1.5)
	4. Mental disorder	
	5. Ignorant	
	6. Others	
C2. Can faith healers treat epilepsy	1. No	98 (74.2)
	2. Yes	30 (22.7)
C3. Have you tried any other forms of treatment	1. No	34 (25.8)
	2. Yes	98 (74.2)
C3. If yes,	1. Spiritual	2 (1.5)
	2. Indigenous	14 (10.5)
	3. Chinese medicine	
	4. Naturopathy	
	5. Ayuvedic	
	6. Others	

The responses to the questionnaire (Table 2) show that most respondents (90.9%) did not know the cause of epilepsy; however 91.7% thought that it was disease of the brain. None of our respondents believed that it was a mental illness or insanity; however 17.4 % believed that it was contagious. While only 22.7% respondents believed that faith healers can treat epilepsy, 74.2% had tried other forms of treatment. Knowledge, attitude and practices of respondents are depicted in table 3.

Table 3: Knowledge, attitude and practices of respondents

		Number (%)
D1. Do you know what was done by other person (your relative or the person who attended you) while you had epileptic attack/fit	1. Take me (patient) away from dangerous site	2 (1.5)
	2. Take me (patient) to hospital	1 (0.8)
	3. Put a spoon in my mouth	
	4. Make me (patient) smell a shoe	1 (0.8)
	5. Other	
D2. Do you know that epilepsy is treatable with modern drugs? (K)	1. Yes	124 (93.9)
	2. No	6 (4.5)
D3. Do you agree that epilepsy is treatable condition? (A)	1. Yes	129 (97.7)
	2. No	3 (2.3)
D4. Are you being treated by a Medical Doctor (P)	1. Yes	132 (100.0)
	2. No	-
D5, Where have you taken treatment from? (P)	1. OPD of government hospital	130 ((8.3)
	2. Public clinic	1 (0.8)
	3. Private clinic	1 (0.8)
	4. Others	-
D6. Do you know you should take regular treatment for your disease? (K)	1. Yes	129 (97.7)
	2. No	2 (1.5)
D7. Do you accept that you should takeregular treatment (A)	1. Yes	121 (91.7)
	2. No	4 (3.0)
	3. Neutral	7 (5.3)
D8. Do you attend regular follow-up at your clinic? (P)	1. Regular	120 (90.9)
	2. Sometimes	12 (9.1)
D9. Do you know that you will be benefited by taking regular treatment? (K)	1. Yes	107 (81.1)
	2. No	4 (3.0)
	3. Neutral	21 (15.9)
D10. Did you benefit from medical treatment? (P)	1. Yes	102 (77.3)
	2. No	30 (22.7)
D11. Effect of medical treatment on your disorder (K)	1. Decreased frequency of fits	68 (51.5)
	2. Stopped	25 (18.9)
	3. No change	32 (24.2)
D13. Current seizure frequency after taking treatment? (Average/month) Median (25th, 75th centiles)		1 (0,3)
14. What is your perception on the cause of break-through seizure? It is due to	1. Non-compliance	10 (76.0)
	2. Intercurrent infection	33 (25.0)
	3. Side-effects of treatment	5 (3.6)
	4. Other	

Certain practices during an epileptic attack, such as putting a spoon in the mouth, were mentioned by 0.8% of respondents. A large majority (94%) of them were aware that epilepsy can be treated with modern drugs and 90.9% of them attended their clinic appointment regularly. Social impact of epilepsy is shown in table 4.

Table 4: Social impact of epilepsy

		Discrimination type					
		Relatives	Community	Work mates	Others and > 1 discrimination	No answer	P-value
Age group (years)	<20	0 (0.0)	3 (50.0)	0 (0.0)	2 (7.4)	20 (21.1)	0.371
	20 - 40	2 (66.7)	2 (33.3)	0 (0.0)	18 (66.7)	56 (58.9)	
	41 - 60	1 (33.30	1 (16.7)	1 (100.0)	5 (18.5)	15 (15.8)	
	>60	0 (0.0)	0 (0.0)	0 (0.0)	2 (7.4)	4 (4.2)	
Gender	Male	0 (0.0)	5 (83.3)	0 (0.0)	11 (40.7)	52 (54.7)	0.80
	Female	3 (100.0)	1 (16.7)	1 (100.0)	16 (59.3)	43 (45.3)	
Occupation	Unemployed	1 (33.3)	2 (33.3)	0 (0.0)	7 (25.9)	33(34.7)	0.001
	Employed	1 (33.3)	2 (33.3)	0 (0.0)	17 (63.0)	40 (42.1)	
	Student	0 (0.0)	2 (33.3)	0 (0.0)	3 (11.1)	18 (18.9)	
	House wife	1 (33.3)	0 (0.0)	1 (100.0)	0 (0.0)	4 (4.2)	
Education	No formal education	1 (33.3)	0 (0.0)	0 (0.0)	1 (3.7)	9 (9.5)	0.628
	Primary	1 (33.3)	2 (33.3)	0 (0.0)	6 (22.2)	11 (11.6)	
	Secondary	1 (33.3)	4 (66.7)	1 (100.0)	16 (59.3)	59 (62.1)	
	Tertiary	0 (0.0)	0 (0.0)	0 (0.0)	4 (14.8)	16 (16.8)	

Discrimination by relatives, community, workmates and others was reported by 2.3 %, 5.5 %, 0.8% and 12.9% respectively while majority of them (72.0%) were not sure whether they were stigmatized.

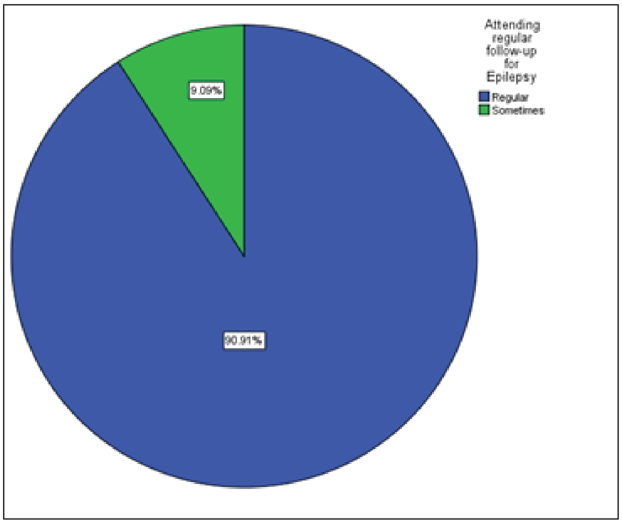

Figure 1: Percentage of compliance to follow-up

Discussion

The present study aimed to obtain information on KAPs of PWE in east coast of Malaysia. Our patients had chronic epilepsy and majority of them were young adults. They had limited knowledge regarding the cause, nature, and treatment of epilepsy, irrespective of their age, educational background and duration of epilepsy, a finding similar to other Asian studies.[20-24]This might indicate lack of adequate education by the health professionals.[25-27]On comparing of our data with previousMalaysian studies we had difficulty in drawing conclusions due to differentcategory of study population.While our study included PWE, the other studies were conducted to evaluate public awareness. PWE are likely to have less negative attitudes than the public. Some general inferences however can be drawn.Analysis of these studies revealed regional differences in KAPs which could be attributed to local factors, such as literacy, awareness about epilepsy, and category of study population. [28-31]Survey conducted on predominantly Malay population in Kelantan, Malaysia, (2000) found that respondents were familiar with epilepsy but many maintained a negative attitude and had poor knowledge on causation and treatment of epilepsy.[28] Another survey (2002) carried out among the university students in University Sains Malaysia indicated favourable level of awareness and knowledge of epilepsy but (70%) of students did not know the cause of epilepsy, 67% believed that it was acquired through inheritance and 5% thought that it was caused by evil spirits.[29] Similarly another study (2009) was carried out in rural areas of East Coast Peninsular Malaysiaamong rural residents. The survey revealed poor awareness and knowledge among respondents.[30]Yet another study (2010) conducted among Chinese population in the selected areas of peninsular Malaysia revealed good knowledge and positive attitudes toward certain aspects of epilepsy but minority of the study participants demonstrated prejudice and discriminatory behaviour towards PWE.[31]

Therewas no significant difference in KAPs based on gender among the respondents in this study. In Malaysia both males and females have equal opportunities in the fields of education, occupation, etc. which can probably explain such results. It could also mean that both males and females received equal exposure with regard to this disease in Malaysia. This particular finding was supported by other Malaysian studies, who claimed that gender did not have a significant association with the awareness of epilepsy.

Among our respondents discrimination by relatives, community, workmates and others was reported by 2.3 %, 5.5 %, 0.8% and 12.9% respectively while majority of them (72.0%) were not sure whether they were stigmatized. From this we speculated that they had self-perceived stigma, which was quite high, a finding similar to other studies.[32-33]PWE assume that they are stigmatised by others even without any such encounter, which causes them to adopt coping strategies through social isolation and withdrawal. Attitude plays an important role in the well-being of PWE as well as the overall success of therapy. Their positive attitude included that they can take a job (66.7%), allowing a child with epilepsy to study (80%), not objecting children to play with a child with epilepsy (54.5%), marry (65.9%) and having children (58.3%). However their negative attitude was reflected in the belief that epilepsy was due to supernatural powers (1.5%) and that epilepsy was contagious (17.4 %) which was a matter of concern. Low levels of literacy and limited medical information contribute to the persistence of these negative cultural beliefs. In many parts of Africa and Asia, epilepsy is considered to be contagious and 17.4% of our respondents felt that epilepsy was contagious. In Nigeria, epilepsy is commonly thought to be contagious, even by medical students; and consequently, PWE may not be attended to during or after seizures, when simple forms of care could prevent dangerous situations.[34]

Despite the fact that epilepsy is still classified with mental illnesses in the health care structure of many countries, none of our respondents believed that it was a mental illness or insanity, which was positive compared to earlier studies done in Malaysia, Vietnam and in South India where 23%, 20.5% and 27.3%, respectively thought epilepsy as type of a mental illness.[28,35,36] The possible reason behind this could be the education level of our respondents, 61.4% of whom had secondary education and 15.2% had tertiary level education. In this study, majority of the patients, (94%) believed that epilepsy can be treated with modern drugs and 90.9% of them attended their clinic appointment regularly.

Even though, Malaysia has established medical services to the international standard and with evidence base practices provided by medical professionals, patients still prefer to use complementary and alternative medicine (CAM) for their illness beside the modern medicine. This is due to their belief that the combination of both CAM and modern medicine will complement each other to cure the disease faster and solve the problem better. Majority of our respondents believed that epilepsy was treatable with modern drugs; most of them (74.2%) had undergone spiritual and traditional treatment previously. Modern treatment, even when well applied, may not seem to be sufficient for the patients and theyoften turn to CAMin desperation for a cure, often under the influence of their families and friends.[37]For example in Kelantan Malaysia, strong emphasis is given on religious practices predominantly among Muslims. On the contrary, the Chinese in Malaysia prefer alternative medicine such as herbal medicines and dietary supplements for healing epilepsy. The CAM of epilepsy remains very popular and is still widely used in many developing countries. It is very hard to control this practice because the CAM sometimes works well in certain disease. It needs to be placed into its socio-cultural context utilizing a holistic approach. It is so rampant and deep rooted in society, especially among the rural and uneducated folk living in the far flung areas of developing countries, that any attempt to oppose them could prove counterproductive. In such circumstances, traditional healers can interfere with timely and appropriate medical interventions.

PWE often choose CAM alone or adjacent to antiepileptic drugs (AEDs) because they believe that natural remedies are better and safer than prescribed AEDs to treat their chronic condition.[38] Since the efficacy and safety of CAM treatment are not yet well documented,this phenomenon thus highlights the need of educational campaigns among PWE and their families as well as the general public to improve their knowledge of epilepsy. Further studies need to be conducted on CAM to ensure their safety and efficacy so that the patients are not be kept in dilemma whether to follow physician's advice or to listen to those who have experience on CAM. Knowledge of CAM would also place treating physicians in a better position to advice on their safety and compatibility. PWE need regular assessment during follow up and theyshould be provided necessary information based on their individual concerns. Rather than just trying to "control seizures," the modern goal of epilepsy therapy has risen to "no seizures, no side effects. Although this goal will not be achievable in all patients, many patients will respond to systematic trials of new AEDs and other therapies.

In recent years, the interest in educational programs for PWE has been growing in different countries.[39-42] Patient education is an effective component of comprehensive care and improving patients' knowledge has been suggested to improve their symptoms and prognosis. A study carried out in Hungary demonstrated that educational campaigns are effective in changing as well as improving knowledge about epilepsy among the population and diminish the negative attitudes against PWE.[43] The international league against epilepsy (ILAE), which represents medical practitioners and scientists and the international Bureau for epilepsy (IBE), which acts on behalf of patients and their families, have joined World Health Organization (WHO) in launching the global campaign to improve the treatment and social acceptance of epileptic patients.[44] However, changing attitudes is a challenging task than increasing knowledge.

There are some limitations to this study. The patients were approached from the neurology clinic of a tertiary care Hospital where they followed-up; hence the results may not be reflective of the whole of Malaysia. Secondly, there is potential for information bias; PWE may have attempted to answer the questions in ways they perceived as socially desirable, rather than revealing the whole truth. Furthermore, the use of structured questions does not allow detailed exploration about a condition such as the one under investigation here.

Conclusion: Irrespective of demographic parameters such as age, education and duration of the illness, PWE had limited knowledge about their disorder. The majority of the respondents believed that epilepsy was not contagious and had greater social tolerance. Most of them were on modern modes of treatment, but CAM was still practiced. The results suggest that there is a critical need to enhance epilepsy education and improve attitudes towards epilepsy beyond seizure control.

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