

Difficulties and Challenges in the Management of Childhood Epilepsy: An Experience in an Epilepsy Clinic of Dhaka Shishu (Children) Hospital

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Abstract

Introduction: Epilepsy is the commonest chronic neurologic disorder in children, affecting about 10.5 million children in the world. Successful management of epilepsy begins with an accurate diagnosis, followed by treatment with an appropriate anti-epileptic drug (AED) with proper dose and duration. Treatment gap and dropout is a barrier to control this disease.

Objectives: To ascertain the difficulties and challenges for the optimum management of childhood epilepsy.

Methods: This retrospective observational study was conducted in an epilepsy clinic of Paediatric Neuroscience Department of Dhaka Shishu (Children) Hospital (DSH) over a period of 3 years from January 2013 to December 2015. During this period 1 year follow up record of each patient was analyzed. Information on bi-demographic data, clinical and developmental assessment made by a multidisciplinary team was analyzed.

Result: Out of 120 patients, 37 (31%) were reported with controlled epilepsy, whereas 40 (33%) were uncontrolled. The major difficulties among total respondents were found non adherence (50%) to drugs and dropped out (35.8%) from the treatment. After association of different predictors with drop out from treatment only medium adherence 16.9%, low adherence 69.8% to drug found as significant predictor ($p < 0.001$). Among the challenges feeding

difficulties (28%), malnutrition (24%) and ignorance (20%) were the leading causes.

Conclusion: Management of childhood epilepsy in underdeveloped country is very challenging. To overcome the difficulties appropriate counseling and education is needed at first. Secondly, by ensuring the cheap and high-quality drugs, this difficulty can be overcome.

Keywords: Antiepileptic drug (AED); Epilepsy; Drug non-compliance; Dropout.

Introduction

Among the chronic neurologic disorders epilepsy is common that affect around 70 million people worldwide.¹ On the other hand it is also the most common condition encountered in most pediatric neurology clinics in many parts of the developing world²⁻⁴ and studies have supported that they are associated with significant sociocultural, economic and health implications in the developing countries.⁵⁻⁷ Epilepsy is a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures, and by the neurobiological, cognitive, psychological, and social consequences of this condition. The definition of epilepsy requires the occurrence of at

least one epileptic seizure.⁸ Although epilepsy is a global disease with an unequal distribution, it is predominant in low-and middle-income countries (LMIC).⁹ The median lifetime epilepsy prevalence in rural areas of developing countries is 15.4 per 1.000 whereas for developed countries it is 5.8 per 1.000.⁹ In high income countries the incidence of epilepsy is 45/100.000/year, compared to 81.7/100.000/year in LMIC.¹⁰ Epilepsy is regarded a treatable condition which has high rates of therapeutic response. It is well known that about 70% of patients with epilepsy are controlled with antiepileptic drugs (AED).¹¹ Durkin et al. reported that in Bangladesh, prevalence rate of 68 out of every 1000 for any seizure history and 9 out of every 1000 for any unprovoked seizure, in children aged 2 to 9 years.¹² Another study reported that in Bangladesh, symptomatic epilepsy was found in 61% and among them generalized, partial, and unclassifiable epilepsy were found in 63.6%, 25.2%, and 11.2% respectively. Epilepsy syndromes were diagnosed in 14.6% which had poor outcome.¹³

Effective management of epilepsy begins at first with an accurate diagnosis that is followed by an appropriate antiepileptic drug (AED) in a sense that optimizes efficacy. The ultimate goals of pediatric epilepsy treatment include: Significant seizure reduction/complete seizure control, absence of adverse drug reactions and assuring appropriate development and the best quality of life for the child.¹⁴ For many reasons treating pediatric epilepsy in resource-poor countries are challenging to the clinicians. Even today epilepsy is considered by many as medically incurable.¹⁵ Before seeking medical treatment most of the people apply various traditional and spiritual remedies that offer no proven efficacy. Some local health professionals are also unaware of the long-term treatment required in epilepsy care.^{14,15} Due to their lack of knowledge they are treating epilepsy by antiepileptic drugs in an insufficient dose and duration.¹⁰ Nonadherence to prolong treatment with AED may be one of the reasons for poor response and thus lack of confidence to the population place in medical treatment of epilepsy.^{14,16} Moreover, many CWE are treated with suboptimal doses of AEDs before referral leading to poor seizure control.¹⁷ Significant adverse effects occur when such patients receive relatively high doses of these medications. A major cause of seizure breakthrough is noncompliance which is a serious barrier to successful treatment.^{16,18} The reasons for noncompliance include inadequate dosing, complicated regimens, treatment costs and adverse drug reactions.¹⁵ Forensuring higher

rates of compliance once or twice daily dosing is preferred.¹⁹

The communities of South-East Asia have so many myths and misconceptions about epilepsy. Epilepsy, is thought to be a punishment for evil deeds or the breaking of certain taboos. These myths and misconceptions often prevent people with epilepsy from seeking medical treatment. The strange behavior caused by some forms of epilepsy has led to a common rural belief that epilepsy is due to "possession by spirits". In some parts of India, Indonesia, Nepal, Sri Lanka and Thailand, people believing in supernatural powers at work offer worship and animal sacrifice. In Bangladesh, rural people consider epilepsy as the "spell of Satan" locally known as "batash" (bad wind). Many epidemiological studies have focused on different challenges in treating epilepsy that are social stigma, poverty, ignorance, and distorted beliefs and practices.^{15,20} To find out the difficulties and challenges this study is designed.

Materials and Methods

This retrospective observational study was conducted in an epilepsy clinic of Paediatric Neuroscience Department of Dhaka Shishu (Children) Hospital over a period of 3 years from January 2013 to December 2015. During this period one year followup record of each patient was analyzed. Total 120 patients were enrolled in the study and they were purposively selected for the study from every consecutive day during the period. Information on biodemographic data, clinical and developmental assesment made by a multidisciplinary team was analyzed. Children with diagnose case of epilepsy less than 18 years were enrolled in the study. Follow up was done up to 1 year and adherence questionnaire were asked at 6 months follow up. Seizure was classified as generalized tonic, generalized clonic, focal seizure, myoclonic and absence seizure.

Those who were seizure free for at least 6 months or more were defined as having controlled seizures. Patients who had seizures in previous 6 months were labeled as having uncontrolled seizures. We have used MMAS-8 scale (Morisky Medication Adherence Scale) to see the drug adherence. The 4item Morisky-Green-Levine Medication Adherence Scale was developed in 1986 to assess antihypertensive medication adherence. Then, the 8item MMAS was developed. MMAS4 and the more recent MMAS8 have both been validated (MMAS4 alpha

reliability = 0.61; MMAS8 alpha reliability = 0.83), and their concurrent validity has been assessed among hypertensive patients (Pearson correlation = 0.64; $p < 0.05$). They are commonly used, patient reported questionnaire, simple to understand and easy to administer. These scales have been also used to assess medication adherence in studies of other chronic diseases such as neurological disease, cardiovascular diseases, asthma, diabetes and cancer.

All items of questionnaire were scored as either zero (No) or one (Yes) except of item five which scored as zero (Yes) or one (No) and the last item which scored zero (Never) and one for other answers. Adherence was categorized as high, medium and low. Score 8 considered as high adherence, score 6–8 medium adherence and score < 6 is low adherence.²¹

All data were incorporate in SPSS version 23.

And to see the association chi square or ANOVA test were done.

Results

Total 120 patients of epilepsy were analyzed for the study period. Most of the patients were diagnosed case of focal epilepsy 37.5% and other were generalized tonic (26.7%) or clonic (17.5%) (Fig. 1). Out of 120 patients 31% (37) were reported with controlled epilepsy, whereas 33% (40) were uncontrolled and 35.8% (43) were dropped out from the study (Table 1). It was noted that 11.63% (5) were drop out after first visit, 53.49% (23) within 6 months and rest 34.88% (15) within 1 year (Table 1). We considered gender, educational status of parents, comorbidities, drug adherence, social status as challenges for dropout. Drug non adherence is found only as independent predictor for dropout (Table 2).

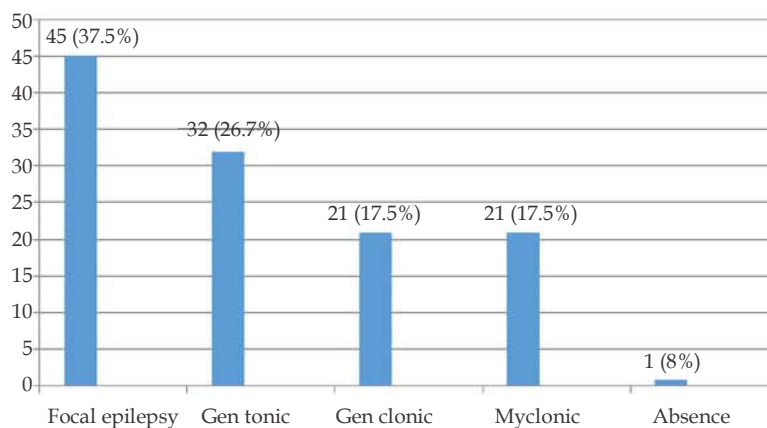


Fig. 1: Distribution of epilepsy patients according to classification.

Table 1: Distribution of epilepsy patients according to treatment response

Variables	Frequency	Percentage
Seizure controlled	37	31.00
Seizure uncontrolled	40	33.00
Dropout	43	36.00
After 1 st visit	5	11.63
Within 6 month	23	53.49
After 6 m-1 yr	15	34.88

Table 3: Association of different predictors with dropout from treatment

Predictors	Drop Out		p-value
	Yes	No	
Patient Adherence			
High adherence	0 (00)	2 (100)	0.001
Medium adherence	13 (16.9)	64 (83.1)	
Low adherence	30 (69.8)	11 (14.2)	

(Contd.)

Predictors	Drop Out		p-value
	Yes	No	
Comorbidities			
Neurological	41 (37.6)	68 (62.4)	0.280
Physical	0 (00)	4 (100)	
Psychiatric	2 (28.6)	5 (71.4)	
Gender			
Male	28 (40.6)	41 (59.4)	0.143
Female	15 (29.4)	36 (70.6)	
Education status of parents			
Illiterate	4 (36.4)	7 (63.6)	0.677
Primary	21 (36.8)	36 (63.2)	
SSC	7 (30.4)	16 (69.6)	
HSC	4 (30.8)	9 (69.2)	
Graduate	7 (43.8)	9 (56.2)	
Economic status of family			
High class	7 (36.8)	12 (63.2)	0.925
Middle class	23 (32.9)	47 (67.1)	
Low class	13 (41.9)	18 (58.1)	

Regarding treatment outcome among different types of epilepsy, poor seizure control and drop out was more in children with focal epilepsy (Table 3). Again, uncontrolled seizure ($n = 23$) and drop out ($n = 36$) was found more in children who had no adherence with antiepileptic drugs (Table 4) and it was found significance ($p < 0.001$). It was also noted that who were treated with monotherapy treatment, dropout is comparatively

less among them to polytherapy treatment (Table 4). When we try to find out the causes of non-adherence with antiepileptic drugs, we had faced different challenges. Among the challenges feeding difficulties (28%), malnutrition (24%) and ignorance (20%) were the leading causes (Fig. 2). Other causes were high cost, cultural belief and practice, unavailability of drugs and they were 15%, 8% and 5% respectively (Fig. 2).

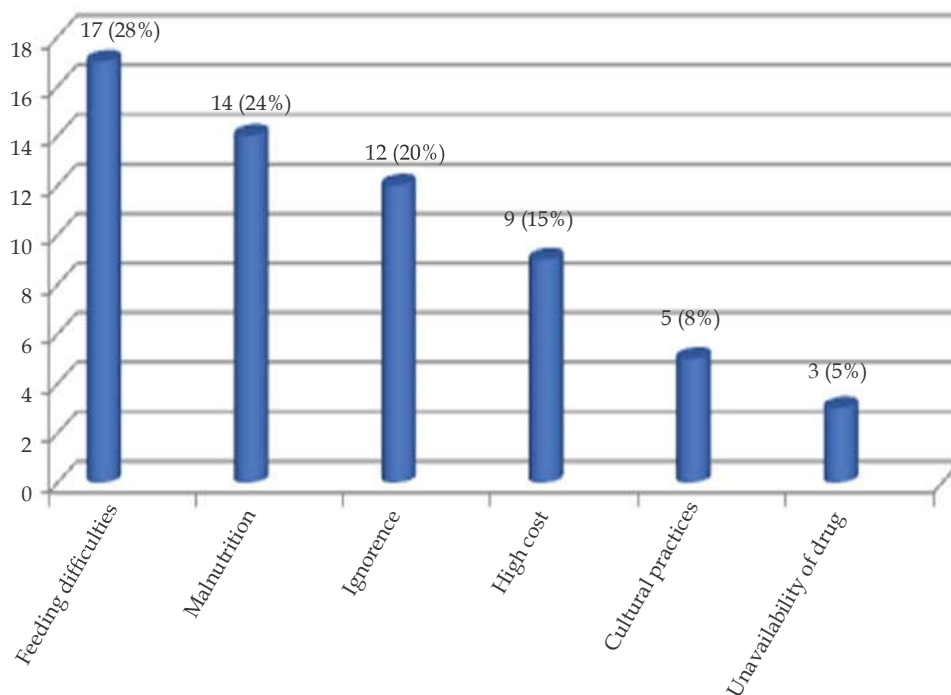


Fig. 2: Distribution of challenges to non-adherence cases ($n = 60$).

Table 3: Treatment outcome among different types of epilepsy after 1 year

Types of epilepsy	Treatment outcome after 1 year			Total
	Controlled	Didn't control	Dropout	
Gen tonic	15	8	9	32
Gen clonic	7	4	10	21
Myoclonic	5	9	7	21
Focal	10	19	16	45
Absence	0	0	1	1
Total	37	40	43	120

Table 4: Effect of treatment adherence on seizure outcome

Treatment adherence	Seizure outcome after 1 year				Total	p-value
	Controlled with monotherapy	Controlled with polytherapy	Didn't control	Drop out		
Yes	27	7	10	7	51	0.001
No	0	3	30	36	69	
Total	27	10	40	43	120	

Discussion

Epilepsy is a global disease with an unequal distribution. Overall 80% of the affected individuals reside in resource poor countries.²² Most of the epilepsies have good therapeutic response with the use of antiepileptic drugs. In this study we found that 31% of the epilepsy cases were controlled (Table 1), though this result differs from the other study where Espinosa-Jovel et al. found about 70% of patients with epilepsy are controlled with antiepileptic drugs (AED).²³ Uncontrolled seizure and dropout were found in 33% and 36% (Table 1). Among total respondents non adherence were found 50% in this study. After association of different predictors with dropout from treatment only medium adherence 16.9%, low adherence 69.8% to drug found as significant predictor ($p < 0.001$) (Table 2). This is similar to a study where Liu et al found nonadherence rate was 48.1% and Molugulu et al. found 49.3%.^{24,25} In rural Thailand, 57% of people with epilepsy were totally compliant with treatment. However, in an out-patient clinic in Brazil, 40% patients reported non-compliance at any time in the previous week. Approximately 60% either changed the medication dose or discontinued the medication, and 48% took another medicine without taking consultation from a doctor.²⁶

We found poor seizure control and dropout was more in children who had focal epilepsy (Table 3) and non-adherence to medication ($p < 0.001$) (Table 4). This is similar to a published literature where patients who had non-adherent

to their medications were found to have poor seizure control as compared with patients who were adherent to their AEDs.²⁷ In a study by Gabr and Shams, no significant difference in discontinuation of treatment was found in patients with generalized compared to focal epilepsy.²⁷ It was also noted in this study children who were treated with monotherapy treatment, dropout is comparatively less among them in polytherapy treatment (Table 4). Our findings differ from other study where Guo et al. and Sweileh et al. showed that nonadherence was not found to be associated with mono or polytherapy.^{28,29} On the other hand, some investigators have shown that patients on monotherapy were significantly more adherent than patients on polytherapy.^{27,30} The treatment of pediatric epilepsy often presents multiple challenges to clinicians in resource-poor countries for many reasons. The social stigma, superstition, and irrational beliefs are well recognized challenges that have negative impact on children and their family.³¹ In the present study, we found the challenges for non-adherence of treatment in higher proportion were feeding difficulties (28%) and malnutrition (24%) (Fig. 2). As this is a hospital-based study most of the epilepsy patient came with associated neurological and physical comorbidities like cerebral palsy. Due to the severity of the underlying neurological disability these patients have poor motor control and increased muscle tone, sucking and swallowing difficulties, drooling, food refusal, leading to malnutrition. On the other hand, due to this feeding difficulties and also insufficient knowledge about proper feeding

techniques parents failed to give AED to their child. Another two important challenges that we found in our study were ignorance (20%) and cultural beliefs and practices (8%) (Fig. 2). Actually, these two are interrelated. In Bangladesh, rural people consider epilepsy as the “spell of Satan” locally known as “batash” (bad wind). As a result, at first they seek care from faith healers such as “fakirs” or “monks” before going to a hospital. These myths and misconceptions often prevent people with epilepsy from seeking medical treatment. Another challenge in our study is high cost of the drug.

The conventional antiepileptic drugs like Phenobarbital, phenytoin or valproic acid are cheap and available in the rural area of our country. But in case of complicated epilepsy recently introduced AEDs, such as lamotrigine, topiramate; etc. are not easily available in the rural area and their costs are also very high. Most of the people in our country are poor and they could not bear their daily expenditure. So, buying antiepileptic drugs are really a burden on them. This economic issue lead to the interruption of treatment.

Our study has few similarities to a study conducted in Kilifi, Kenya, found that the main risk factors associated with epilepsy challenges were: traditional religious beliefs, negative attitudes towards medical treatment, residing far away from health facilities, the cost of AEDs, learning difficulties, long-lasting epilepsy and focal seizures.³² Another study in India found the main reasons for AEDs discontinuation were financial issues, spiritual thoughts about epilepsy and unavailability of AEDs were.³³ A study done in Thailand where Asawavichienjinda et al. showed the most frequently reported reasons for non-compliance are misunderstanding (48%), forgetfulness (16%) and economic limitation (13%).³⁴ In this study unavailability of the drugs was found in 5% (Fig. 2).

The unavailability of drugs poses a challenge to effective epilepsy care. Even though about 80% of people with epilepsy live in developing countries, only 20% of them have access to available AEDs.²² Children with epilepsy have other co-existing health conditions that can significantly affect child’s health as well as emotional, psychological and social well-being. Epilepsy is associated with a wide array of other comorbid conditions. These include learning disorders, mental retardation, psychiatric and behavioural problems, and even mortality. In this study we found that 109 had neurological comorbidity, 4 physical and 5 with psychological comorbidity.

Conclusion

As epilepsy can be controlled with appropriate treatment, it is very important to find out the difficulties and challenges to obtain it. With adequate counseling on the need for regular medications, appropriate education to dispel misconceptions about epilepsy, and the provision of cheap and high-quality drugs, this difficulty can be overcome. Extensive awareness is need to overcome these issues in the society.

Limitation

The limitation of our study is its relatively small sample size. It is a single center study. Patients were recruited only from the clinic of our hospital, and this limits the implication of results being generalize.

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References

1. Neurological and psychiatric disorders: Meeting the challenge in the developing world. Washington DC, Institute of Medicine 2001:1.
2. Izuora GI, Iloeje SO. A review of neurological disorders at the Paediatric Neurology Clinic of the University of Nigeria Teaching Hospital, Enugu. *Ann Trop Pediatr* 1989 Dec;9(4):185-90.
3. Ojuawo A, Joiner KT. Childhood epilepsy in Ilorin, Nigeria. *East Afr Med J* 1997;74:72-7.
4. Izuora GI, Anis AS. Neurologic disorders in Saudi Children at the Al-Majardah General Hospital, Asir region. *Ann Saudi Med* 1992;12:191-5.
5. Dent W, HelbokR, Matuja WB. Prevalence of active epilepsy in rural Tanzania: A door-to-door survey. *Epilepsia* 2005;46:1963-9.
6. Velez A, Eslava-Cobos J. Epilepsy in Colombia: epidemiologic profile and classification of epileptic seizures and syndromes. *Epilepsia*. 2006;47(1):193-201.
7. Rwiza HAT, Kilonzo GP, Haule J. Prevalence and incidence of epilepsy in Ulanga, a rural Tanzania district: A community based study. *Epilepsia* 1992 Nov-Dec;33(6):1051-6.
8. Fisher RS, Acevedo C, Arzimanoglou A, et al. ILAE official report: A practical

- clinical definition of epilepsy. *Epilepsia* 2014 Apr;55(4):475-82.
9. Ngugi AK, Bottomley C, Kleinschmidt I, et al. Estimation of the burden of active and life-time epilepsy: a meta-analytic approach. *Epilepsia* 2010;51(5):883-90.
 10. Ngugi AK, Kariuki SM, Bottomley C, et al. Incidence of epilepsy: a systematic review and meta-analysis. *Neurology* 2011;77(10):1005-12.
 11. Brodie MJ, Barry SJ, Bamagous GA, et al. Patterns of treatment response in newly diagnosed epilepsy. *Neurology* 2012;78(20):1548-54.
 12. Durkin MS, Davidson LL, Hasan MZ, et al. Estimates of the prevalence of childhood seizure disorders in communities where professional resources are scarce: Results from Bangladesh, Jamaica, Pakistan. *Pediatr Perinatal Epidemiol* 1992;6:166-80.
 13. Banu SH, Khan NZ, Hossain M, et al. Profile of childhood epilepsy in Bangladesh. *Developmental medicine and child neurology* 2003 Jul;45(7):477-82.
 14. Privitera M. Current challenges in the management of epilepsy. *Am J Manag Care*. 2011;17 Suppl 7:S195-S203.
 15. Shorvon SD, Farmer PJ. Epilepsy in developing countries: A review of epidemiological, socio-cultural, and treatment aspects. 1988;29 Suppl 1:S36-54.
 16. Lappik IE. Issues in the treatment of epilepsy. *Epilepsia* 2001;42(Suppl 4):1-6.
 17. Lappik IE, Schmidt D. Consensus statement on compliance in epilepsy. *Epilepsy Res* 1988;1:179-82.
 18. Quet F, Odermatt P, Preux PM. Challenges of epidemiological research on epilepsy in resource-poor countries. *Neuroepidemiology* 2008;30(1):3-5.
 19. Cramer J, Vachon L, Desforges C, et al. Dose frequency and dose interval compliance with multiple antiepileptic medications during a controlled clinical trial. *Epilepsia* 1995 Nov;36(11):1111-7.
 20. Ogunlesi T, Ogundeyi M, Olowu A. Pattern of childhood epilepsy in Sagamu, Nigeria. *Indian J Pediatr* 2009;76:385-9.
 21. Morisky DE, Ang A, Krousel-Wood M, Ward HJ. Predictive validity of a medication adherence measure in an outpatient setting. *J Clin Hypertens (Greenwich)* 2008;10(5):348-54.
 22. Birbeck GL. Epilepsy care in developing countries: Part I of II. *Epilepsy Curr* 2010;10(4):75-9.
 23. Espinosa-Jovel C, Toledano R, Aledo-Serrano Á, García-Morales I, Gil-Nagel A. Epidemiological profile of epilepsy in low income populations. *Seizure* 2018;56:67-72.
 24. Liu J, Liu Z, Ding H, et al. Adherence to treatment and influencing factors in a sample of Chinese epilepsy patients. *Epileptic Disord* 2013;15:289-94.
 25. Molugulu N, Gubbiyappa KS, Vasudeva et al. Evaluation of self-reported medication adherence and its associated factors among epilepsy patients in hospital Kuala Lumpur. *J Basic Clin Pharm* 2016;7:105-9.
 26. Gomes MM, Maia FH. Medication-taking behavior and drug self regulation in people with epilepsy. *Arq Neuropsiquiatr* 1998 Dec;56(4):714-19.
 27. Gabr WM, Shams ME. Adherence to medication among outpatient adolescents with epilepsy. *Saudi Pharm J* 2015;23:33-40.
 28. Guo Y, Ding XY, Lu RY, et al. Depression and anxiety are associated with reduced antiepileptic drug adherence in Chinese patients. *Epilepsy Behav* 2015 Sep;50:91-5.
 29. Sweileh WM, Ihbesheh MS, Jarar IS, et al. Self-reported medication adherence and treatment satisfaction in patients with epilepsy. *Epilepsy Behav* 2011 Jul;21(3):301-5.
 30. Ferrari CM, de Sousa RM, Castro LH. Factors associated with treatment non-adherence in patients with epilepsy in Brazil. *Seizure* 2013 Jun;22(5):384-9.
 31. Baker GA. People with epilepsy: what do they know and understand, and how does this contribute to their perceived level of stigma? *Epilepsy Behav* 2002;3(6S2):26-32.
 32. Julie A, Catherine S, Caroline K, et al. The reasons for the epilepsy treatment gap in Kilifi, Kenya: Using formative research to identify interventions to improve adherence to antiepileptic drugs. *Epilepsy & Behavior* 2012;25(4):614-21.
 33. Das K, Banerjee M, Mondal GP, et al. Evaluation of socio-economic factors causing discontinuation of epilepsy treatment resulting in seizure recurrence: A study in an urban epilepsy clinic in India. *Seizure* 2007;16(7):601-07
 34. Asawavichienjinda T, Sitti-Amorn C, Tanyanont W. Compliance with treatment of adult epileptics in a rural district of Thailand. *J Med Assoc Thai* 2003;86:46.