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ORIGINAL ARTICLE

KNOWLEDGE, ATTITUDE AND PRACTICES OF PARENTS AND GUARDIANS OF CHILDREN WITH EPILEPSY AT PEDIATRIC NEUROLOGY CLINIC OF TIKUR ANBESSA SPECIALIZED HOSPITAL. ADDIS ABABA, ETHIOPIA

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ABSTRACT

Introduction: *Epilepsy is considered to be present when 2 or more unprovoked seizures occur in a time frame of longer than 24 hr. Public awareness and attitudes towards epilepsy differ across cultures. It has been noted that traditional beliefs and lack of knowledge strongly influence attitudes towards epilepsy. Epilepsy remains a stigmatized disease especially in Sub-Saharan Africa.*

Objectives: *To assess knowledge, attitude and practices of parents and guardians of children with epilepsy attending follow up at pediatric neurology clinic in Tikur Anbessa Specialized Hospital.*

Methods: *A hospital based cross-sectional descriptive study was conducted among 186 parents and guardians of children with epilepsy attending pediatrics neurology clinic from September 1 to October 30, 2018.*

Results: *More than 138(60%) of the parents/guardians had some knowledge on the type of antiepileptic drug treatment their children were receiving and 67(36%) of parents/guardian know the type of illness they suffering from. Fifty-eight percent of the parents/guardians administered some recommended first aid measures to their epileptic children during a fit, but many of them combined these with potentially harmful first aid measures. Spiritual healing and to a lesser extent traditional medicine were perceived to be important components of therapy for epilepsy when used in conjunction with hospital treatment. An increased level of education of the parents/guardians had a positive influence on their knowledge, attitudes and practices towards epilepsy.*

Conclusions: *Overall parental attitude seems to be more positive. Even though there were encouraging results on the parental knowledge there is still a gap that can cause misconception on the practice. Ensuring education and support at community and school levels for both parents and children with epilepsy should be the principal goal of health-care service.*

Key words: *Epilepsy, Knowledge, Attitude, Practice, Children, Ethiopia*

INTRODUCTION

Epilepsy is two or more unprovoked seizures unrelated to acute metabolic disorders or withdrawal of drugs or alcohol. It is characterized by a tendency to recurrent unprovoked seizures which can lead to loss of awareness or consciousness, disturbances of movement, sensation (including vision, hearing, and taste), autonomic function, mood, and mental function (1, 2).

Epilepsy is a common chronic neurological disorder of considerable public health importance. Approximately 50 million people worldwide have epilepsy, making it one of the most common neurological diseases globally. Nearly 80% of the people with epilepsy live in low- and middle-income countries (2).

The main reasons for a higher incidence of epilepsy in developing countries are the higher risk of acute and chronic brain infections, pre- and post-natal obstetric complications leading to brain damage (1).

The median incidence of acute symptomatic seizures is 29–39 per 100,000 per year. Acute symptomatic seizures predominate in the youngest age class (under1 year of age) and in the elderly. The pooled incidence rate of epilepsy was 61.4 per 100,000 person-years. The incidence was higher in low/middle-income countries than in high-income countries(3). The prevalence of epilepsies in childhood and adolescence is 4-6 per 1000. The peak prevalence is in the 1-4-year age range (1). In a large community-based study, the prevalence of epilepsy in Ethiopia was reported to be 5.2/1000 population (4).

Public awareness and attitudes towards epilepsy differ across cultures. It has been noted that traditional beliefs and lack of knowledge strongly influence attitudes towards epilepsy. Epilepsy in children has wide repercussions on social, emotional, and overall family functioning, particularly in families where younger children are affected and in those with single parents (5).

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Epilepsy remains a stigmatized disease, especially in Sub-Saharan Africa. Lack of information and illiteracy has been blamed as the cause of the stigmatization. This Stigmatization stems from the fact that the traditional African belief views epilepsy as a spiritual disease (6).

Epilepsy is the commonest neurological condition seen in children's outpatient clinics in TASH pediatrics neurology outpatient clinic (7). It is a treatable condition in the majority of patients, yet majority of our epileptic patients are untreated. Inappropriate attitude, and lack of knowledge regarding epilepsy have been shown to significantly influence the size of the treatment gap and the level of compliance to treatment. It is also being associated with increased morbidity and mortality (1). So far, the information gathered on knowledge, attitude and practice regarding epilepsy has been on the general community in people not necessarily having epilepsy and those who may not necessarily have taken care of an epileptic person. Despite the high burden of epilepsy to our knowledge no research is done on assessment of parental knowledge and attitude toward child with epilepsy in our set up.

MATERIALS AND METHODS

Study setting

The study was conducted at the pediatrics neurologic clinic of Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia. The hospital is the largest teaching hospital and tertiary referral hospital in the country providing undergraduate as well as post graduate teaching service. The pediatric neurology clinic works in all of the five working days. It is run by trained nurses, Pediatric and Child Health Residents, and a pediatric neurologist. It is attended by children and adolescents in the age ranges of 0-18 years. The average number of patients attending the clinic on daily basis is around 30.

Study Population

All parents or guardians of children with a clinical diagnosis of epilepsy attending neurology clinic at TASH during the study period were eligible for the study.

Study Design

The study was a hospital based cross-sectional descriptive study conducted from September 1 to October 30, 2018.

Sample size

The sample size was calculated using Leslie Fishers formula

$n = Z^2P\ (1\text{-}P)/\ d^2$

Where: n is the sample size, z = 1.96 (normal distribution curve). P is the expected prevalence = 50%, as there has not been a published study done regarding KAP of parents and guardians of children with epilepsy at TASH before.

d is the error of the estimate (absolute precision) (±5%); with 95% confidence level.

$n= 1.96^2 \times 0.5\ (0.5)/\ 0.05^2 = 384$

Sample size correction for finite population is valid to be used for sample sizes with proportion greater than 5% of the source population (i.e. n/ N>0.05). Our source population was 300.

$$n' = \frac{NZ^2P(1-P)}{d^2(N-1) + Z^2P(1-P)}$$

Where n, = sample size with finite population correction

N= population size (300)

The corrected sample using EPI info statistical package for sample size was 169.Taking an additional 10% non-responder, **186** patients were included in the study.

Sampling Technique

Convenience sampling technique was used .

Operational Definition

Stigma is defined as any social attribute that is deeply discrediting for an individual and, in the case of epilepsy, it can significantly affect the health-related quality of life of the patients in many everyday activities such as going to school, working, driving and creating a family.

A seizure is defined as a transient occurrence of signs and/or symptoms resulting from abnormal excessive or synchronous neuronal activity in the brain (3, 12).

Epilepsy is defined as two or more unprovoked seizures that occur in a time frame of longer than 24 hours.

Data collection, quality, data analysis and statistical methods

A structured questionnaire was designed by extrapolating from reviewed literatures for the study. It comprises 5 sections: parental socio demographic characteristics, demographic and clinical characteristics of children with epilepsy, knowledge, attitude and practices related to epilepsy. Data collectors were 3 nurses recruited from neurology clinic and trained on how to fill the questionnaire. Piloting of the questionnaire was done among 10% of the intended sample size. Data were entered, cleaned and analyzed using SPSS version 24. Descriptive and analytical statistics was used as applicable. Statistically significant association was taken for p values of <0.05.

Ethical Consideration

Ethical clearance was obtained from the Pediatrics and Child Health Department's Research and Publications Committee of the School of Medicine, College of Health Sciences, and Addis Ababa University. Respondents were clearly informed about the purpose of the study and the information required from them

Participant confidentiality was assured. Patients who refuse to take part in the study received the same quality of health care service as the participants. All participants included in the study were kept anonymous.

RESULTS

Socio-demographic characteristics

More than half of the children115 (61.8%) were males. The mean age was 8.4 years with standard deviation of 4. 6 years. The commonest type of seizure recorded was generalized tonic-clonic type 154 (78.6%). About 61(32.8%) of children had been on treatment for a period of 2-4years followed by 58 (31.2%) >6years. Half 94(50.5%) of patient had good control of seizure with the remaining patients with fair and poor control.

Majority of the respondent parents/guardians were mothers 105(56.5%). Most of the parents/guardians 88 (47.3%) were 30-39 years old and 84(45.2%) of them attended secondary school. Majority of our patients are from Addis Ababa. A significant proportion of parents/guardians 118(63.5%) are unemployed and for 65(43%) of parents /guardians their income is less than 2000birr per month.

Knowledge assessment of parents /guardian: Each parent/guardian was asked to mention the type of illness his/her child was suffering from and only 67 (36%) of parents know the terminology 'epilepsy'. Forty eight percent of the parents/guardians said they did not know what causes epilepsy.

The commonest causes of epilepsy mentioned by the others were head injury 33(17.7%) followed in order by perinatal events 30(16.6%), infection 15 (8.1%) and evil spirit 11(5.9%).

The knowledge on features of convulsion and the type of drugs their children taking was presented on Table 1. The commonest mentioned feature being jerky movement of the limbs.

Majority 159(85.5%) of the parents/guardian said epilepsy is not contagious, 24(12.9%) said they did not know, and 3(1.6%) said that it can be contagious. For more than half of the parents 117 (57.9%), their primary source of information for epilepsy was medical doctor (Table2).

Table 1: Knowledge on the current antiepileptic drug treatment and features of convulsion among 186 parents/ guardian of epileptic children at Tikur Anbessa Specialized Hospital, 2018

Variables	**Frequency**	**Percent**
Antiepileptic drug (n=225)		
Phenobarbital	42	18.7
Phenytoin	51	22.7
Valporic acid	34	15.1
Carbamazepine	10	4.4
Clonazepam	1	0.4
Other	1	0.4
Don't know	86	38.2
Knowledge on the features of a convulsion (n=288)		
Jerky' limb movements	104	36.1
Rolling of the eyes	18	6.3
Loss of consciousness	25	8.7
Urine/stool incontinence	10	3.5
Frothing/drooling of saliva	35	12.2
Stiffening of the limps	29	10.1
Staring gaze	6	2.1
Closing of the eyes	5	1.7
Child falls to the ground	2	0.7
Twitching of the eyes	22	7.6
Twitching of the mouth	8	2.8
Falls asleep	3	1.0
Staggering gate	3	1.0
Weakness	1	0.3
Aggressiveness	3	1.0
Biting the tongue	3	1.0
Don't know	11	3.8

Table 2: Distribution of knowledge on transmission of epilepsy and curability and type of care given to an epileptic child during a fit

Variables	Frequency	Percent
Epilepsy transmitted		
Yes	3	1.6
No	159	85.5
Don't know	24	12.9
Curable		
Yes	141	75.8
no	14	7.5
don't know	31	16.7
Source of information		
Radio/TV	9	4.5
Community	69	34.2
Health profession	117	57.9
Other	7	3.5
The type of care given to an epileptic child during convulsion		
Put spoon/finger in the mouth	19	9.8
Hold the child to avoid falling	19	9.8
Loosen tight clothes	8	4.1
Stay with the child till convulsion is over	24	12.4
Hold the child for comfort	24	12.4
Hold to restrict movements	2	1.0
Remove harmful objects around the child	14	7.3
Put to lie on the side	11	5.7
Put child to lie on the back	7	3.6
Support the head with something soft	12	6.2
Give a cold drink	9	4.7
Wipe with wet cloth	33	17.1
No first aid measures	5	2.6
Other	6	3.1

Bivariate analysis of socio-demographic characterstics of parents with their knowledge: Those parents/ guardians who have government job and those with higher income >4000 had an appropriate knowledge with (P =0.04). Parents/guardians with secondary school educational level and higher (38.5%) were more likely to mention head injury as a cause of epilepsy compared to those with below secondary school educational level (10.7% and 14.3% respectively). (P = 0.00). A significantly higher proportion of the parents/guardians with secondary school education and below (56% and 52.4% respectively) did not know the causes of epilepsy (P = 0.01) (Table 3).

Assessment of parents/guardian practices during epilepsy

The first aid measures administered by many of the parents/'guardians 33(17.1%) wiping with wet cloth followed by those who stay with their child till the convulsion was over 24(12.4%), holding for comfort 24(12.4%) and 19(9.8%) put spoon/finger in the mouth.

Majority of parents/'guardians 108(57.9%) administered at least one recommended first aid measure, however significant number of parents/guardians 42.1% combined recommended first ai measures with unnecessary, and potentially harmful and harmful first aid measures.

A statistically significant higher proportion of parents/guardians with post-secondary school education stay with their children till convulsion is over 20.5% and also remove harmful objects around the child compared to parents/guardians with secondary school education and below (P = 0.03 and 0.04 respectively).

About 38.1% of parents/guardian who attend primary school or below don't give any first aid measure (P=0.01) (Table 2).

Table 3: Distribution of knowledge on the type of illness, perceived causes of epilepsy and antiepileptic drug treatment by educational level and income of parents/guardians

Variables	Total	Knowledge of type of illness Appropriate (%)	Inappropriate (%)	Chi square	p-value
Job					
Government	43	26(60.5)	17(39.5)	6.5	0.04
Private	25	12(48.0)	13(52.0)		
Unemployed	118	45(38.1)	73(61.9)		
Monthly income					
<2000	65	27(41.5)	38(58.5)	6.3	0.04
2000-4000	49	20(40.8)	29(29.2)		
>4000	37	24(64.9)	13(35.1)		
Variables	Total no	Knowledge of Drug Appropriate (%)	Inappropriate (%)	Chi square	p-value
Educational status of parents					
Primary school and below					
Secondary school	63	25(39.7)	38(60.3)	15.5	0.00
Above secondary	84	44(52.4)	40(47.6)		
	39	31(79.5)	8(20.5)		
Monthly income					
<2000	65	34(52.3)	31(47.7)	7.7	0.02
2000-4000	49	26(53.1)	23(46.9)		
>4000	37	29(78.4)	8(21.6)		
Cause	Educational status			Chi square	p-value
	Primary and below 63	Secondary 70	Above secondary 34		
Head injury	14.3	10.7	38.5	14.8	0.00
Infection	4.8	10.7	7.7	1.7	0.42
Perinatal event	15.9	15.5	20.5	0.53	0.77
Others	14.3	7.1	5.1	3.2	0.21
Don't know	52.4	56.0	28.2	8.7	0.01

Parents' attitudes towards their children's epilepsy:

The attitude of parents is shown in **Table 4**. The strongest positive attitude was obtained for the assertion "I want my family and friends to know that my child is suffering from epilepsy" in 161(86.6%).

On the contrary, the least positive attitude was observed for the assertion most parents felt that the child will not achieve a lot in the future, and they treated him/her differently, and 122 (65.6 %) felt that epileptic patients should work in special job and with each other.

Table 4: Attitude of parents towards epilepsy

Variables	Frequency	Percent
Do you want your family and friends to know that your child is suffering from epilepsy?		
Yes	161	86.6
No	25	13.4
Do you feel that other people treat your child as less valuable?		
Yes	88	47.4
No	89	47.8
Don't know	9	4.8
Do you think that your child will be able to achieve professional success later in life?		
Yes	150	80.6
No	36	19.4
Do you have a concern that your child has problems making friends?	81	43.5
Yes	105	56.5
No		
Yes	139	74.7
No	47	25.3
The intelligence of epileptic persons is lower than normal persons		
Yes	108	58.1
No	78	41.9
Epileptic patients should work in special jobs and with each other		
Yes	122	65.6
. No	64	34.4
Could the child with epilepsy get married in the future?	154	82.8
Yes	32	17.2
No		

DISCUSSION

The important causes of epilepsy in developing countries are acute and chronic brain infections, pre- and post-natal obstetric complications (1). In this study most of the parents/guardians (43.5%) knew of at least one possible cause of epilepsy. This is better than what was found by Levy' in Zimbabwe <1% and Tekle- Haimanot et al in Ethiopia where 6% parents knew of at least one cause of epilepsy. This result was attributed to the fact that most of parents included in this study live in the urban set-up and 84% have primary education and above unlike the above studies which was done at rural set-up (8, 9).

Only 5.9% of the parents/guardians in this study ascribed epilepsy to supernatural causes as evil spirit. Such misconceptions can have significant negative implications on the medical management with a higher risk of non-compliance (1, 8-11). The finding in this study is better than Muasya CK, in Kenya where 12% of parents attributed epilepsy to supernatural causes. Even though both studies were done in urban setup, most of the study participants in the later study had educational level below secondary school (1).

A few numbers of parents/guardians (1.6%) thought that epilepsy is contagious. These finding is also better than what was found by Tekle-Haimanot et al in Ethiopia and other studies done in Africa and Asia where many of the respondents thought that epilepsy was contagious. The notion that epilepsy is contagious by direct physical contact during an attack is the base of stigmatization of these patients (1, 5, 9, 12,13).

Almost all the parents/guardians (96.2%) recognized at least one feature of a convulsion. The most frequently recognized features were Jerky' limb movements, frothing/drooling of saliva and Stiffening of the limps which are common manifestations of a GTCS, the commonest reported seizure type in this study and in many other published reports (1,9). This showed that parents notice only those with obvious motor activity to have a seizure, other types of seizures are not known by many parents. It is therefore important to recognize the features of a convulsion in order to act fast and avoid complications which may result from a poorly managed convulsion.

Fifty-eight percent of parents/guardian administered at least one recommended first aid measure to their epileptic children during a fit. But many, combine this with potentially harmful and harmful first aid measures. The overall effect of such combinations was at times more harmful than useful to the child. These practices, however, were better than the one found by Al. Zubaidi et al in Jeddah and Tekle-Haimanot et al in Ethiopia where 31.1% and 11% of the respondents respectively knew of some recommended care to give to an epileptic person during a fit (9, 13).

A small number of parents/guardians (2.6%) in this study did not administer any first aid measure to their epileptic children during a fit. The reasons given in order where they take the child to health facility and the convulsions were usually very brief. This is, in contrast to study done in Kenya where many did not administer first aid because they did not know the type of first aid to be administered to a convulsing child. Other studies done in Ethiopia revealed that many people did not attempt to assist an epileptic person during a fit in fear that they would contract the disease (1, 8, 10).

Majority of the parents/guardians in this study 66.2% had only used hospital treatment for managing their epileptic children. All the rest 33.8% combined hospital treatment with spiritual healing, and a few of them also used traditional medicine. These findings suggest that many parents/ guardians perceived some continuing benefits from alternative methods of treatment, even though they continued to seek "modern" medicine. It is higher than found in Kenya 18.2%. Similar findings were also found in other studies done in Africa (1, 9, 11).

Majority of the parents in this study had positive attitude in contrast to the findings revealed by Dung-Dung et al and Al. Zubaidi et al (12,13). which was predominantly negative. This was attributed to the fact that most parents want to share their child's illness with their families and relatives. This also indicates that parents had felt less stigmatized due to their child's epilepsy. Specifically, fear of discrimination and social stigmatization represent major problems both for children with epilepsy and for their parents.

On the other hand, there was negative attitude among the parents pertaining to academic performance and intelligence. Epilepsy was also regarded as an obstacle for a successful life. These findings were consistent with what was found in Jeddah by Al. Zubaidi et al where 84.4% of parents agreed that epilepsy is an obstacle for a good life (13).

Conclusion

In conclusion, parental knowledge and practice requires improvement in some epilepsy-related issues. Although parents encounter challenges at various levels, overall parental attitudes seem to be more positive. An increased level of education had a positive influence on KAP towards epilepsy. We recommend more effort by the health sector to ensure education and support at the community and school levels for both parents and children with epilepsy.

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Conflict of Interest

Authors have no conflict of interest to declare.

REFERENCES

1. Muasya CK, Wafula EM. Knowledge, attitude and practices (KAP) of parents and guardians of children with epilepsy at Kenyatta national hospital, Nairobi, Kenya. Nairobi: University of Nairobi;2000.
2. Angula N, Small LF, Koogongelwa S. Knowledge, attitude and practices towards epilepsy among secondary school teachers in Oshana region. Masters of public health (dissertation). University of Namibia;2016.
3. Ettore B.Epidemiology of Epilepsy. Neuroepidemiology. 2020; 54:185–191
4. Shibre T, Alem A, Tekle-Haimanot R, Medhin G, Jacobson L. Perception of stigma in people with epilepsy and their relatives in Butajira, Ethiopia. Ethiop.J.Health Dev. 2006; 20(3):170-176
5. Gazibara T, Nikolovski J, Lakic A, Pekmezovic T, Kisic-Tepavcevic D. Parental knowledge, attitudes, and behaviors towards children with epilepsy in Belgrade (Serbia). Epilepsy & Behavior .2014; 41:210–216.
6. Bertha CK, Udeme EK. The Knowledge, Attitude, and Perception toward Epilepsy amongst Medical Students in Uyo, Southern Nigeria. Advances in Medicine.2015; Vol.2015:1-6
7. Moges A, Gizae S, Zenebe G, Kotagel S. Pattern of neurological disorders at pediatrics outpatient neurologic service at Tikur anbessa specialized hospital. EthiopJ.pediatr.child health.2017;14(2)
8. Levy LF. Epilepsy in Rhodesia, Zambia and Malawi. Afr. J. Med. Sci., 1970; 1: 291-303
9. Tekle-Haimanot R, Abebe M. Attitudes of rural people in Central Ethiopia towards epilepsy. Soc. Sci. Med. 1991; 32(2): 203-209.
10. Kale R. Bringing epilepsy out of the shadows in Africa. Press release WHO.Org.2000;5(3):191-194
11. Giel R. The problems of epilepsy in Ethiopia. Trop. Geog. Med. 1970; 22:439-442.
12. Dung A, Singh H, Kumari S, et al. Knowledge, Attitude and Perception of Caregivers of Children with Epilepsy. Delhi psychiatry journal.2009; 12 (2): 275-275.
13. Alzubaidi M, Alsudairy N, Alzubaidi B, et al. Assessment of Knowledge and Attitude and Practice of Parents towards Epilepsy among Children in Jeddah City. EJHM .2017; 69 (6): 2685-2689