

Effects of Epilepsy on Children Living in Riyadh, 2012

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Abstract

Background: Epilepsy affects almost 70 million people globally. Studies to assess quality of life issues among children are scant in Saudi Arabia. This study was conducted to assess physical and psychosocial aspects of life of epileptic children at King Saud Medical City and King Fahd Medical City, in Riyadh.

Methods: It was a cross sectional, self-administered questionnaire based survey among 100 mothers having epileptic child below 12 years of age, who attended outpatient clinics from November to December 2012.

Results: Epileptic child of 47% mothers suffered 10 or less epileptic attacks during last 12 months. 40% mothers felt that their epileptic child can harm themselves during an epileptic attack, 58% mothers mentioned that their children always need close watch for fear of injury or harm. 71% of the families had visited Raqi (persons who use Quran for epileptic peoples) and 4% visited Sorcerer (persons who use magic for treatment). 36% mothers always had difficulty to find time for the personal needs due to being busy for the child health care. 59% mentioned that they were mostly satisfied, 50% mothers like to know how to act during an epileptic attack.

Recommendations: Ministry of health should develop a program for health education for parents, of epileptic children focusing on nature of disease; need of compliance to treatment and follow-up even after improvement; adjustment of doses in different life- scenarios; actions to be taken during an epileptic attack. Development of social support mechanism for epileptic patients is also recommended.

Keywords: Epileptic child; Quality of life; Pediatric epilepsy; Saudi Arabia

Introduction

Epilepsy is a chronic neurological condition characterized by recurrent seizures. Epilepsy is the most common serious neurological disorder [1].

According a meta-analysis median prevalence of active epilepsy was 4.9/1000 for developed countries, 12.7 per 1,000 in rural developing countries and 5.9/1,000 in urban developing countries [2].

About 1 in 26 people will be diagnosed with epilepsy at some point in their lives. 370% to 80% of people with epilepsy could lead normal lives if properly treated. In developing countries, 60% to 90% of people with epilepsy receive no treatment due to inadequacies in health care resources and delivery; and due to social stigma [3].

There are many types of seizures and their symptoms can vary from a momentary disruption of the senses, to short periods of unconsciousness or staring spells, to convulsions. Epilepsy can be described as a spectrum disorder because of its different causes, different seizure types, its range of co-existing conditions, and because the disorder can vary in severity and impact from person to person [4].

The incidence and prevalence of epilepsy may vary widely because of their different causes. The cause of epilepsy remains unknown in nearly 70% of cases. Etiology varies significantly with age.

The use of "Disability Adjusted Life Years" (DALY) has revealed the large global burden of neurological and psychiatric disorders, of which epilepsy is a part. Epilepsy itself is thought to contribute around 1% of the total days lost. Epilepsy also often have a psychological or an emotional impact. It is increasingly recognized that people with epilepsy may be affected far more by social and psychological aspects than by the seizures themselves. Uncontrolled seizures can be very unsettling. People with epilepsy may fear going outside their homes unaccompanied. They may also fear what people might think of them if they are seen having a seizure [5].

Throughout the world's history epilepsy has been a culturally devalued condition. Such devaluing often leads to people with epilepsy being stigmatized and causes psychosocial burden on those affected. Many studies from around the world have shown people with epilepsy as having a lower annual income, a lower quality of life, lower school performance, low self-esteem, worse chances of marriage and be generally excluded from social life. The search for the best medication for any individual child may take quite a long time. Informed, understanding relatives are a wonderful source of strength when a child has epilepsy. But the rest of the family-grandparents, aunts, cousins may have beliefs about this condition that hail from an earlier time. They may think it is somehow linked to mental illness (it isn't), or someone's fault (wrong), or is related to mental retardation (usually not), or is even a signoff spiritual possession (an old myth that still lingers). Helping other family member understand the true nature of epilepsy as a medical condition affecting brain function will set these fears to rest.

Epilepsy is surrounded by a dilemma, where you go and which direction to seek the treatment, do you go further or wait, the problems may resolve by itself. The disease has multiple aspects including cultural, religious, legal, and medical problems and a stigma. The traditional medical goal in the management of epilepsy has focused almost exclusively on seizure control with minimal or no adverse medication effect, whereas the importance of assessing QOL has been ignored [6,7]. Studies from developing countries, assessing the QOL of children with epilepsy and their parents are so sparse, the researcher could not find any study related to this important topic in the Kingdom of Saudi Arabia. So, it was felt necessary to explore this problem as a part of the systematic approach to challenges in epilepsy management. Assessing the effects of life that the epileptic children and their families are facing in our community, and recognising the difficulties that they are dealing with daily, will help to concentrate on their needs and focus the services to help them overcome the difficulties. This will help improve the prognosis of the disease and consequently save much of the time, effort and money that is being spent on the treating the complication of epilepsy.

Study objectives

- To assess physical and psychosocial aspects of life of epileptic children presenting at Neurology departments of King Saud Medical City and King Fahd Medical City, in Riyadh.
- To identify the social and health care related difficulties that these children and their families are facing due to epilepsy.
- To explore knowledge and beliefs that might affect their quality of life.

Materials and Methods

Study design

It was a cross sectional, self-administered questionnaire based survey among mothers having epileptic child.

Study setting

Study was conducted in 2 hospitals. First was Neurology Department of Children's hospital in King Saud Medical City, Riyadh. Department was established in 1983 and have 3000 patient under follow up, 40 percent of them are estimated to have epilepsy. It has 3 consultants, 2 specialist and 3 residents. It has neurophysiology labs including EEG, EMG, VE. Second was Pediatric Neurology department of National Neuroscience Institute in King Fahd Medical City, Riyadh.

Vast majority of the patients attending these two governments hospitals are Saudi.

Study population

The study population included all children, below 12 years of age with epilepsy who attended outpatient clinics of above neurology departments during data collection period, along with their mothers. Exclusion criteria included newly diagnosed epilepsy (less than 6 months); and presence of an associated chronic disease that can independently affect the quality of life of the family e.g. cerebral palsy, Down's syndrome, type 1 diabetes, brain tumors, chronic renal diseases.

Sampling

As there was no previous documented information about estimates of effects of epilepsy on children life, so for the purpose of sample size estimation, a prevalence of 50% is assumed to achieve highest sample size for a given level of precision. With estimated effects on life of 50% and percent of confidence limit 10%, at a confidence level of 95%, with z value: 1.96, a sample size of 96 children was estimated and rounded off to 100.

All children fulfilling the criteria for study population were included in the study till the specified sample size was achieved.

Data collection

Data collection instrument: A self-administered questionnaire was designed including the following:

- Demographic characteristics of child and parents including age, sex, educational status, occupation
- Availability of care at school and Health care facilities
- Effect of illness on child's and family's activities
- Psychosocial status of the child and the family
- Mother's knowledge and beliefs about epilepsy causation and its management Questionnaire was later translated to Arabic, to facilitate its filling by mothers of epileptic children.

Approval for data collection: After approval by the research committee of FETP, a request along with study proposal was sent by Supervisor General of FETP to the Directors of both Paediatric hospitals in King Fahd Medical City and King Saud Medical City to grant permission to collect data in their hospitals. Proposals were reviewed and approved by research committees of both the hospitals.

Field work: After obtaining necessary approvals, work plan was prepared in consultation with the head of neurology departments. Each hospital was visited by the principal investigator according to the outpatient schedule of the participating clinics. All the eligible children and their mothers were identified by the local staff and the investigator asked for their consent after explaining the purpose of the study. Arabic copies of the questionnaire were given to consenting mothers. The mothers who had difficulties in filling the questionnaire were assisted and the illiterate ones were interviewed by investigator. Data was collected from 6th November to 6th December, 2012.

Data analysis

Epi Info software (version 3.5.3) was used to make data entry form, data entry and data analysis. After necessary cleaning, data was analyzed in line with the study objectives.

Results

The study recruited a total of 100 children from the two hospitals in Riyadh. 56% of the children were from King Saud Medical City and 44% of the children were from King Fahd Medical City.

Demographic characteristics of children

The mean age of children was 7.5 years (SD 3.3 years). 16% of the children were 1-3 years old, 23% were 4-6 years old, 23% were 7-9 years old and 38% were 10-12 years old. Boys formed 62% of the study

sample and girls formed 38% of the study sample. 60% of these children were from the families that have 5 or less children while 40% were from families that have 6 or more children (Table 1).

Characteristics	Frequency	Percentage	95% Conf Limits	
Age				
1-3 Years	16	16.00%	9.40%	24.70%
4-6 Years	23	23.00%	15.20%	32.50%
7-9 Years	23	23.00%	15.20%	32.50%
10-12 Years	38	38.00%	28.50%	48.30%
Gender				
Male	62	62.00%	51.70%	71.50%
Female	38	38.00%	28.50%	48.30%
Number of children in family				
5 or less	60	60.00%	49.70%	69.70%
6 or above	40	40.00%	30.30%	50.30%

Table 1: Demographic characteristics of epileptic children (N=100).

About the disease

The children who were diagnosed in the first year represent 26%, between 2 and 6 years 46% were diagnosed and 28% were diagnosed between the 8 and 12 years. During the last 12 months, 23% of the children had no attack, 47% had 10 attacks or less and 30% cases had more than 10 epileptic attacks. 35% of the mothers reported that epilepsy effect the overall health of the child a lot, 50% reported that it effect somewhat while 15% mothers reported that it had no effect on the overall child health. 23% of the mothers reported that their epileptic children always had problems in social interaction in contrast to 51% who reported that they never had any such problems. 22% of the epileptic children had positive family history of epilepsy (Table 2).

Characteristics	Frequency	Percentage	95% Conf Limits	
Age at diagnosis				
First year	26	26.00%	17.70%	35.70%
2nd-7th year	46	46.00%	36.00%	56.30%
8th – 12th year	28	28.00%	19.50%	37.90%
Number of attacks in the last 12 months				
None	23	23.00%	15.20%	32.50%
10 or less times	47	47.00%	36.90%	57.20%
More than 10	30	30.00%	21.20%	40.00%
Effect overall health of the child				
A lot	35	35.00%	25.70%	45.20%
Somewhat	50	50.00%	39.80%	60.20%
Not at all	15	15.00%	8.60%	23.50%

Problems in social interaction				
Always	23	23.00%	15.20%	32.50%
Sometimes	26	26.00%	17.70%	35.70%
Never	51	51.00%	40.80%	61.10%
Family history of Epilepsy				
Yes	22	22.00%	14.30%	31.40%
No	78	78.00%	68.60%	85.70%

Table 2: Disease related characteristics of epileptic children.

Safety concern

Regarding harming self, 40% reported that their children might harm themselves during the epileptic attack; while 12% reported that their children might harm others during the epileptic attack. 58% mothers mentioned that their children always need close watch for fear of injury or harm, 30% mentioned that they need close watch sometimes, while 12% mentioned that they never need close watch (Table 3).

Safety concerns	Frequency	Percentage	95% Conf Limits	
Might harm to self during an epileptic attack				
Yes	40	40.00%	30.30%	50.30%
No	60	60.00%	49.70%	69.70%
Might harm to others during an epileptic attack				
Yes	12	12.00%	6.40%	20.00%
No	88	88.00%	80.00%	93.60%
Need close watch for fear of injury or harm				
Always	58	58.00%	47.70%	67.80%
Sometimes	30	30.00%	21.20%	40.00%
Never	12	12.00%	6.40%	20.00%

Table 3: Safety concern of mothers of epileptic children (N=100).

Emergency and outpatient care

Regarding emergency care, 36% children never visited emergency room in the last 12 months, 35% visited emergency room 1-3 times, 21% visited emergency room 4-11 times, 8% visited emergency room 12 times or more during the last 12 months. Overall 36.0% of the mothers were fully satisfied with the care provided to their child in emergency room, 47% were satisfied and 17% were not satisfied.

Regarding outpatient care, 95% of the children in this study were regular on the appointments of the outpatient clinics, in contrast to 5% who were not regular (Table 4). Two of the mothers did not specify the reason for irregularity while one each gave the reasons as improvement in child's health, waiting for the disease to stop by itself or they were outside country.

Care factors	Frequency	Percentage	95% Conf Limits	
Number of visits in last 12 months				
Never	36	36.0%	26.6%	46.2%
1 - 3 times	35	35.0%	25.7%	45.2%
4 -11 times	21	21.0%	13.5%	30.3%
12 or more	8	8.0%	3.5%	15.2%
Satisfaction with care				
Fully satisfied	36	36.0%	26.6%	46.2%
Satisfied	47	47.0%	36.9%	57.2%
Not satisfied	17	17.0%	10.2%	25.8%

Table 4: Care provided in emergency room of hospitals to epileptic children.

About free of cost availability of prescribed medicines from hospital, 67% of the mothers mentioned that the prescribed medicine was available most of times, 26% mentioned that it was available sometimes. According to their mothers, 11% of the children stopped their medications due to side effect, while 89% never stopped their medications due to side effects (Table 5).

Outpatient care factors	Frequency	Percentage	95% Conf Limits	
Regularity in following appointments				
Regular	95	95.00%	88.70%	98.40%
Irregular	5	5.00%	1.60%	11.30%
Free of cost availability of prescribed medicines from hospital				
Yes, Most of the time	67	67.00%	56.90%	76.10%
Yes, Some times	26	26.00%	17.70%	35.70%
No	7	7.00%	2.90%	13.90%
Ever stopped taking medications due to side effects				
Yes	11	11.00%	5.60%	18.80%
No	89	89.00%	81.20%	94.40%

Table 5: Outpatient care provided to epileptic children (N=100).

Spiritual healing

Some of the families tried different methods to treat their epileptic child, 71% of the families had visited Raqi (persons who use Quran for epileptic peoples) and 4% visited Sorcerer (persons who use magic for treatment).

Member of epileptic society

Among 100 mothers just only 2% mentioned that they were members of a society for epilepsy children.

Cooperation at the school

For those 47 children who went to school 33 (70.2%) of the mothers usually noticed a cooperation from the school staff members with epileptic children regarding absence related to medical appointments; 11 (11%) of the mothers notice cooperation sometimes while 1 (2.1%) % mothers mentioned that they never cooperated (Table 6). Regarding the action of the school authorities during episode of epileptic attack, they called the family 11% times, teacher took care of him 6% times and the social worker took care 3 times (Table 6).

	Frequency	Percentage	95% Conf Limits	
Cooperation of school authorities regarding absence related to medical appointments				
Usually cooperate	33	70.20%	23.90%	43.10%
Sometimes cooperate	11	23.40%	5.60%	18.80%
Never cooperate	1	2.10%	0.00%	5.40%
No such absence	2	4.30%	0.20%	7.00%
Action of school authorities during last epileptic attack of child				
Teacher took care	6	12.80%	2.20%	12.60%
Social worker took care	3	6.30%	0.60%	8.50%
They called the family	11	23.40%	5.60%	18.80%
Never had an attack in the school	24	51.10%	16.00%	33.60%
Other	3	6.40%	0.60%	8.50%
*53 children did not go to school				

Table 6: School environment and epileptic children (N=47*).

View of the mothers about causes of epilepsy

When the mothers were asked about the causes of epilepsy, 62% mentioned that they don't know. Only 17% considered epilepsy a medical illness and 5% considered it as a psychiatric illness. 13% considered that it is caused by bad or evil eye and 3% considered the cause as devil or evil (Shaitan) (Table 7).

Causes of Epilepsy	Frequency	Percentage	95% Conf Limits	
Medical illness	17	17.00%	10.20%	25.80%
Psychiatric illness	5	5.00%	1.60%	11.30%
Effect of devil/evil (Shaitan)	3	3.00%	0.60%	8.50%
Effect of bad/evil eye	13	13.00%	7.10%	21.20%
I do not know	62	62.00%	51.70%	71.50%

Table 7: Belief about causes of epilepsy among mothers of epileptic children (N=100).

Psychological aspects

36% mothers always had difficulty to find the time for the personal needs due to being busy for the child health while 46% sometimes had

such difficulty. 20% mothers always found difficulty to explain the disease of epilepsy to their children while 26% sometimes had this difficulty. 8% mothers believed that having epileptic child affected their relationship with their husbands while 22% believe that they sometimes had the effect. 13% mothers always felt shy to tell other people about their child's epilepsy, while 14% mothers sometimes felt it (Table 8).

Aspects of life	Always		Sometimes		Never	
	N	%	N	%	N	%
Have difficulty to find the time for the personal needs due to being busy for the child health	36	36%	46	46%	18	18%
Have difficulty to explain the disease of epilepsy to their child	20	20%	26	26%	54	54%
Having an epileptic child adversely affected relationship with husband*	8	8%	22	22%	67	67%
Feel shy to tell other people about their child's epilepsy	13	13%	14	14%	73	73%

Table 8: Psychosocial aspects of life of the mothers of epileptic children (N=100).

Support

From the mother's point of view, the child was the main source of difficulties in dealing with his/her epilepsy (31%), followed by relatives/family friends (19%), family in the house (11%), health staff (9%) and friends of child (6%) (Table 9).

Sources	Frequency	Percentage	95% Conf Limits	
The epileptic child	32	32.00%	22.10%	41.00%
Relatives and family friends	19	19.00%	11.00%	26.90%
Family in the house	11	11.00%	5.60%	18.80%
Friends of child	6	6.00%	2.20%	12.60%
Health staff	9	9.00%	4.20%	16.40%
No source of difficulty	9	9.00%		
Others*	12	5.00%	16.90%	34.70%

*2 transportation, 1 each school, need of frequent follow-up, permission from work and 7 did not specify any source.

Table 9: Sources of difficulties for hard to deal problems among mothers of epileptic children (N=100).

On the other hand, health staff was considered the main source of support in dealing with the child's epilepsy i.e. 62%. It was followed by family in the house (36%) and relatives/family friends (12%) (Table 10).

Sources	Frequency	Percentage	95% Conf Limits	
Health staff	62	62.00%	51.70%	71.50%
Relatives and family friends	12	12.00%	6.40%	20.00%

Family in the house	36	36.00%	26.60%	46.20%
The child	2	2.00%	0.20%	7.00%
Other	2	2.00%	0.20%	7.00%

Table 10: Sources of support for hard to deal problems among mothers of epileptic children (N=100).

Satisfaction of quality of live

When mothers were asked to rate their quality of life as a mother having epileptic child, 59% mentioned that they were mostly satisfied while 28% have mixed feeling and 13% were mostly dissatisfied (Table 11).

Perceived quality of life	Frequency	Percentage	95% Conf Limits	
Mostly satisfied	59	59.0%	48.7%	68.7%
Mixed	28	28.0%	19.5%	37.9%
Mostly dissatisfied	13	13.0%	7.1%	21.2%

Table 11: Perceived quality of their life among mothers of epileptic children.

Regarding the health advice required by mothers 50% like to know how to act during an epileptic attack, 39% like to know the long-term effects of epilepsy, 21% like to know the adjustment of medicine dosage, 20% like to know the precautions during the travelling and 6 like to know precautions during sports (Table 12).

Identified Health Advices	Frequency	Percentage	95% Conf Limits	
How to act during an epileptic attack	50	50.00%	39.80%	60.20%
Long term effects of epilepsy	39	39.00%	29.40%	49.30%
Adjustment of medicine dosage	21	21.00%	12.70%	29.20%
Precautions during travelling	20	20.00%	12.70%	29.20%
Precautions during sports	6	6.00%	2.20%	12.60%
Others*	4	4.00%	7.90%	22.40%

*2 each causes of epilepsy, everything on epilepsy

Table 12: Health advice requirements identified by the mothers of epileptic children (N=100).

Discussion

Epilepsy affects over 65 million people worldwide. That's more than multiple sclerosis, cerebral palsy, muscular dystrophy and Parkinson's disease combined [8]. At 6.5/1000 prevalence of epilepsy in Saud Arabia is highest in Arab countries, but its importance is not well recognized by the community [9,10]. "Purple Day" is celebrated on 23rd March annually to increase the awareness about the epilepsy. People in countries around the world are invited to wear purple and host events in support of epilepsy awareness.8 Increased awareness can help in reducing the stigma associated with the illness. Non-profit

organizations are instrumental in providing the social support for the needy in many parts of the world, but apparently such organizations are not very active in Saudi Arabia as only 2 respondents were aware of their existence.

Epilepsy is not known to have a gender difference in occurrence or severity of the illness. This male preponderance may be due to gender discriminating health seeking behavior of communities found in developing countries, which need further exploration [11]. These treatment gaps are not restricted to the gender of the patients but are observed between different socioeconomic and rural/urban strata. Although no such study is available for Saudi Arabia but it is well known that there is major treatment gap for epilepsy between and within countries [12].

Conventional treatment for epilepsy is based on long term administration of antiepileptic drugs. Although these antiepileptic drugs results in long-term seizure remission in most patients, in a European study it was observed that about 30% do not achieve seizure freedom as a result of treatment with currently available AEDs [13]. However, in our study only 23% of the patients did not have any seizure in the last 12 months, which is quiet alarming and should be taken seriously by the treating physicians whether the problem is with poor patient compliance or with the medical management prescribed. As inadequate seizure control is associated with a higher incidence of major depression and poorer quality of life as perceived by the patient [13]. An prospective study from Riyadh showed that 30.8% of the patients were non-compliant while low level of education and adverse effect of the diseases on patients were the most important significant factors for poor compliance [14].

A study from Abha showed that 27% of the epileptic patients had a Family History of Epilepsy (FHE), which is quiet close to 22% participants in this study with FHE. This difference can be due to the variation how people define family history [15]. Another Jordanian study has shown that family history of epilepsy is a strong risk factor for epilepsy reaching an OR 9.8 (95% CI 3.3- 38.9) for first degree relatives [16].

A major problem in the management of epilepsy and its social acceptability is the confusion among masses regarding its aetiology. As physicians are usually unable to pinpoint an organic cause for this illness, people try to attribute the illness to supernatural causes. In a recent study from Saudi Arabia, it was observed that 40.3% of the university teachers and 50.4% of university students considered possession by Jinn as a cause of epilepsy [17]. Even in our study, where mothers were interviewed while seeking care for treatment of their children in hospitals 16.0% believed that it is the effect of devil or evil eye. And in the past 71% of the families had visited Raqi and 20% visited sorcerers for treatment of their child. In the absence of changing the beliefs of the people it is quite difficult to expect a change in attitudes towards its management.

With the current medications epileptic children can remain seizure-free for long durations, in this study 23% children had no attack and another 47% had less than 10 attacks in last 12 months. However, the apprehension of an impending attack with need for close watch can be a perpetual disturbing factor. In a study conducted in Nigeria in 2010, it was observed that majority of the caregivers feel high burden due to the care of epileptic patients, while shorter seizure-free period was found significantly associated with this perception [18]. In our study mothers are usually satisfied with the care provided to their children in

the schools in case of seizures. However, absence of any regular mechanism for such care is a point of concern.

But the sources of knowledge for a neglected illness like epilepsy are not many. Medical staff has proved to be the main source of information for majority of the respondents, which highlight the need for training of the medical staff in principles of health education. However, patients and their families have diverse needs for information specifically regarding dose adjustments and MOH should provide such information to the patients through internet so that they can retrieve the information whenever need arise.

Taking care of an epileptic child is a great source of stress for parents, especially the mothers. In a study in Jeddah it was observed that mothers of children with intractable epilepsy were increasingly fatigued. Factors associated with increased maternal fatigue included child's age <2 years and severe motor deficits. Factors associated with lowered fatigue included performing regular exercise, lack of mental retardation, seizure control, using one AED, infrequent ER visits and lack of recent hospitalization [19]. Reduced sleep is another source of fatigue for parents of epileptic children as they wake up frequently to check on their children [18].

The parenting stress can increase the risk of depression among parents of epileptic children [20]. Parents of children with epilepsy may benefit from parent training programs that, to reduce parenting stress, address epilepsy education, the management of difficult child temperament, building social support networks, and the modification of inadequate parental coping behaviors [20,21].

It was observed that about one third mothers perceived that the epileptic child is the main source of difficulty for hard to deal problems. Leaving aside the actual problems this perception alone reflects on the quality of the parent-child relationship. As has been observed that some families of children with epilepsy, may have difficulties finding appropriate levels of protective behaviors, control, and parental warmth and building positive mutual relationships between parents and children [22,23].

Conclusion

Only 23% of patients remained seizure free during last 12 months and 22% had family history of epilepsy. 40% mothers feel that their epileptic child can harm themselves during an epileptic attack and 58% feel that they need close watch for fear of injury. 36% mothers were satisfied with care provided in ER at hospital. 36% mothers always had difficulty to find time for their personal needs, and 59% were satisfied with their quality of life.

Recommendations

- Ministry of health should develop a comprehensive training program for health education program for parents, especially mothers, of epileptic children focusing on nature of disease; need of compliance to treatment and follow-up even after improvement; adjustment of doses in different life-scenarios; actions to be taken during an epileptic attack; and precautions during travel and sports.
- Ministry of health along with other related organizations should initiate a community awareness program to eliminate disease associated stigma while explaining medical nature of disease and absence of role of spiritual healers.

- Focal persons should be identified in each school who should be trained in care of epileptic children and they should be assigned to have improved coordination with parents of epileptic children.
- Social support mechanism for mothers of chronically ill children, including epilepsy, should be developed to provide them help in patient care.

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