

Health Education and Counseling in Childhood Epilepsy

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Epilepsy has always been a part of human existence. It has been recognized since the earliest medical writings and it is much more common than was previously thought to be. To the ancient Greeks epilepsy is an extraordinary phenomenon; they believe that only God or as in other cultures demons or evil spirits could knock someone down, battering their bodies around uncontrollably, being brought back without apparent ill-effect. Long ago, around 400 BC Hippocrates had fiercely, argued the supernatural explanation of epilepsy.¹ Epilepsy is a disorder of nerve cells it is not a disturbance of personality or intelligence. Charles Dickens, Vincent van Gogh, and Marion Clignet besides being famous and successful, each of them had epilepsy.²

Despite the immeasurable increase in understanding and improvement in diagnosis and management of epilepsy, the idea of possession by evil spirits as a cause of these frightening attacks, is still deeply rooted in many developing countries,^{3,4} Sudan is not an exempt. Many children with seizures of any cause are seen and managed first by 'El sheikh' a religious traditional healer or in some cultures in Africa by "Al Kujour" particularly, following an antiepileptic drug failure or appearance of its side effects.⁵

Children with epilepsy are at increased risk of behavioral and emotional problems compared with both healthy children and children with other chronic illnesses not involving the central nervous system.^{1,3,4} Risk factors are multiple and include additional neurological impairment, intractable seizures and family dysfunction. The misunderstanding of epilepsy and the social stigma of those living with the disorder often leads to feelings of isolation, low self-esteem and sometimes violation.

Many studies have shown that education and counseling involving the entire family structure help to alleviate some of the negative attitudes towards patient with epilepsy or seizure disorders.⁶ Parents or a child attendants are usually not well counseled.

We believe that counseling skills are a weak component in managing patients in all medical disciplines and they need to be strengthened. The art of counseling should be dealt with earlier particularly at medical schools.

This review is intended to address the childhood epilepsy in terms of its impact on the child care, schooling and psychosocial activities, to help both the families and treating doctors or nurses.

Keywords: *Epilepsy, Childhood, Adolescence, Counseling, Stigma, Behavioral management, Psychological help.*

NEGATIVE ATTITUDES TO EPILEPTIC PATIENTS:

As a heavily stigmatized disorder, both in the general community and among the medical profession, epilepsy is surrounded by a number of common misconceptions which can contribute to poor psychosocial adjustment and problems in the medical management and home care of this condition.^{1,7,8}

Behavioral management enables the epileptic to live with his/her seizures, and to overcome the psychosocial impacts of the disease. For many people with epilepsy, the myths are about as hard to live with as the medical disorder itself. Even harder is the discrimination, especially in schooling and later in employment that often limits and isolates people with epilepsy.⁸ Lack of

self-confidence and self-esteem often go along with the disorder as well.

Epilepsy is not related to mental illness. A person having a seizure does not need to be restrained. And people having convulsive seizures cannot swallow their tongues. These are all myths that people with epilepsy hear every day. These myths result from both prejudice about and ignorance of epilepsy.^{9,10}

THE NEUROPSYCHIATRIC ASPECTS OF EPILEPSY:

In spite of remarkable progress in drug therapy, childhood and adolescent epilepsy is often a distressing condition lasting several years before possible recovery. Adaptation problems to the disease and also to health recovery are likely to occur. Stigma and discrimination may persist also after recovery.^{11,12}

Depression in children and adolescents with epilepsy is a common but often unrecognized disorder. Both epilepsy and depression are characterized by a chronic course and poor long-term psychosocial outcome. Educating parents about mood disorders may allow them to be more receptive to psychiatric treatment for their child or themselves. The early identification and treatment of childhood-onset depression is an important clinical task for all pediatric specialists.¹³

Learning problems involve a high number of patients. Neuropsychological problems related to localization of the epileptic focus may be present; intellectual deterioration in more severe cases and in some specific syndromes may occur.¹ These problems are not unknown, but therapeutic effort is often directed only towards seizure control. The importance of counseling children and parents need no emphasis. Children and adolescents with epilepsy and their families need more than medical therapeutic support to get an acceptable quality of life.

COUNSELING SKILLS

Counseling is an art defined as "a formal or informal intervention that consists of a discussion between the counselor and the client, in order to adopt needed behaviour". In counseling the following questions should be answered; what are the information and counseling needs? What is the preferable method and timing for counseling and

information delivery? What are the expected outcomes?

The factual knowledge of epilepsy is often insufficient among patients with this disorder or their families. Compliance problems due to ignorance are common and counseling is extremely important.¹⁰

Counseling in epilepsy means support for people with epilepsy and their families to help with emotional and social consequences of epilepsy. The goals of counseling are to provide guidance for families with children with epilepsy in making informed choices, to promote self-management practices that will decrease health risks and to provide comprehensive answers about relevant issues.⁶

Individuals and family members are encouraged to take advantage of the counseling sessions, to receive help from therapists who understand and can relate to those with special needs.⁶ The counseling sessions may be performed at individual, family and a group of six to eight people. Sharing of experience with other patients is the most valuable element. Heterogeneity concerning age, sex and competence increase the interaction within the groups.

Some of the Goals of Counseling

1) Creating a greater understanding of seizures and their impact. 2) Helping families cope with the various aspects of epilepsy. 3) Helping persons to overcome obstacles caused by seizures and gets more out of life.

Professional staff or therapists, who possess a deep concern for others and have been provided with special training to better understand the needs of those with seizure disorders, are usually responsible of the counseling activities. Each counselor has to be skilled in applying the healing resources of faith with psychological techniques to help families resolve problems.^{8,9}

The following simple approach may be of help; (APAC model):

- Ask the child guardian or care giver what she/he does?
- Praise for good correct practice.
- Advice on what to be done.
- Check understanding.

Seizures frequency and medication intake must be documented in an accurate record or calendar of the child. It can be helpful to both the child and his/her physician.⁸ Such records help the child guardian remembering to give the child antiepileptic drugs and it can also help the physician evaluates and anticipates the antiepileptic drugs levels in the child blood.

Any use of other medications for other conditions should be discussed. Drug interactions between antiepileptic drugs and other over-the-counter medications must be recognized.

Parents and Caregivers Counseling

The following advices should be given to patients starting treatment for epilepsy.^{9,14}

- Avoidance of precipitants where feasible may be helpful, such as sleep deprivation, menstruation and flickering of lights (from TV screen, computer games and discotheques). However, photosensitive patients are very few, so the majority is able to enjoy computer, TV programs, and discotheques.
- The aims of treatment and the need for its continuity even if seizures are controlled should be fully explained. Stress the necessity of regular medication.
- Advise the care-givers about the risk of anti-epileptic drugs (AEDs) withdrawal, severe seizures usually follow abrupt AEDs withdrawal.
- Discuss the AEDs side effects, particularly the sedative effects of some AEDs and the possible drug interactions (including hepatic enzymes inducers).
- Advice should be given about how to cope with frightening science of seizures. Stress that the child is not in pain, seizures are generally self-limited, and serious injury is rare. Patients should be made as comfortable as possible, preferably lying down (they should be eased to the floor if sitting), the head should be cushioned, loose any tight clothing. During seizures, patients should not be moved, unless they are in a dangerous place, e.g., in the road, by a fire, at the top of stairs, or by edge of water.⁹
- No attempt should be made to open the patient's mouth or force anything between teeth.
- The epileptic may still be confused or in coma in the post-ictal phase and needs care. Hence, it is wise to remove him or her to recovery position when seizures stop.
- When starting AED explain to the child caretaker that AED is not curative, but rather suppresses seizures. They should be warned that in failure of the first AED to stop the seizures, dose adjustment or change of AED may be required. To judge AED efficacy, an interval of 5 times the average interval between seizures will be necessary. Always the treating doctor should be consulted about any generic substitution or drug interaction or predicted side effects.

Adolescents and Pre-Pregnancy Counseling

Epilepsy is the most common neurological disorder in adolescence. The convulsive disorders may conveniently be divided into epilepsy beginning before adolescence and epilepsy arising during adolescence. Juvenile myoclonic epilepsy typically begins in early adolescence with a peak of onset between 13 and 15 years of age. Primary generalized epilepsy namely the juvenile absence epilepsy is an age-related onset usually at puberty is a distinct syndrome from childhood absence epilepsy. Established temporal lobe epilepsy may be increasingly complicated by behavioural disorders in adolescence and should be distinguished from genuine seizures pattern.^{1, 14, 15}

Increase in seizure frequency beginning immediately before or during menses. In women with epilepsy seizures can be influenced by variations in sex hormone secretion during the menstrual cycle. The pro-convulsant effects of estrogen have been demonstrated in both animals and humans, whereas progesterone has been found to have anticonvulsant properties.^{16, 17, 18}

It is well-accepted in developing societies that women with epilepsy can not bear healthy children and be capable parents. Many young women living with epilepsy are still erroneously being advised not to have children or are being rejected by health care providers who simply do not want to care for them. The key to a successful pregnancy term and postpartum adjustment relies on strong communication and a supportive link between the mother and her health care provider(s). Four broad areas that should be covered in counseling adolescent girls with

epilepsy include access to care, unique health needs of women with epilepsy, personal care, safety, and social relationships.¹⁶

The fertility rate in epileptic women is up to 33% lower than average. Furthermore, marriage rates are also lower. Social and familial pressures on women with epilepsy to cease having children are a main factor in their lower rate of childbearing. Biological factors may play a small role in the higher rates of infertility in women with epilepsy. The effects of epilepsy, seizures and antiepileptic drugs on fertility are not entirely understood.^{16,17}

Counseling regarding lactating mothers

There is slight increase in perinatal problems as lower Apgar scores, Increase risk of difficult labour, asphyxia, prematurity and low birth weight. The risk of neonatal jaundice may decrease as a result of hepatic enzymes induction by AEDs.

AEDs are present in breast milk, at a concentration depending on the plasma protein binding (the more highly protein bound the drug, the lower the concentration in breast milk). Phenobarbitone and primidone (which is metabolized to phenobarbitone) sometimes cause sedative problems, hypotonia and poor suckling, these make it necessary to stop breast feeding. Drug withdrawal may cause jitteriness. Hyperexcitability and poor suckling have also occasionally been reported with ethosuximide. Women taking acetazolamide or topiramate are advised not to breast feed.

Counseling Regarding Antiepileptic Drugs and other Medications Usage

- Child guardian, his or her teachers and the child him or herself (if age appropriate) must understand the type of seizure that is occurring and the type of medications that are needed.
- They must know the dose, time, and side effects of all antiepileptic medications.
- Other medications must be given after consultation. Medications for seizures can interact with many other medications, and result in side effects.
- Inform young women of childbearing age, who are on seizure medications, that seizure medications are harmful to a fetus, and the medication may also decrease the effectiveness of oral contraceptives.

- Epileptics must check with the authority to understand any laws about people with epilepsy or seizures operating a motor vehicle.

Counseling and Advices to bystanders

- Recurring seizures reinforce the view of witnesses that the epileptic individual cannot be relied upon to participate fully in society because he/she is liable, unexpectedly and at any time, to go out of control. The following health education messages are useful.^{1,9} Table¹
- It is physiologically impossible for the tongue to be swallowed. During a seizure, there is a chance that the tongue might block air passages. To prevent this occurrence, turn the person's head to the side. Never put anything in the person's mouth.
- Someone having a seizure is not a danger to bystanders. Restraint is not necessary, will not stop the seizure and could cause injury. People should be moved away from sharp objects and hard floor surfaces during the seizure.
- No medical attention is needed for most seizures. No need to call for an ambulance. Usually, the patient just needs to rest. Stay with a person during a seizure until it subsides and the person is lucid. Do, however, call for help if;
 - The seizure lasts more than 5 minutes,
 - Is followed immediately by another seizure,
 - If this is the patient's first seizure,
 - The patient is injured or,
 - If the person is pregnant.

Table (1): Messages to Bystanders.

- (1) Epilepsy is not a disturbance of personality or intelligence and it is not contagious.
- (2) To prevent the tongue blocking the airway, turn the person's head to the side.
- (3) Do not restrain the patient with seizures on the road just move him or her away from sharp objects and hard floor surfaces during the seizure. Call for help if indicated.
- (4) Call for an ambulance or any help, if the seizure lasts more than 5 minutes or recurred immediately

- Most people with epilepsy are seizure-free or experience an occasional seizure. They have the same range of intelligence and ability as the general population and work at all levels of business, government, art and the professions. Yet, people with epilepsy cannot hold good jobs.
- Some children and adults do have severe forms of epilepsy which may be life-threatening, demand intense care and drastically inhibit their activities.
- People who experience seizures should see a physician.

Allowable Activities for an Epileptic Child

Parents themselves may reject their epileptic child, but they are more likely overprotecting the child against life's stressful and potentially dangerous situations. Although children with epilepsy may wish to join normally in everyday childhood activities, parents, friends, teachers and doctors often impose restrictions on children with epilepsy that are out of all proportion to the severity of the epilepsy. These restrictions however, interfere with the child's experience of normality. This concept needs to be discussed.¹⁹

Generalized tonic-clonic seizures (grand mal) associated with loss of consciousness present the greatest risk of child death. Status epilepticus which is still a serious medical emergency problem especially in the very young is much more amenable now to modern treatment.

Overprotection must be avoided if possible in dealing with the school age child who has epilepsy. As with all chronic long-term disorders, epilepsy requires adjustment on the part of the child and the family. The consulted doctor should have a wide knowledge of this common disorder to give the appropriate advice.

Swimming

Epileptic children who swim are four times more likely to drown or suffer brain damage from anoxia after near drowning, than are normal children but the absolute risk of drowning is low particularly if these children are properly supervised while swimming. Patients with rare seizures are discouraged from swimming in water-pools, rivers, lakes or seas, or diving in deep waters even in the presence of a lifeguard.

Children with frequent seizures are advised against any ordinary swimming without immediate and constant supervision. The British Epilepsy Association advocates the 'pairing system' whereby all children were advised and expected to swim in pairs.¹⁹

Drowning in the domestic bathtub carries greater hazards for the epileptic patients however; this particular risk lacks the needed awareness. Showering while seated is less hazardous.

Fishing as well carries another risk of accidental drowning and death during seizures induced by the shimmer of bright light on rippling water in photosensitive patients. Other risk factors as in reflex epilepsy as in the rare water immersion epilepsy or hot water epilepsy have to be considered as important provocation factors.^{1,19}

School Activities

Most children with epilepsy can and they should attend normal schools. They should have a normal school life as possible, and their activities there should be limited only with consideration to the following factors; severity and frequency of attacks, the seizures timing in relation to waking and sleeping, and the child's judgment and perception of expected risks. Their teachers should be correctly informed about epilepsy and encouraged to have open minded and positive and optimistic attitude towards the condition. The school teachers and the class mates should be instructed about the emergency treatment of a child having a major seizure in the classroom. Other children may be quite helpful if they are armed with the correct information regarding the benign nature of the seizure. They should be motivated to offer help and carry the messages of epileptic care to their family and friends.^{1,19}

Sports in the School

"One must strike a balance between the needs of the child to participate with his peers in their daily activities and the limitations to living a full life which any restriction may impose" American Academy of Pediatrics, Committee on Children with Handicaps 1968^{1,19}

If a child has a good control over the seizures, only minimal restrictions need to be placed on the child's activities. The child should always wear a helmet with sports and bike riding.

Gymnastics and athletics activities at school may carry some risk for an epileptic child with active epilepsy, and his participation should be put into consideration. Children with seizures without warning should be barred from games where a fall is expected when the attacks develop. These restraints might be loosened if the child is seizure free for a long time. Some children may have their epileptic discharges activated during exercise and during post-exercise recovery phase. The hazard of repeated head trauma during contact sports mainly boxing that leads to further neuronal damage and loss and thus compound the preexisting epileptic problems should be considered.^{1,9,19} Some researchers suggested the prohibition of competitive games, such as swimming, since somatic stress to the point of exhaustion may trigger an attack. However, this factor could be influenced by training and conditioning of the child.

*"Many children with epilepsy have far fewer seizures when active and engaged in normal childhood activities than they are idle or at rest or bored. Some may even excel in athletics and, provided their epilepsy is under satisfactory control, there seems little point in making distinctions between epileptic and non-epileptic children as far as their participation in athletics is concerned"*²⁰

Daily Activities

All children are subject to risks in their daily lives, especially in overcrowded urban communities. Bicycling is a hazard in traffic, both for normal and epileptic children. Seizures discharges occurred less frequently in circumstances which were neither boring nor excessively stressful. Some degree of concentration or arousal reduces the seizures frequency, whereas too stressful attention the seizures discharges increased and performance declined. Thus each case has to be judged on its own merits. The modern traffic complexity, limits unnecessary risks exposure of epileptic children unless their seizures are well controlled.^{1,9,19}

Loud sounds

Although loud music and flashing lights performed in discotheques or during wedding parties may provoke seizures in photosensitive epileptics or other cases of reflex epilepsies, some researches suggested that most epileptic children were not particularly vulnerable in these parties. The

energetic exercise of disco dancing may have a protective or normalizing effect on these children. However, the small minority of children with reflex epilepsies induces e.g. by exercise, voluntary eye closure, music and hyperventilation may be at risk from stroboscopic illumination even at a relatively low frequency employed in discotheques or wedding parties.¹

Television Viewing

The greatest concern for parents of children who actively play video games is to know whether they are photosensitive or not. If there is a history of epilepsy in the family, especially a form of generalized epilepsy (which is more likely to be associated with photosensitivity), or if a close relative, like a sibling, had or has light-induced seizures, it may be wise to consult a doctor. It only takes a simple EEG test to find out if the subject is at risk and if special precautions are warranted.¹⁹ The American Epilepsy Foundation's professional advisory board has issued general recommendations for television viewing (see Table 2).

For video game playing, in addition to the above precautions, the professional advisory board recommends the following:

- *Players should not play if they are tired, especially if they are sleep deprived.*
- *Avoid excessive use of alcoholic beverages.*
- *Take frequent breaks from the game and look away from the screen every once in a while.*
- *If strange or unusual feelings develop, turn the game off.*
- *If players start feeling their bodies jerking, cover one eye with one hand and immediately look away or turn the game off.*

Table 2:2-General Recommendations for Television Viewing.

- **Watch television in a well-lit room to reduce the contrast between the screen light and background light.**
- **Reduce the brightness of the screen.**
- **Keep as far back from the screen as possible (minimum five feet).**
- **Use remote controls to ensure proper distance from the television is maintained.**
- **Use small screens. When watching large screens, increase the distance from the screen.**

Monocular vision (covering one eye) is a most useful practice because it works in most circumstances and still allows the subject to see. It is important to know that just closing the eyes does not prevent photosensitive reactions because the red-tinted light filtering through the eyelids will be just as provocative, if not more.

Nowadays, video games contain a generic warning alerting the player of the risk of seizures. Hopefully, in a not-too-distant future, games will carry a statement specifying whether their visual content is unrestricted or if they have been built in compliance with the specifications outlined in the Epilepsy Foundation's consensus statement. The Foundation and its professional advisory board believes there is a market for "safe" video games, and that parents and consumers will appreciate the opportunity to make informed choices.¹⁹

All in all, photosensitivity is a relatively infrequent and benign condition, similar to but not synonymous with epilepsy. It raises interesting medical and public health issues when it comes to identification of the condition and prevention of its consequences.

Large group of affected individuals are unaware of the risks while environmental hazards that can cause seizures by chance stimulation are ever-present in modern society. Methods of prevention and remedies are available and should be modified to the specific needs of the single individual, and this requires intense involvement by the treating physician. It also requires constant self-surveillance and encouragement.

The Epilepsy Foundation has taken a leading role in promoting knowledge about the condition and disseminating information to consumers and interested professionals. If consumers have questions, or if events like seizures occur, they are encouraged to contact the Epilepsy Foundation for guidance.

Advice Regarding Follow Up

Children with epilepsy require frequent referred clinic visits during the titration and adjustment phase of anticonvulsants. Specific follow-up will be determined by the treating physician. Medications for seizures may not be needed for the entire life of the child. Some children may be taken off their medications if they have been

seizure-free for one to two years. This will be determined by the physician.

- Examination should include evaluation for excessive nystagmus, tremor, and ataxia. Evaluation should include the child general and school performance. Assess specifically the side effects of AEDs in use.
- Baseline and follow-up blood testing may be needed.
- When seizure free on maintenance dose of medication, children may be asked to come for follow-up 1-3 times a year.
- Children who are seizure free for 2-5 years may be considered for a trial of medication withdrawal, depending on the individual case.

CONCLUSION

The misunderstanding of epilepsy and the social stigma of those living with the disorder often leads to feelings of isolation, low self-esteem and sometimes violation. Many children with epilepsy or seizure disorders in developing communities are denied normal life and schooling, become exposed to acts of violence or even sexual assault.

Many studies have shown that education and counseling involving the entire family structure help to alleviate some of the negative attitudes towards patients with epilepsy or seizure disorders. During this time in a child's life a support group would be extremely helpful. Understanding a trustful relative, or friend, or someone who is willing to advocate for patient can be of help in case of failure to involve the family in these counseling services.

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