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REVIEW ARTICLE

Association of Child Neurology-Indian Epilepsy Society Consensus Document on Parental Counseling of Children with Epilepsy

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Abstract

When a child is diagnosed with epilepsy, counseling regarding the same is done by the treating doctor. Most parents are frightened and have poor knowledge about epilepsy. Therapeutic advice including drug dosage, administration and side effects takes up the major part of physician's time, thereby neglecting important issues like home seizure management, follow up and others. These lacunae in knowledge require systematic patient and family education. To address these issues, an expert group meeting of pediatric neurologists and epileptologists in India along with social workers/epilepsy educators, legal experts, parents, and teachers was held. The various aspects regarding parental counseling in children with epilepsy were discussed and a consensus document was formulated. Here authors present the group consensus statement on counseling parents and caregivers of children with epilepsy. This document is intended to help physicians and pediatricians counsel the families when a child is diagnosed with epilepsy.

Keywords Families · Activity restriction · Schooling

Introduction

When a child is diagnosed with epilepsy, counseling regarding the same is done by the treating doctor [1]. Doctors themselves may not be aware of the gaps in their knowledge and thus, many aspects of management remain uncovered in daily practice [2]. An epilepsy educator/ nurse can play a vital role in patient education but this is not feasible at most centres [3]. Hence physicians need to be sensitized regarding counseling elements as better informed patients have better adherence to therapy [4].

Experts were invited to discuss the various elements of parental counseling by doctors,when a child is diagnosed with epilepsy (see Process in preceding AOCN Consensus Document on Social and Legal Aspects of Childhood Epilepsy). A consensus document was formulated.

The document was prepared for publication in the form of two articles; 1) Consensus document on Social and Legal aspects of epilepsy; and 2) Consensus document on parental counseling of children with epilepsy, after approval by the participating members.

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The following aspects need to be covered in counseling parents of children with epilepsy.

General Information about Epilepsy and Seizures

What are Seizures and What are the Common Seizure Types in Children?

The brain has millions of cells called neurons. Sometimes, they generate excessive electrical activity resulting in seizures. When this abnormal electrical activity remains confined to one part of the brain, the child may get funny sensations or movements in a part of the body, *e.g.* face, a hand, a leg. These are called **focal seizures**.

If these abnormal discharges involve the whole brain, either from beginning or spread from a focus, the child loses consciousness, gets violent limb movements with frothing from mouth, these are called **generalised seizures** and can be dangerous if prolonged.

Other types of seizures include sudden falls (atonic), blank spells (absence), or sudden jerking (myoclonic) *etc.* [5]. A special type of seizure seen in infants is called **spasm** (baby suddenly stiffens); these cause slowing of development, so should be treated early.

What is Epilepsy and What Causes Epilepsy?

Conditions which alter the electrical activity of brain *e.g.* low sugar or calcium levels, fever, injury, brain infections, *etc.* can cause seizures. These are called **acute seizures**. However, if the brain has tendency to develop repetitive seizures, without any immediate cause; this is called **Epilepsy.** Physicians diagnose epilepsy when a child gets two or more such seizures [5].

Many conditions cause acute seizures as well as epilepsy later, *e.g.* when a child gets meningitis- he may get acute seizures during the illness- these require short term treatment. The same child may later develop repeated seizures from the damaged parts of the brain; these are called **epileptic seizures** and will require prolonged treatment. Seizures may also arise due to genetic faults in the electrical networks of the brain, called **idiopathic or genetic epileptic seizures.** The brain is structurally normal and there may be a family history of seizures.

Is Epilepsy Common?

In India, 3 to 12 out of 1000 people have epilepsy [6]. Different names (mirgi/ jhatka /fits /aakdi *etc.*) are prevalent in different parts of the country.

Epilepsy is Not Limited to a Particular Age and Locality

Some causes are age related; *e.g.*, brain hypoxia in newborn, meningitis in infancy, head injuries in adults. Neurocysticercosis is common in India, and occurs due to tapeworm larva trapped in the brain and causes acute as well as epileptic seizures. Genetic epilepsies may have a particular age of onset and remission [7].

All Jerks and Abnormal Movements are Not Seizures

Many movements look like seizures, but do not require treatment with anti-seizure drugs. A detailed history and a video of the event is useful in such cases [8].

Information about the Diagnosis of Epilepsy

Diagnosis of Epilepsy is Mainly Clinical

Clinical means the detailed description of the seizure - what exactly happened, how did it start, progress, and end. History from an eye-witness or a video record helps to diagnose the type of seizure. History of birth events, development and family helps to arrive at the possible cause [9].

Blood Tests are Not Routinely Required

Serum calcium and sugar levels are advised in infancy, during the first seizure. If needed, special tests to rule out metabolic, genetic, autoimmune disorders are advised [10].

Role of EEG (Electroencephalography) in Diagnosis of Epilepsy

EEG shows a map of the electrical activity of the brain, abnormal discharges supporting the diagnosis of epilepsy [11]. The distribution and type of abnormalities help to classify the epilepsy and decide the best treatment. Certain abnormalities help to predict the outcome, *e.g.*, how long will seizures remain and whether the child's intelligence will be affected.

The EEG Procedure

Electrodes are applied on scalp to record the electrical signals in the brain, and displayed on a computer. EEG is recorded in both sleep and awake states, if possible [12]. Video EEG is ideal to record abnormal events.

A Normal EEG Does Not Rule Out Epilepsy

Mostly, first EEG may be normal in up to 50% of cases. Electrical discharges arising from deeper regions of the brain may not be detected [13]. Repeated EEGs and EEG done in a sleep deprived state (*e.g.*, sleeping for only 4 h at night prior to EEG) improve the yield.

We May Need to Repeat EEG Sometimes

EEG may be repeated if it is normal and there is a strong suspicion of epilepsy [13]. EEG is also repeated before withdrawing treatment if the child has been seizure free for 2–3 y.

A Brain Scan is Usually Needed

MRI scan is preferred to CT as it shows detailed brain structure, *e.g.,* prior brain damage, neurocysticersosis, tumors and subtle abnormalities like dysplasia which cause difficult to control seizures and need to be surgically removed to treat the epilepsy [14].

MRI Scan May be Normal in Epilepsy

MRI may be normal if there is only electrical disturbance and no structural problem, *e.g.*, in genetic epilepsies [14]. Your doctor will decide whether a scan is required at all.

Information Regarding First Aid for Seizures

Recovery Position When a Child Gets a Seizure

Most seizures are brief and stop themselves. It is important to be calm, and not panic. The child should be brought **away from any danger** (*e.g.*, if on road, on edge, near any sharp objects *etc.*) and put in **recovery position**, *i.e.*, turned to one side gently so that the froth/saliva drains out of mouth by gravity and is not inhaled into the lungs [15].

No Forcible Opening of the Mouth if Teeth are Tightly Clenched

Restraining a seizing child or opening mouth forcibly can cause injury. Only if the mouth is full of food, a finger can be gently inserted inside the cheeks to remove the food particles.

Nothing Should be Put in the Mouth; *e.g.*, Water, Spoon *etc.* till the Child is Unconscious

If Possible, a Video Recording of the Seizure Should be Made, and Duration Noted

First Aid Medicines to Stop the Seizure

Midazolam nasal spray is available and easy to use [16]. The doctor will show how to use it and how many puffs to give. It can be used if the seizure does not stop in 5 min. It should be stored safely *e.g.*, in custody of school nurse (out of reach of children). The nurse can use it in case of a prolonged seizure till help arrives. Expiry date should be periodically checked.

Calling an Ambulance or Shifting to Nearby Hospital if Prolonged Seizure

When seizure is prolonged, or lasts longer than the usual seizure, or the child is unconscious for a prolonged period after the seizure, has got injured badly, or has trouble breathing, he/she should be taken early to the nearest hospital (rather than the best, if far) [17].

Sometimes, Patients May be Able to Feel the Warning Signs– Aura

When seizures arise from a particular part of the brain (focal onset), some children may experience warning signs like tingling, flashes of light, vomiting, tummyache, headache, sudden fear *etc*; these are called 'Aura' [18]. These may warn him and prevent severe injuries. In generalised onset seizures, there is no aura and child may be unconscious from the beginning.

Most Seizures are Short-Lived, but Get Dangerous if Prolonged

Seizures are very frightening events, many parents worry whether there is a risk of dying during the seizures. Prolonged seizures or burns, drowning *etc.* during seizures can cause death [19].

All Caretakers Should be Well Versed in First Aid

These include family members, school teacher, personnel ferrying him to school *etc.*

Use of Onion, Shoe, Keys *etc.* to Stop the Seizure Wastes Precious Time

As most seizures are brief and stop by themselves, it appears that these measures have helped. Putting hard objects forcibly into the mouth to 'break' the seizure is harmful and can injure

the teeth, tongue or lips [20]. Bringing the child to recovery position is most important.

Management of Febrile Seizure

If seizures occur only with fever, most are brief and stop by themselves. Clothes should be removed to lower the temperature and Paracetamol should be given in the prescribed dose. Midazolam spray should be used if the seizure is prolonged. If febrile seizures are prolonged, or happen repeatedly, seizure preventive medications (Clobazam) may be given during fever [21].

Information about Treatment of Epilepsy

Does Every Child Need Prolonged Treatment with Anti-Seizure Medicines?

Prolonged treatment is not required after febrile seizures, first seizure without any immediate cause, infrequent seizures or if the risk of a repeat seizure is very low [22].

How Long Should the Child be Treated with Anti-Epileptic Drugs (AEDs)?

If decided to treat, AEDs are given for 2–3 seizure free years [23]. The duration may vary according to the cause of epilepsy and ease of control of seizures. Some patients require very prolonged periods of treatment - *e.g.*, in children with severe brain damage.

The Medicines Must Always be Carried When Visiting the Doctor

The preparation, dose and formulation needs to be verified. AED should be given regularly even when the seizures are controlled, for the prescribed duration.

Can there be a Return of Seizures after Stopping Treatment?

Sixty to 70 % of children become seizure free with 1 or 2 AEDs. After 2–3 y seizure-free period, the drugs are slowly tapered and stopped. The majority of such children remain seizure free, some may relapse and need to be restarted on AEDs [24]. Some types of epilepsies *e.g.*, Juvenile myoclonic epilepsy (JME) may require lifelong treatment, mostly in low doses.

Follow-up is Essential While on Treatment

First follow-up should be within 7–14 d, to look for any acute side-effects. Later, 3 monthly follow-up with a seizure diary is good to assess seizure control and monitor side-effects.

Other Options are Available if Medications Fail

Ketogenic diet or steroids (*esp*. for spasms) may be prescribed [25]. The doctor will investigate to rule out metabolic/genetic conditions as they need specific treatment [26].

Sometimes, Surgery May be Suggested

Surgery may be advised if, seizure frequency is high, poor response to AEDs and there is a surgically removable abnormality picked up on brain MRI [27].

Measures to Prevent Seizures

Adequate sleep, avoiding TV, flickering lights (if EEG shows abnormal discharges during light flashes) and preventive medications to prevent seizures during fever can be advised [28].

Information about Anti-Seizure Drugs

Medications are Chosen by the Doctor on the Basis of Seizure Type on History and EEG

Different AEDs are available– chemicals which block abnormal electrical discharges in the brain. The right drug for your child is decided by the type of seizure and EEG findings [29].

Precautions Regarding Formulation

The doctor will prescribe the AED name, dose, formulation (*e.g.*, plain/ slow release) and timing. Changing the brand may lead to change in the blood levels causing toxic effects or loss of control of seizures [30]. If the prescribed brand is not available, please verify with your doctor.

The tablets are prescribed as plain tablets or slow release. The slow release ones (Chrono/ SR/CR) can be given once or twice a day, but cannot be crushed and should be swallowed. The dose should be repeated if the child vomits within half an hour.

The Syrup bottle should always be shaken before use. The plastic caps on bottles have 2.5 and 5 ml markings, hence best to use a calibrated syringe/ dispenser to give the exact dose, *e.g.*, 1.5 ml. The syringe should be washed after every use, and replaced when markings become faint.

Timing

Timing of the medications should be strictly adhered to. It can be marked on a calendar after the dose is taken as it may be difficult to remember whether medication has been taken.

The Dose of Medication Needs to be Titrated till Seizures are Fully Controlled

The aim is to control the seizures at the lowest dose, to minimize side-effects. Many children are controlled on low doses, or the dose is gradually increased till seizures are controlled. If seizures are not controlled at a reasonable dose, or adverse side-effects appear; another AED may be tried.

Regular Follow-up with Treating Physician is Necessary

Follow-up every 3 mo is advised as the treatment may need to be tailored according to the child's response.

Treatment Should Not be Stopped During Other Illnesses

The AED should be continued with other medications during minor illnesses like cough- cold, diarrhea *etc.* Consult your doctor if the sick child is not accepting anything orally.

First Medicine is Effective in Controlling Seizures in about 50% Patients

First drug controls seizures in about 50% children, at low to moderate doses [31]. Others require another AED or combination therapy. Response to the subsequently added drugs is lower.

Drugs Should Not be Stopped without Consulting the Doctor

AEDs are mostly given for 2–3 y seizure free period, but the duration may vary depending on doctor's judgement [32]. The treatment should never be stopped without medical advice.

Important Side-Effects of Anti-Epileptic Drugs (AEDs)

Specific side-effects for a particular AED should be counseled, *e.g.*, acute (within hours to days) and chronic (days to months) ones. Some AEDs cause sleepiness, vomiting *etc.* when started, and are usually tolerated on reducing the dose and gradual escalation [33].

A serious, life-threatening reaction presenting with blisters on skin along with mouth and eye ulcers is called Stevens-Johnson syndrome (SJS); hence any AED should be immediately stopped if a rash is noticed [34]. It is more likely in people who carry a HLA B1502 mutation.

US FDA advises to test all Asian people for this mutation before starting certain AEDs: Carbamazepine, Phenytoin and Lamotrigine [35].

At present the consensus view is: This testing is not routinely required in our patients in view of several factors: prevalence of this mutation in Indians is not known, SJS can develop even without this mutation, all patients carrying this mutation don't develop SJS. Hence, this test is not cost-effective when applied to a large population, especially in government/ rural setup. But parents need to be counseled properly regarding stopping AED if rash appears.

Other Side-Effects

Some AEDs gradually reduce Vitamin D, causing weaker bones; hence, supplementation is advisable [36]. Some AEDs cause slowing of thinking processes, memory and behavioral problems [37]. The doctors aim to achieve best control of seizures with minimal side-effects.

Issues in School

Child's Learning May be Affected, but Help is Available

Children with only epilepsy mostly have normal intelligence, especially if on newer AEDs. Learning disabilities are common in those with brain damage, untreated seizures for prolonged periods and on high doses of multiple AEDs [38]. Remedial help can be sought from interventional psychologist, taking school counselor and other authorities into confidence.

Schools Cannot Discriminate Against a Child with Epilepsy, it is an Offence

No school can expel a child from school for epilepsy, under the right to education act.

The School Should be Adequately Informed about the Child's Epilepsy and First Aid

Midazolam spray can be kept with the school teacher (not in child's bag) with instructions and emergency contact number. A hospital near the school should be identified beforehand, in case the child needs hospitalization during school hours. School authorities should have the parental consent to act in the best interest of the child.

A letter from the doctor can be issued to the Principal for allowing school when seizures are controlled. Excellent

guides for teachers to cope with a student with epilepsy are available [39].

Precautions to be Taken During Outdoor Activities

Well controlled children can participate in school excursions [40]. They should take AED on time, have good sleep, and carry first aid medications. A nearby hospital can be pre-identified.

Blanket Restriction of Activities is Not Advisable

If seizures are not well controlled; cooking, cycling *etc.* should be under supervision. For swimming, buddy system can be followed where every child is being watched by someone (a friend/parent/coach with lifeguard on standby); this helps them feel equal to others, as well as ensures safety [41]. Participation in high risk sports like diving, motor sports, horse riding, *etc.* should be avoided where a loss of consciousness can result in a major injury or death [42].

Special Issues

Activities Which Provoke Seizures in Certain Individuals Should be Avoided

Children with abnormal discharges provoked by flashing lights or patterns (on EEG) should avoid exposure to flickering lights *e.g.*, Discotheques, night driving, some video games, *etc.* [28].

Teenage Children with Uncontrolled Seizures Should Not be Allowed to Drive

Cycling (wearing a helmet) is allowed if seizures are controlled. Most countries allow motorbike/car driving after 3–18 mo of seizure freedom. In India, if the person declares his epilepsy condition, driving licence is not issued [43]. Thus most people drive without disclosing with potential for serious harm to themselves and others.

Some Jobs May Not be Suitable for Patients with Reflex Epilepsy

Some jobs like pilots, running heavy machinery, fire fighting, *etc.* are best avoided. Otherwise, most other jobs are suitable for people with epilepsy. Also, those who get abnormal EEG discharges by flashing lights should avoid working in flickering lights *e.g.*, discotheques.

Special Issues in Girls with Epilepsy

Some epilepsies like Juvenile myoclonic epilepsy need treatment from adolescence to old age. Females face additional health issues, *e.g.*, AED may affect menstrual cycles or interfere with oral contraceptives leading to unplanned pregnancies. Pregnancy should be planned carefully. Most women can have a safe pregnancy and healthy child under expert guidance, *i.e.*, use of safe AED to avoid birth defects in babies [44].

Stigma attached to epilepsy forces many people to hide their condition from their partners, creating marital discord, domestic violence and divorce. All patients with epilepsy, especially girls should be educated and helped to be self-sufficient to prevent exploitation. Samavedana Foundation, Pune runs a marriage bureau for people with epilepsy.

Social and Financial Resources are Available [45]

More Genetic Causes for Epilepsy are Being Discovered

New genes increasing the risk of seizures are being discovered. Complex interplay with other factors makes it difficult to predict whether other family members will get seizures, and what type. Your doctor may advise regarding the need for genetic tests if required [46].

Many Myths are Prevalent in Our Society Regarding Epilepsy

As epilepsy was poorly understood in the past, many myths are prevalent. It does not spread by contact, it is not due to prior sins/ black magic/devils *etc.* [47]. This leads many parents to wrongly hide this condition from the school and society, adversely affecting the child's health and self esteem, also leaves other people clueless about how to deal in the event of a seizure.

Role of Alternative Therapies Like Homoeopathy, Ayurveda *etc.* is Not Well Established

Parents often try other systems of medicine [48]. The doctor should be informed if such therapies are being given, as it may affect the anti-epileptic drug levels and also cause compliance issues.

Routine Vaccination Should be Given, Except in Special Situations

If the child has uncontrolled seizures, or specific genetic epilepsies, the doctor may ask to avoid Pertussis (the 'P' in DPT) [49]. Also, if the child is on steroids *e.g.*, for West syndrome,

live vaccines such as oral polio and measles should be avoided till 4 wk after stopping steroids.

Family Issues

Epilepsy May be Associated with Behavioral, Mood and Depressive Disorders

Many children with epilepsy suffer from low self- esteem, anxiety *etc.* Some anti-epileptic drugs can cause depression, mood disturbances and even suicidal tendencies. Referral to a Child psychologist or psychiatrist may be made if intervention is required [50].

Avoid Overprotection

Overprotection will give rise to more behavioral problems. Parents, *esp*. mothers may need help to achieve the right balance of parenting style. Parents need to be attentive regarding medications and studies, and encourage outdoor physical activity, participation in family functions, social gatherings *etc.* to prevent isolation [51].

Will the Brother/Sister (Sibling) Also Get Epilepsy?

Most parents harbour this fear, as few types of epilepsy have a genetic basis. However, all siblings may not inherit those genes or even if inherited they may or may not get seizures. The chances of a sibling being affected varies from 1 to 4 times of the general population [52].

Equal Care and Attention Should be Given to the Siblings of the Child with Epilepsy

Children with epilepsy get more attention, causing psychological issues in siblings, *e.g.*, rivalry, anxiety *etc.* [53]. Their concerns should be resolved, can involve them in care plan, teach first aid (if old enough). Help of school counselor and psychologist may be taken if required.

Epilepsy, Cerebral Palsy, Autism *etc.* are Not the Same

These are different manifestations of brain dysfunction. Cerebral palsy affects muscle control, due to structural brain problems. Autism affects interaction and communication, with mostly normal brain structure. Both have a higher prevalence of epilepsy and intellectual disability [54].

Some Causes of Epilepsy Can be Prevented

Majority of brain damage causing epilepsy can be prevented, *e.g.*, wearing helmets while driving, washing fruits and vegetables thoroughly before eating (prevents Neurocysticercosis), timely vaccination of children against brain infections (BCG, HiB, Pneumococcal) *etc.* [55].

Sudden Death in Epilepsy (SUDEP)

Sudden death in sleep, called SUDEP (Sudden death in epilepsy) may occur *esp*. in cases of frequent uncontrolled seizures and irregular treatment [56]. Exact mechanism is not known.

Parents' Support and Advocacy Groups

Various support groups are active in different regions, these provide psychosocial support and a platform to share problems and solutions with each other. Indian Epilepsy Society (IES) and International Bureau for Epilepsy (IBE) have played an important role in providing knowledge to epilepsy professionals and governments to take decisions that benefit people with epilepsy.

For further information, web based resources (Appendix A) can be freely accessed by parents.

Conclusions

The various aspects of counseling parents of children with epilepsy are consolidated in this document. It includes information regarding the causes of seizures and epilepsy, the diagnostic tests, first aid for seizures, issues related to treatment, school and family *etc.* Counseling may occur over several visits, as parents raise pertinent questions during the course of treatment. Hand-outs of this document can be provided by the physicians/pediatricians to the parents.

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Compliance with Ethical Standards

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References

1. Jones B. Counselling the epileptic patient. Can Fam Physician. 1983;29:107–11.
2. Vancini RL, Benedito-Silva AA, Sousa BS, et al. Knowledge about epilepsy in health professionals: a cross sectional survey in Sao Paulo, Brazil. BMJ Open. 2012;2:e000919.
3. Fitzsimons M, Normand C, Varley J, Delanty N. Review- evidence based models of care for people with epilepsy. Epilepsy Behav. 2012;23:1–6.
4. Ridsdale L, Morgan M, O' Connor C. Promoting self care in epilepsy: the views of patients on the advice they had received from specialists, family doctors and an epilepsy nurse. Patient Educ Couns. 1999;37:43–7.
5. Brodie MJ, Zuberi SM, Scheffer IE, Fischer RS. The 2017 ILAE classification of seizure types and the epilepsies: what do people with epilepsy and their caregivers need to now? Epileptic Disord. 2018;20:77–87.
6. Bharucha NE. Epidemiology of epilepsy in India. Epilepsia. 2003;44:9–11.
7. Gadgil P, Udani V. Pediatric epilepsy: the Indian experience. J Pediatr Neurosci. 2011;6:126–9.
8. Tatli B, Guler S. Non epileptic paroxysmal events in childhood. Turk Pediatr Ars. 2017;52:59–65.
9. Glauser TA, Sankar R. Core elements of epilepsy diagnosis and management: expert consensus from the Leadership in Epilepsy, Advocacy and Development (LEAD) faculty. Curr Med Res Opin. 2008;24:3463–77.
10. Ciccone O, Mathews M, Birbeck GL. Management of acute seizures in children: a review with special consideration of care in resource-limited settings. Afr J Emerg Med. 2017;7:S3–9.
11. Noachter S, Remi J. The role of EEG in epilepsy: a critical review. Epilepsy Behav. 2009;15:22–33.
12. Smith SJM. EEG in the diagnosis, classification and management of patients with epilepsy. J Neurol Neurosurg Psychiatry. 2005;76: ii2–7.
13. Carpay JA, de Weerd AW, Schimsheimer RJ, et al. The diagnostic yield of a second EEG after partial sleep deprivation: a prospective study in children with newly diagnosed seizures. Epilepsia. 2005;38:595–9.
14. Roy T, Pandit A. Neuroimagimg in epilepsy. Ann Indian Acad Neurol. 2011;14:78–80.
15. Epilepsy Society First Aid: What To Do if Someone Has a Seizure. Leaflet. Available at: www.epilepsysociety.org.uk/system/files/attachment/FirstaidAugust2018.pdf. Accessed 14th Dec 2018.
16. Zelcer M, Goldman RD. Intranasal midazolam for seizure cessation in the community setting. Can Fam Physician. 2016;62:559–61.
17. Jenssen S, Gracely EJ, Sperling MR. How long do most seizures last? A systematic comparison of seizures recorded in the epilepsy monitoring unit. Epilepsia. 2006;47:1499–503.
18. Perven G, So NK. Epileptic auras: phenomenology and neurophysiology. Epileptic Disord. 2015;17:349–62.
19. Camfield C, Camfield P. Injuries from seizures are a serious, persistent problem in childhood onset epilepsy: a population based study. Seizure. 2015;27:80–3.
20. Singh S, Mishra VN, Singh R, Chaurasia RN. Myths and superstition about epilepsy: a study from North India. J Neurosci Rural Pract. 2018;9:359–62.
21. Mohammadi M. Febrile seizures: four steps algorithmic clinical approach. Iran J Pediatr. 2010;20:5–15.
22. Newton RW. When is drug treatment not necessary in epilepsy? Factors that should influence the decision to prescribe. J R Soc Med. 2004;97:15–9.
23. Expert Committee on Pediatric Epilepsy, Indian Academy of Pediatrics. Guidelines for diagnosis and management of childhood epilepsy. Indian Pediatr. 2009;46:681–98.
24. Srivastava K, Kishore KK, Topiwala K, Rajadhyaksha S. Recurrence rate and risk factors for recurrence of seizures after withdrawal of antiepileptic drugs (AED) in Indian children treated for epilepsy. Int J Epilepsy. 2017;4:12–8.
25. Sharma S, Jain P. The ketogenic diet and other dietary treatments for refractory epilepsy in children. Ann Indian Acad Neurol. 2014;17:253–8.
26. Ottman R, Hirose S, Jain S, et al. Genetic testing in the epilepsies-report of the ILAE genetics commission. Epilepsia. 2010;51:655–70.
27. Dwivedi R, Ramanujam B, Sarat Chandra P, Sapra S. Surgery for drug resistant epilepsy in children. N Engl J Med. 2017;377:1639–47.
28. Okudan ZV, Ozkara C. Reflex epilepsy: triggers and management strategies. Neuropsychiatr Dis Treat. 2018;14:327–37.
29. Glauser T, Ben-Menachem E, Bourgeois B, et al. Evidence based analysis of anti-epileptic drug efficacy and effectiveness as initial monotherapy for epileptic seizures and syndromes. Epilepsia. 2006;47:1094–120.
30. Atif M, Azeem M, Sarwar MA. Potential problems and recommendations regarding substitution of generic antiepileptic drugs: a systematic review of literature. Springerplus. 2016;5:182.
31. Kwan P, Brodie MJ. Effectiveness of first antiepileptic drug. Epilepsia. 2001;42:1255–60.
32. Rathore C, Paterson R. Stopping antiepileptic drugs in patients with epilepsy in remission: why, when and how? Neurol India. 2014;62: 3–8.
33. Guerrini R, Zaccara G, la Marca G, Rosati A. Safety and tolerability of antiepileptic drug treatment in children with epilepsy. Drug Saf. 2012;35:519–33.
34. Frey N, Bodmer M, Bircher A, et al. The risk of Stevens-Johnson syndrome and toxic epidermal necrolysis in new users of antiepileptic drugs. Epilepsia. 2017;58:2178–85.
35. Leckband SG, Kelsoe JR, Dunnenberger HM, et al. Clinical pharmacogenetics implementation consortium guidelines for HLA-B genotype and carbamazepine dosing. Clin Pharmacol Ther. 2013;94:324–8.
36. Menon B, Harinarayan CV. The effects of antiepileptic drug therapy on serum 25-hydroxyvitamin D and parameters of calcium and bone metabolism- a longitudinal study. Seizure. 2010;19:153–8.
37. Ijff DM, Aldenkamp AP. Cognitive side-effects of antiepileptic drugs in children. Handb Clin Neurol. 2013;111:707–18.
38. Vinayan KP. Epilepsy, anti-epileptic drugs and educational problems. Indian Pediatr. 2006;43:786–94.

39. Guide for Teachers. Available at: http://www.edmontonepilepsy.org/documents/Epilepsy%20-%20A%20Guide%20For%20Teachers.pdf. Accessed 4th Feb 2019.
40. Brna PM, Gordon KE, Woolridge E, Dooley JM, Wood E. Perceived need of restrictions on activity for children with epilepsy. Epilepsy Behav. 2017;73:236–9.
41. ILAE Commission Report. Restrictions for children with epilepsy. Epilepsia. 1997;38:1054–6.
42. Capovilla G, Kaufman KR, Perucca E, Moshe SL, Arida RM. Epilepsy, seizures, physical exercise and sports: a report form ILAE task force on sports and epilepsy. Neurology. 2016;57:6–12.
43. Husain M, Rizvi SJ, Usmani JA, Hanif SA. Epilepsy and the law: an Indian perspective. J Clin Forensic Med. 2002;9:61–4.
44. Bangar S, Shastri A, El-Sayeh H, Cavanna AE. Women with epilepsy: clinically relevant issues. Funct Neurol. 2016;31:127–34.
45. Kaushik JS, Kadwa RA, Sahu JK, Sharma S, Mittal R; Association of Child Neurology (AOCN)-Indian Epilepsy Society (IES) SOLACE Expert Group. Association of child neurology-Indian epilepsy society consensus document on social and legal aspects of childhood epilepsy (SOLACE). Indian J Pediatr. 2019. https://doi.org/10.1007/s12098-019-02927-2.
46. Crino PB. Gene expression, genetics and genomics in epilepsy: some answers, some questions. Epilepsia. 2007;48:42–50.
47. Kankane AK, Kankane A, Siddiqui MZ, Mishra P, Sharma A. Knowledge, attitude and practice of epilepsy among persons attending tertiary care hospital of Bundelkhand region, Central India. Indian J Community Health. 2015;27:281–5.
48. Farrukh MJ, Makmor-Bakery M, Hatah E, Tan HJ. Use of complementary and alternative medicine and adherence to antiepileptic drug therapy among epilepsy patients: a systematic review. Patient Pref Adherence. 2018;12:2111–21.
49. Mcintosh AM, McMahon J, Dibbens LM, et al. Effects of vaccination on onset and outcome of Dravet syndrome: a retrospective study. Lancet Neurol. 2010;9:592–8.
50. Kanner A. Mood disorder and epilepsy: a neurobiologic perspective of their relationship. Dialogues Clin Neurosci. 2008;10:39–45.
51. Soltanifar A, Moharreri F, Soltanifar A, Mokhber N, Ebrahimi A, Akbarzadeh F. Behavioral problems in children with epilepsy, and parenting stress and parenting styles of their mothers. Eur Psychiatry. 2013;28:1.
52. Jain S, Bhatia M, Tripathi M, Srivastava A, Padma MV, Pandey RM. Seizures among families of Indian probands with different epileptic syndromes. Acta Neurol Scand. 2004;110:27–38.
53. Kroner BL, Ardini MA, Bumbut A, Gaillard WD. Parental perspectives of the impact of epilepsy and seizures on siblings of children with epilepsy. J Pediatr Health Care. 2018;32:348–55.
54. Suren P, Bakken IJ, Aase H, et al. Autism spectrum disorder, ADHD, epilepsy and cerebral palsy in Norwegian children. Pediatrics. 2012;130:e152–8.
55. Thurman DJ, Begley CE, Carpio A, et al. The primary prevention of epilepsy: a report of the prevention task force of the international league against epilepsy. Epilepsia. 2018;59:905–14.
56. Harden C, Tomson T, Gloss D, et al. Practice guideline summary: sudden unexpected death in epilepsy incidence rates and risk factors: report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology and the American Epilepsy Society. Epilepsy Curr 2017;17:180–187.