Epilepsy In The Family-Children

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Epilepsy

Common chronic brain disorder
~ 1% general population
International disorder
~50 million worldwide
~85% in developing countries

Annual incidence
50 per 100000 in developed countries
100 per 100000 in developing countries

Chandra RS et al 1993
WHO fact sheet 2003
Epileptic Seizures

Epileptic seizures are symptoms that occur in acute illness (provoked seizures) or in epilepsy (unprovoked seizures) and result from hyperexcitability, that is an imbalance between excitatory and inhibitory activity, of the cerebral neurons.
Misdiagnosis occurs 18-30% \(^1,2\) mainly by misinterpretation of the clinical and non-epileptogenic paroxysmal interictal EEG activity \(^3,4\) either by the reporting doctor or the physician reading the report.


Misdiagnosis leads to wrong therapy, treatment failures, long term consequences and stigma.

The correct diagnosis is mandatory & has therapeutic, prognostic and social implications e.g. benign syndromes.
The initial parental reaction to their child’s “episode” is relevant to the type of seizure.

**Absences:** psychological problems, tic

**Focal seizures involving the face:** stroke

**Generalized tonic clonic seizures:** Feeling that the child is dead or that this may happen in the future with relapses
During a GTCS the child looses contact & control of movements

A journey via madness to death and return to life

Complete therapy or otherwise he/she will be different, rejected and isolated
First seizure has worse effect on parents than the child
Parental reaction to the diagnosis

They often ask with a trembling voice: *is it epilepsy?*

- **Guilt**
- **Depression**
- **Anger**

why my child?

- Fear that everything is lost

- Is not the child they knew anymore
- The dreams for his future, are now lost

Parental reaction to the diagnosis

- **Fear that everything is lost**

  - Losing control
  - The unexpected seizure
  - Lost activities
  - Their life

- **Grief**

  - Is not the child they knew anymore
  - The dreams for his future, are now lost

Children also fear & grieve for

- Losing control
- The unexpected seizure
- Lost activities
- Their life
Parental reaction to the diagnosis

OVERPROTECTION & PAMPERING

rarely

REJECTION

The fear of having a seizure, especially in the presence of others is a constant problem for the family, even if the seizures are well controlled.
What is necessary to do from start

- Assess the patient correctly
- Define type of epilepsy/syndrome
- Explain fully to parents/child [give written info]
- Listen feelings/experiences of family
- Give quality medical care [epilepsy clinic : team]
- Protect the child from over-protection
- Discuss disclosure with family/child
- Create good liaise with the family and school
What is necessary to do from start

- To encourage the family to continue to leave normally [The child’s activities are related to the type and frequency of seizures, but also to the child’s and family’s lifestyle]

- Remember Tolstoy’s statement:

  “All happy families, resemble each other. Each unhappy family, is unhappy in its own way”
Epilepsy: the impact of diagnosis

Epilepsy even in the most mild forms, even in the most advanced societies has a negative psychosocial profile for the individual and the family.
Epilepsy in childhood: consequences

- **Behaviour problems** [mood fluctuations, isolation, aggressiveness, irritability, anti-social behaviour: signs of poor adaptation with their condition]
- **Low self-esteem**
- **Poor self-image**
- **Lasting dependency**
- **Negative personality**
- **Educational difficulties**: intelligence, attention, memory
**Epilepsy in childhood: Consequences**

**Family**

- Disharmony, isolation, depression
- All social activities are affected
Some studies compared behavior in children with epilepsy to behavior in children with several other chronic illnesses. More behavior problems in children with epilepsy than in children with

- Chronic illnesses not affecting the central nervous system\(^1\)
- Diabetes\(^2\) [48% in chronic epilepsy vs 17% in chronic diabetes]
- Asthma\(^3\)
- Heart disease\(^4\) [hyperactivity: 28% epilepsy, 13% heart disease]
- Rheumatoid arthritis\(^5\) or
- Other chronic illness\(^6\)

### Behavior problems in children with epileptic seizures

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control group</td>
<td>7%</td>
<td>Rutter et al. 1970</td>
</tr>
<tr>
<td>Chronic disease</td>
<td>12%</td>
<td>Davies et al. 2003</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>29%</td>
<td></td>
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<tr>
<td>Epilepsy difficult to treat</td>
<td>58%</td>
<td></td>
</tr>
<tr>
<td>* Control group</td>
<td>9%</td>
<td></td>
</tr>
<tr>
<td>* Diabetes</td>
<td>11%</td>
<td></td>
</tr>
<tr>
<td>* Epilepsy</td>
<td>26%</td>
<td></td>
</tr>
<tr>
<td>* Epilepsy difficult to treat</td>
<td>56%</td>
<td></td>
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</tbody>
</table>
Specific problems of children with epilepsy

- **Autism** [epilepsy + MR: 27%]
- **Psychosis** [0.7% vs 2-9% in adults] *
- **Anxiety/stress** [3%]
- **Depression**
  - Ettinger 26% (Epilepsia 1998;39:595)
  - Dunn 23% (JAACAP 1999;38:1132)
  - Alwash 23% (Seizure 2000;9:412)
  - Oğuz 28.6% (J child Neurol 2002;17:37)

- **ADHD** [7% but in some with GS or CPS 37%]

* Watch AEDs such as zonisamide, vigabatrin, topiramate.
Educational problems

Seidenberg et al 1986: WISC-R
  Word recognition 10.5%
  Orthography 33.3%
  Maths 28.1%
  Reading 22.5%

Fastenau et al. 2005
  Reading 13%
  Writing 38%
  Maths 20%
Risk factors for behavior problems

- **Additional neurological impairment**\(^1\) [MR + Epilepsy: 59% psychiatric impairment] \(^2\)
- **Neuropsychological deficits**
- **Intractable seizures** \(^3\)
- & AEDs
- **Societies attitudes to epilepsy**
- **Disharmony in the family** \(^4\)

The impact of seizures in adolescence

**Life-style:** independent mind, alter sleep habits, reject advice, mature relations, drinking, smoking, driving, talk about the future...

- Refuse diagnosis
- Experiment not taking
- Do not report minor seizures
- Disturbed relations family/society
- More prone to depression, suicide, sexual & substance abuse
- Lack personality, become dependent
- Seizures ? more restriction, isolation
What affects QOL?

- Age of onset, duration of epilepsy
- Type of seizures, frequency
- Type of epilepsy, syndrome
- Intractability, polytherapy
- Perception of epilepsy
- Intellectual level, physical handicap
- Poor memory
- Social stigma
Children with epilepsy
• must know everything about seizures and epilepsies
• must learn to live with epilepsy & demand treatment/care for co-morbidities

Explain, no restrictions!
The doctor should know
- All about epilepsy
- The family/school/advisors
- The educational settings
- The law about epilepsy
- The workplace / work settings

Quality medical care

The doctor should act
- Prevent overprotection
- Upgrade autonomy, self-confidence
- Encourage normal life-style
Important
The initial explanations to the family and the child play an important role to his subsequent development
Points to consider

• Create in all countries lay & scientific societies
• Global knowledge about epilepsy
• Bring to light misapprehensions, expectations, & needs
• Quality medical care
• Create multidisciplinary approach
• Develop a net work of information, intervention, communication
• Collect epilepsy material internationally
• Educate educationalists, employers, employees, society
Thank you for your attention