Marseille

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11th EUROPEAN CONFERENCE ON
EPILEPSY & SOCIETY
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Epilepsy In The Family-Children

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Epilepsy

Common chronic brain disorder

~ 1% general population

International disorder

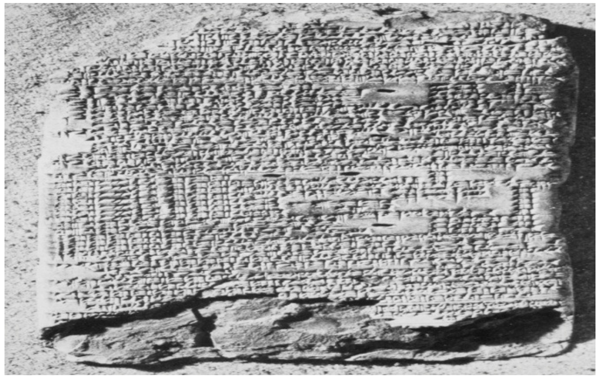
~50million worldwide

~85% in developing countries

Annual incidence

50 per 100000 in developed countries

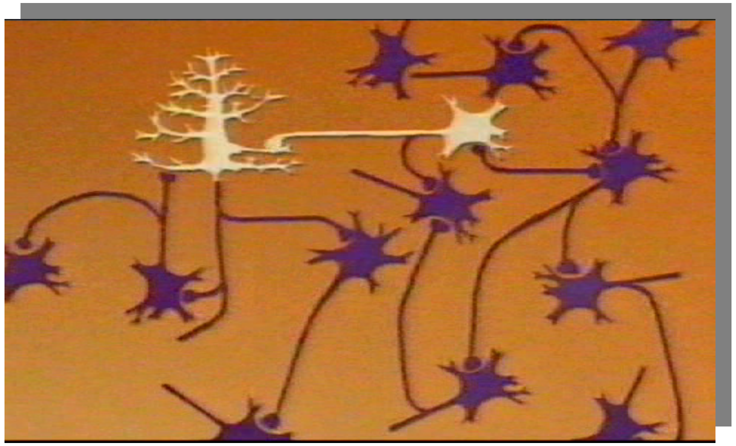
100 per 100000 in developing countries



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



10 pulse news

Misdiagnosed epilepsy costs millions

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**

1. Covanis A 1991, 2. Gates & Rowan 2000,

3. Olofsson O et al 1971, 4. Klass DW 1985.

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

perception →

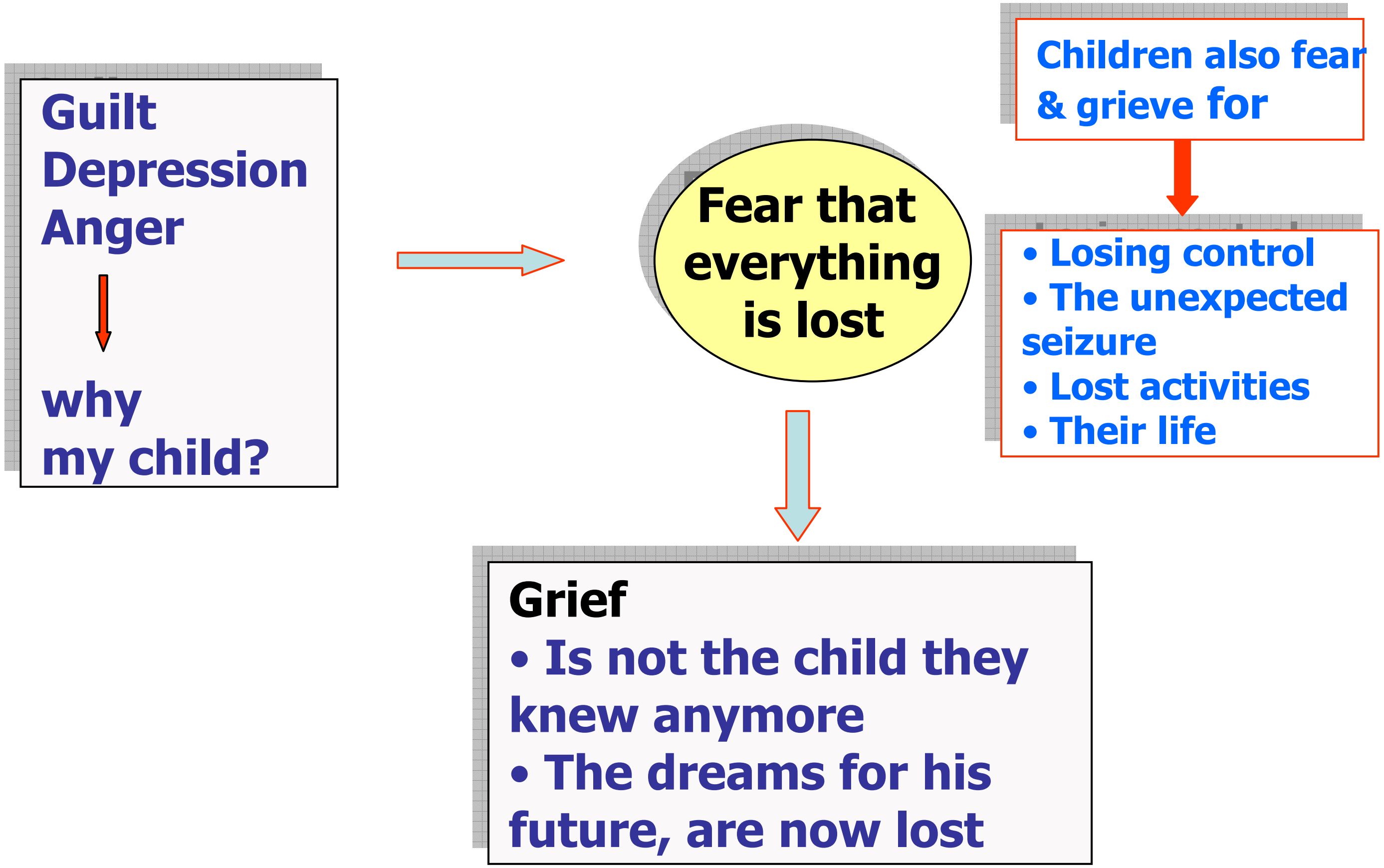
A journey via madness
to death and
return to life

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

Children also fear & grieve for

- **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**

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 life style]**

- ***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]

1. Rutter et al 1970. 2. Hoara P 1984. 3. Austin JK 1989.

4. McDermott S et al 1995. 5. Wirrell EC et al 1997.

6. Westbrook LE et al 1991

Behavior problems in children with epileptic seizures

Control group	7%
Chronic disease	12%
Epilepsy	29%
Epilepsy difficult to treat	58%

Rutter et al. 1970

* Control group	9%
* Diabetes	11%
* Epilepsy	26%
* Epilepsy difficult to treat	56%

Davies et al. 2003

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]**

1. Rutter M et al1970. 2. Steffenburg S et al 1996

3. Oguz A et al 2002. 4. Mitchell WG et al 1991

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

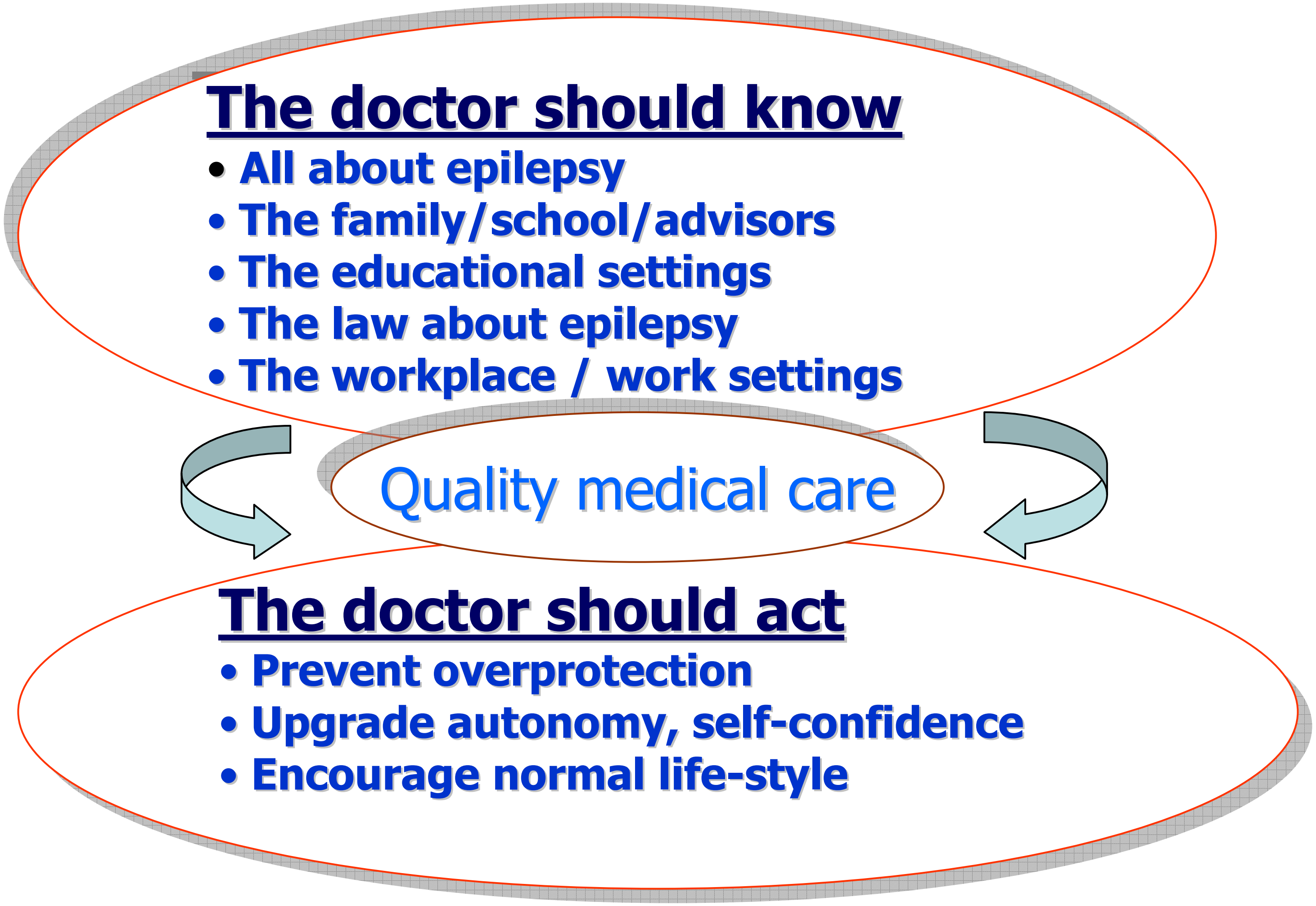
What affects QOL ?

- 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-morbities

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

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Thank you for your attention