

Quality of life in childhood epilepsy

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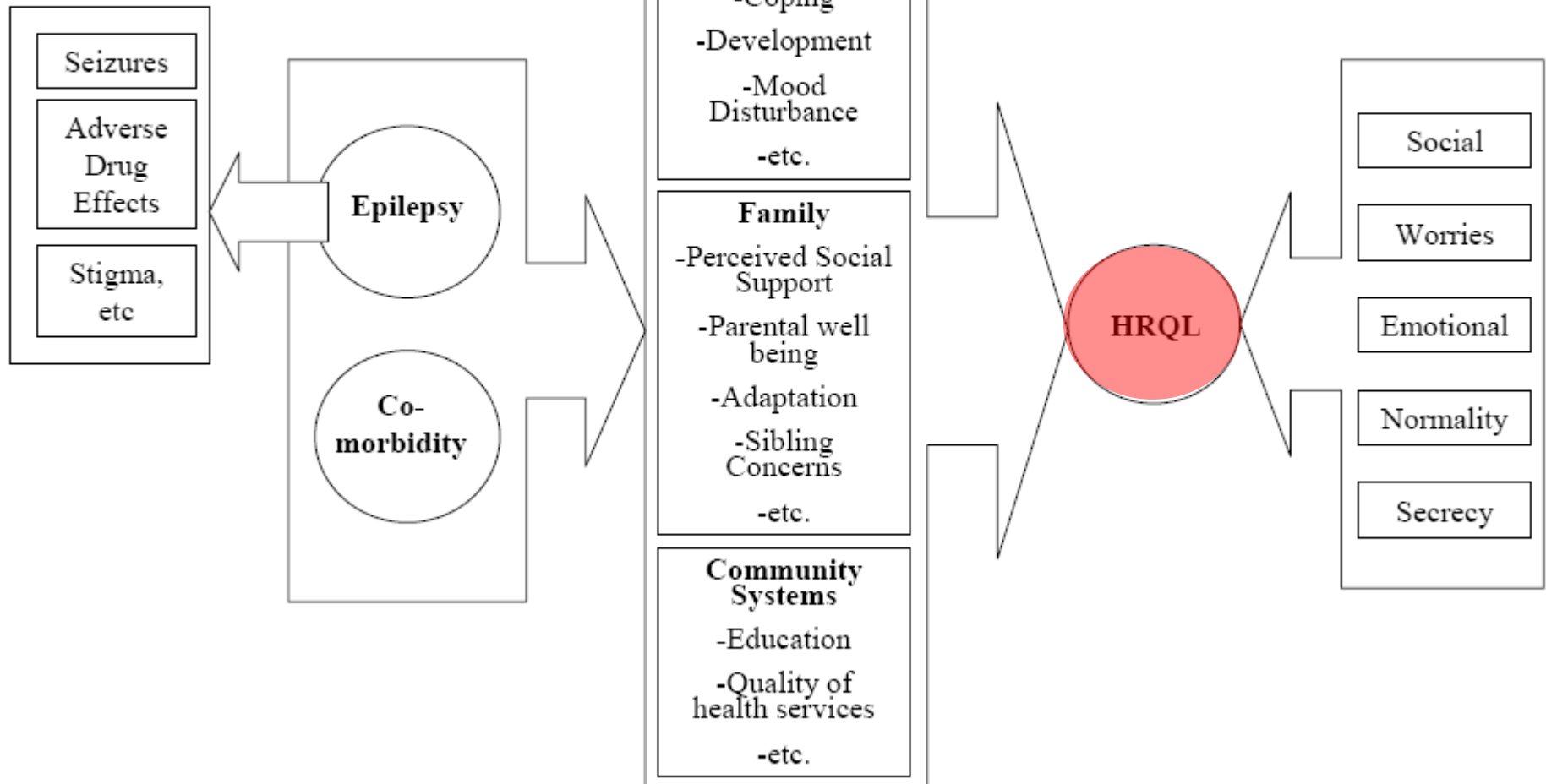
Quality of life determinants in epilepsy

- Seizures and syndromes
- Side effects of treatment
- Co-morbidities :
 - behavioural and psychiatric problems
- Cognitive and learning problems
- Everyday life 'adjustments', activities in daily life

Impairment

Mediating & Moderating Factors

Outcome





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Perceived impact of epilepsy in teenagers and young adults: An international survey

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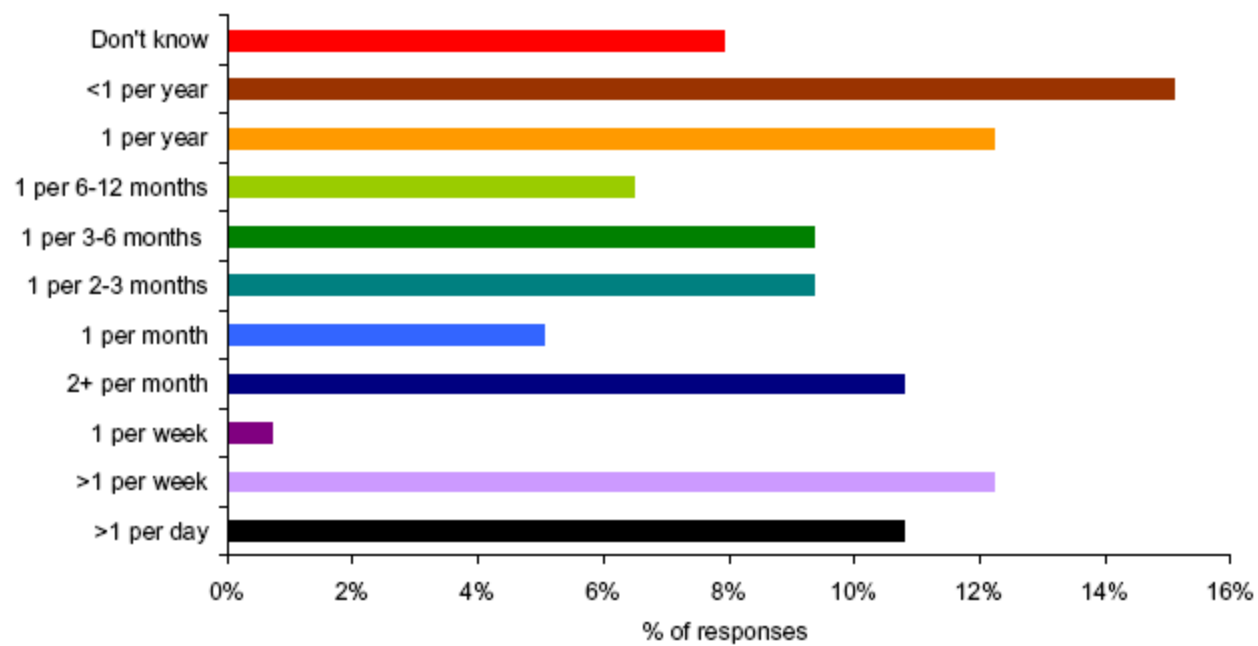
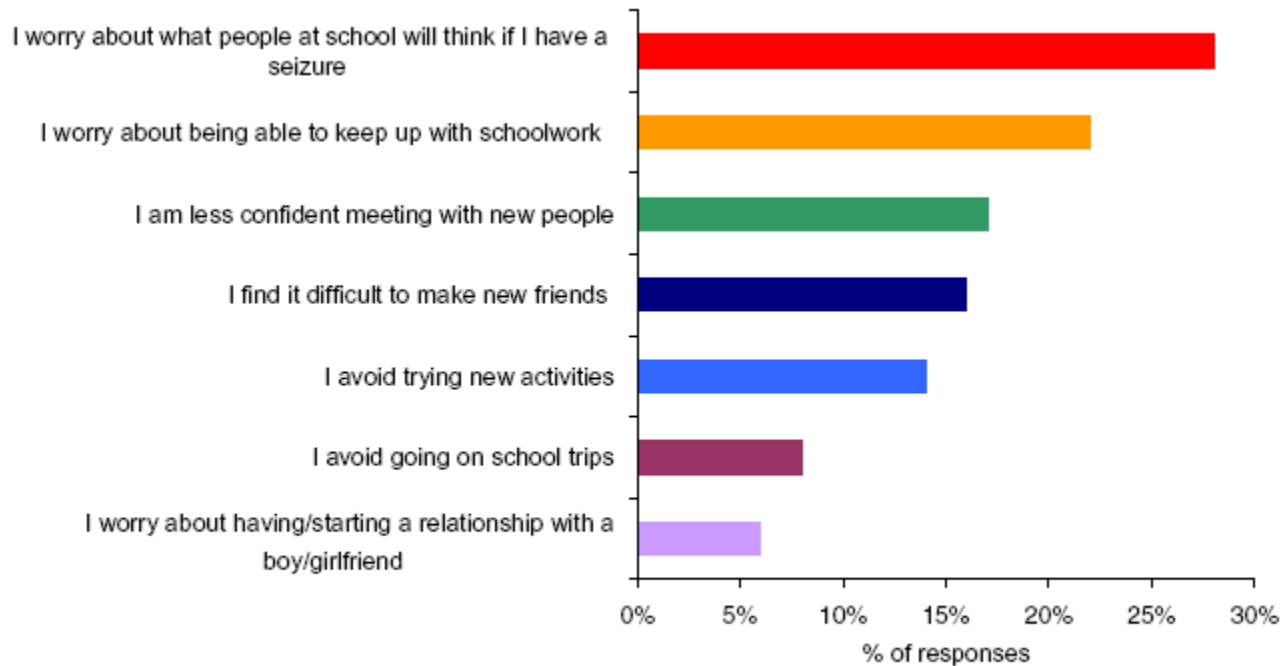


Fig. 1. Distribution of seizure frequency as reported by children and teenagers.



Cognition and
behaviour...

Fig. 2. Areas of regular concern for children and teenagers with epilepsy.

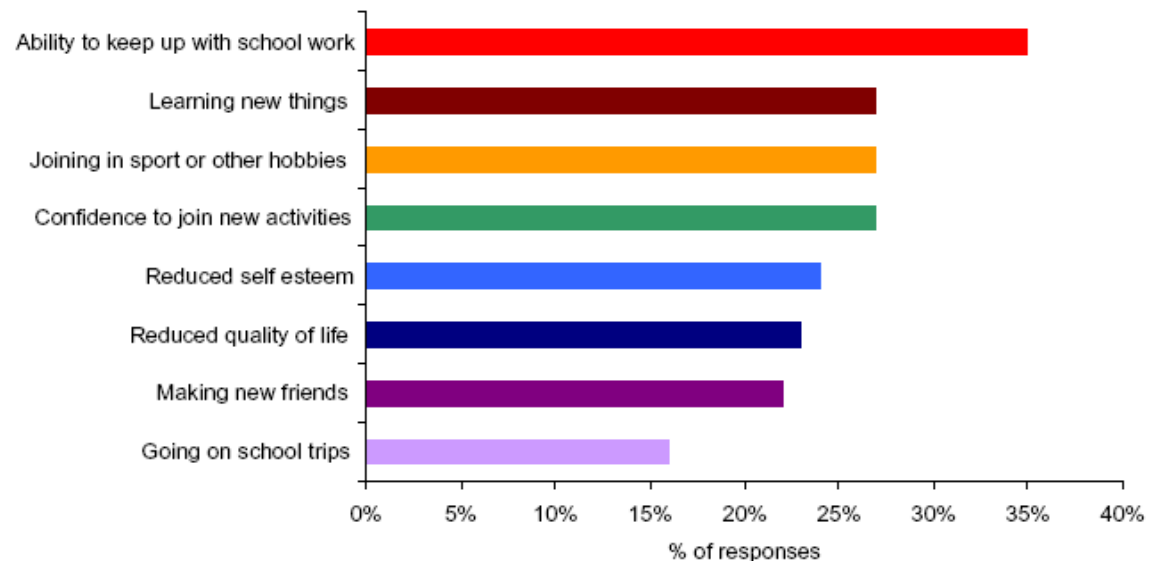


Fig. 4. Areas of regular concern for parents/caregivers of children/teenagers with epilepsy.

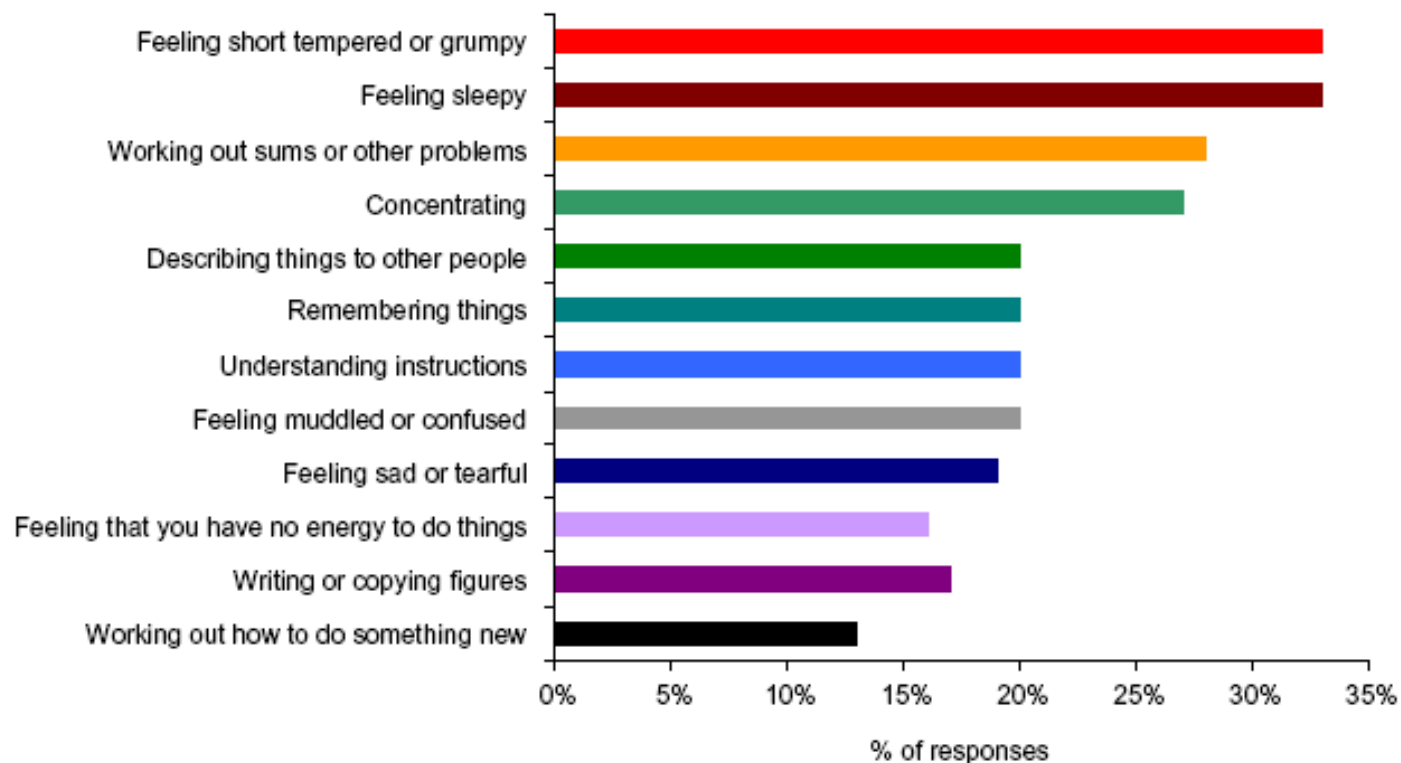


Fig. 3. Common problems reported by children and teenagers with epilepsy.

The Hague Side effect Scale

TOP 20 QOL

Item	Number (%) of 108 children reported to have a mild to very serious problem
1. Drowsiness/sleepiness	47 (44%)
2. Dizziness	16 (15%)
3. Uncertainty when walking	13 (12%)
4. Falling	10 (9%)
5. Sickness	19 (18%)
6. Difficulty with defecation	18 (17%)
7. Diarrhea	11 (10%)
8. Shaking, trembling	16 (15%)
9. Speech difficulties	14 (13%)
10. Double or blurred vision	9 (8%)
11. Headache	40 (37%)
12. Fatigue	55 (51%)
13. Loss of appetite	28 (26%)
14. Depression	15 (14%)
15. Hyperactivity	32 (30%)
16. Temper tantrums, aggression	37 (34%)
17. Slowness	49 (45%)
18. Poorer school results	39 (36%)
19. Decreased concentration	51 (47%)
20. Behavioral disturbance	25 (23%)

Parental reporting

Children 4-16 years

Epilepsy > 1 year

Not seizure free

Correlation of score on the HASES with clinical variables in univariate analysis and stepwise multiple linear regression ($N = 108$)^a

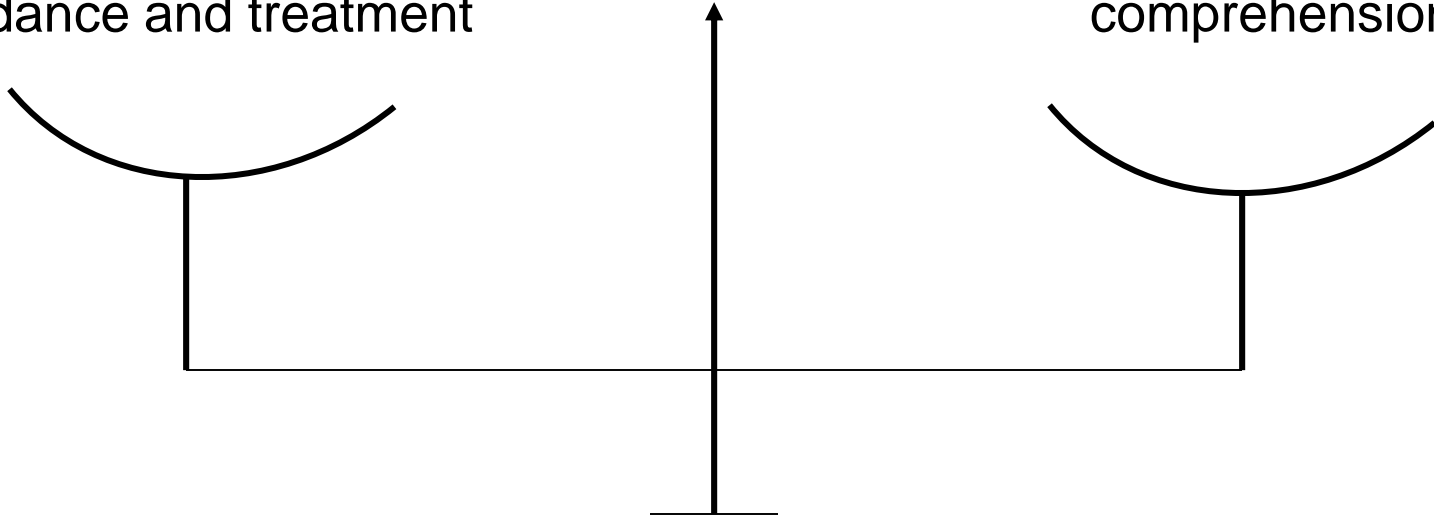
	Univariate		Multiple regression
	r_s	P	P
AED load (PDD/ADD)	0.12	0.21	0.60
Number of AEDs	0.23	0.16	0.11
Duration of epilepsy	0.18	0.07	0.33
Seizure severity	0.30	0.005	<0.001
Restrictions	0.34	<0.001	0.23
Number of seizures last year	0.25	0.01	0.27
Number of seizures last month	0.23	0.02	<0.001

^a r_s , Spearman correlation coefficient; PDD, prescribed daily dosage; ADD, average daily dosage of an antiepileptic drug in the study group (in mg/kg).

Reported side effects are related to seizure frequency

Correct information,
Guidance and treatment

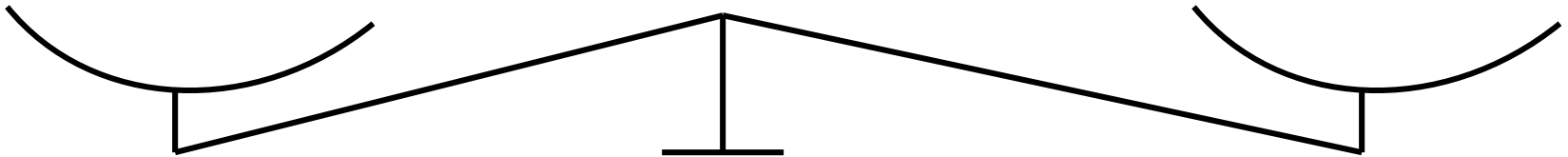
Empathy and
comprehension



'NORMAL' Life

Bad seizure control,
Wrong life adjustment

Overprotection, too much
attention, compassion



Disaster

1. Information

- School and teacher should know about the epilepsy
- Explain type and normal frequency of the seizures.
- Explain the provoking factors (believe the parents...)
- Discuss emergency treatment (benzodiazepines)
- Explain that the child might be absent because of seizures
- Discuss exams after convulsive seizures

2. Adjustments in the classroom

- What is the best school for the child?
Epilepsy should not be a reason to refuse children in school
- Not always necessary to put the child 'in focus'
- When attentional problems or learning problems are present
 - Extra remedial teaching
 - Seat in front of the teacher
 - Discuss medication

3. Sports

In **well controlled** epilepsy:

swimming allowed
with extra supervision

Cycling on the street allowed
with extra supervision

Other sports allowed
with extra supervision

- Age important factor
- Type of epilepsy : generalized versus partial with aura

4. Camps / trips

Because of important social peer contacts,
the child with epilepsy should participate !

Be aware

- Compliance medication
- Emergency medication
- Excitement, stress and less sleep can provoke seizures
- Identify local medical service

5. Night supervision

- ? SUDEP
- No reliable system available
- Infants with impact of seizures on cardiovascular and respiratory system
- High nr of e-children sleeping in bedroom of parents