Epilepsy surgery – when, why and for whom?

Kristina Malmgren

Epilepsy Research Group
Sahlgrenska Academy
Göteborg, Sweden

Outline

- Drug resistant epilepsy
- Impact of epilepsy and predictors of HRQoL
- Aims of epilepsy surgery
- The multidisciplinary team
- Patients' hopes and fears
- Counselling patients

Drug resistant epilepsy

Definition:

Drug resistant epilepsy is defined as failure of adequate trials of two tolerated, appropriately chosen and used antiepileptic drug schedules (whether as monotherapies or in combination) to achieve sustained seizure freedom.

ILAE Commission report Epilepsia 2009

Why only 2 AEDs?

Observational cohort studies of newly diagnosed epilepsy in adults suggest that once a patient has failed trials of two appropriate AEDs, the probability of achieving seizure freedom with subsequent AED treatments is modest.

(Kwan & Brodie, 2000; Mohanraj & Brodie, 2006)

The impact of epilepsy

- Unpredictability of seizures
- Risks of seizures
- Social effects of seizures
- Side effects of AEDs
- Negative effect on HRQoL
- Co-morbidities
- Stigma

Predictors of reduced HRQOL

- Increased seizure frequency
- Increased seizure severity
- Level of depression
- Level of anxiety
- Presence of comorbidity

Taylor et al 2011, review

Determinants of HRQoL in drug resistant epilepsy

Italian observational multicentre study:

809 patients answered questionnaires: QOLIE-31, AEP, BDI

The strongest predictors of HRQOL were AEP total scores and BDI-II scores

Luoni et al 2011

Determinants of HRQoL in drug resistant epilepsy

Significance:

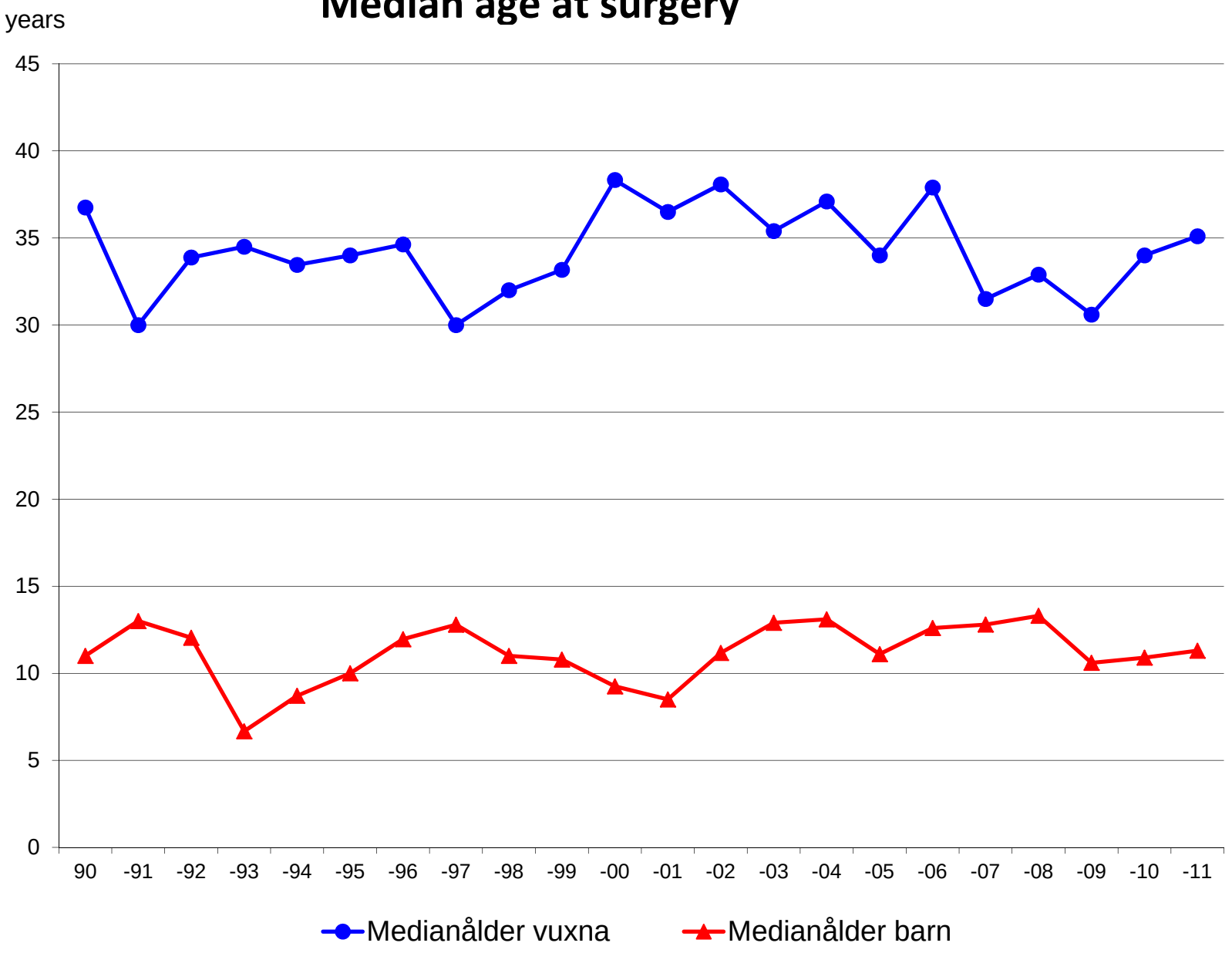
- Side effects of AEDs and depression are far more important determinants of HRQOL than seizures.
- When seizure freedom cannot be achieved, treating depression and reducing AED toxicity is most important

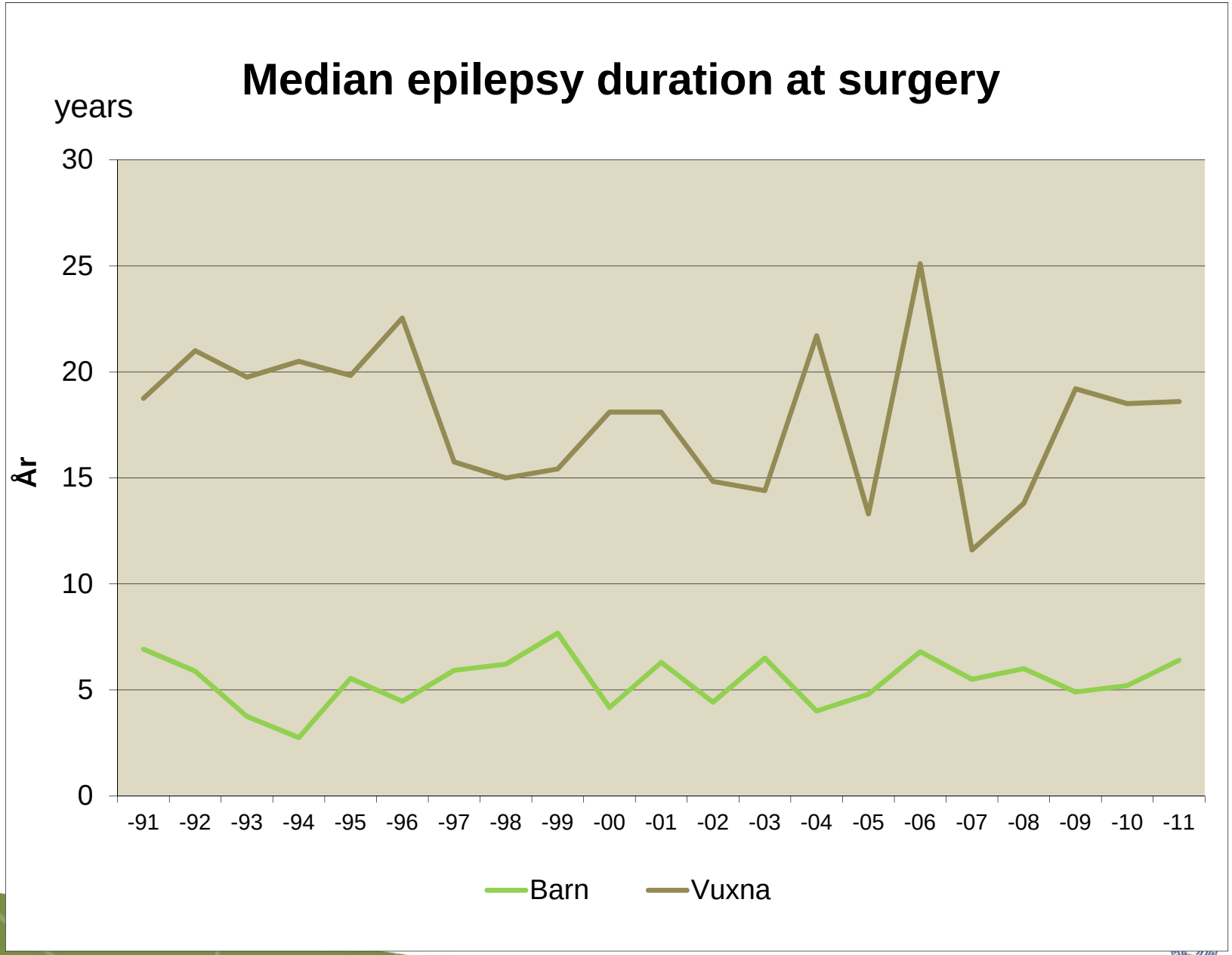
Luoni et al 2011

Epilepsy surgery – when?

- ’Too little too late…’
- Patients have had epilepsy half of their lives when they are referred
- What they have lost during this time cannot be repaired

Median age at surgery




Median epilepsy duration at surgery
years
År
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20
15
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5
0
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-92
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-94
-95
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-10
-11
Barn
Vuxna

Epilepsy surgery – when?

- **Sooner!**

Epilepsy surgery – for whom?

- One of several treatment options for persons with drug resistant epilepsy
- Refer patients for consultation after failure of two appropriately chosen and used AEDs
- Epilepsy surgery will only be suitable for a minority

Svenska Epilepsisällskapets rekommendationer för samverkan mellan olika vårdnivåer kring patienter med svårbehandlad epilepsi

Syfte

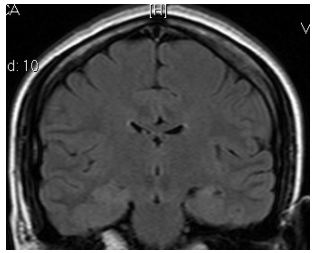
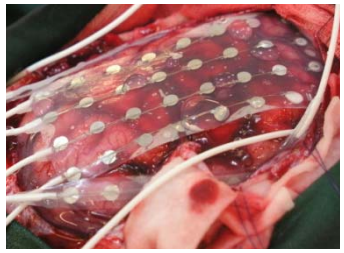
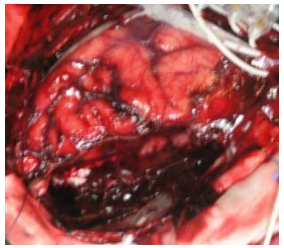
Syftet med detta dokument är att förbättra utrednings- och behandlingsmöjligheterna för patienter med svårbehandlad epilepsi genom att underlätta kommunikationen mellan allmänneurologer och regionepilepsiteamen. Målsättningen är att varje person med epilepsi ska få bästa möjliga utredning och behandling i rätt tid.

Bakgrund

De flesta patienter uppnår anfallsfrihet med första epilepsiläkemedlet och i låga doser, men 20-30% uppnår inte anfallskontroll trots adekvat utprovning av epilepsiläkemedel. Sannolikheten att uppnå anfallsfrihet är låg vid behandlingssvikt efter två läkemedel. Många patienter har en svår livssituation där såväl sjukdomen som biverkningar av behandlingen påverkar livskvaliteten. De är målgruppen för ytterligare diagnostiska och terapeutiska insatser. Både svensk och internationell erfarenhet talar för att många individer med svårbehandlad epilepsi remitteras till regionepilepsiteam för bedömning först efter långvarig sjukdom.

Aims of epilepsy surgery

The aim of epilepsy surgery is to improve patients' quality of life through obtaining seizure freedom or a substantial reduction of the seizure burden without disabling side effects

So what do patients want to know when being counselled about epilepsy surgery?

What is my chance of becoming seizure free - or at least better off?

What is my risk of having a major complication?

If I become seizure free, will I remain that way?

Does that mean I am cured?

Will I be able to taper the AEDs?

Will I have a better life if I have surgery?

The Multidisciplinary Team

- Neurologist
- Neuropaediatrician
- Clinical neurophysiologist
- Neurosurgeon
- Neuropsychologist
- Psychiatrist
- Epilepsy Nurse

The MDT conference

In the MDT conference

- All relevant information from the patient's history and presurgical evaluation is presented and discussed
- From a professional point of view the risk:benefit ratio for individual patients is assessed
- We then advise, but the patient must make a personal decision about the trade-off

Trade-offs

The idea of a trade-off often implies a decision to be made with full comprehension of both the upside and downside of a particular choice *Wikipedia*

Patients' trade-off

Positive

- Seizure free or substantially improved
- Stop AEDs
- Better HRQoL

Negative

- Continued seizures
- Risk for complications
- Foreseeable adverse effects

Patients' fears

- Patients with epilepsy overestimate the risks of and have a negative attitude towards epilepsy surgery

  Swarztrauber et al 2003, Pruss et al 2010

- Patients also feel that their health care providers portray epilepsy surgery negatively

  Swarztrauber et al 2003

- In one recent Canadian questionnaire-based study, brain surgery was rated as having a mean dangerousness of 8.3 (on a scale of 1 to 10)

  Hrazdil et al 2013

Patients' fears contd

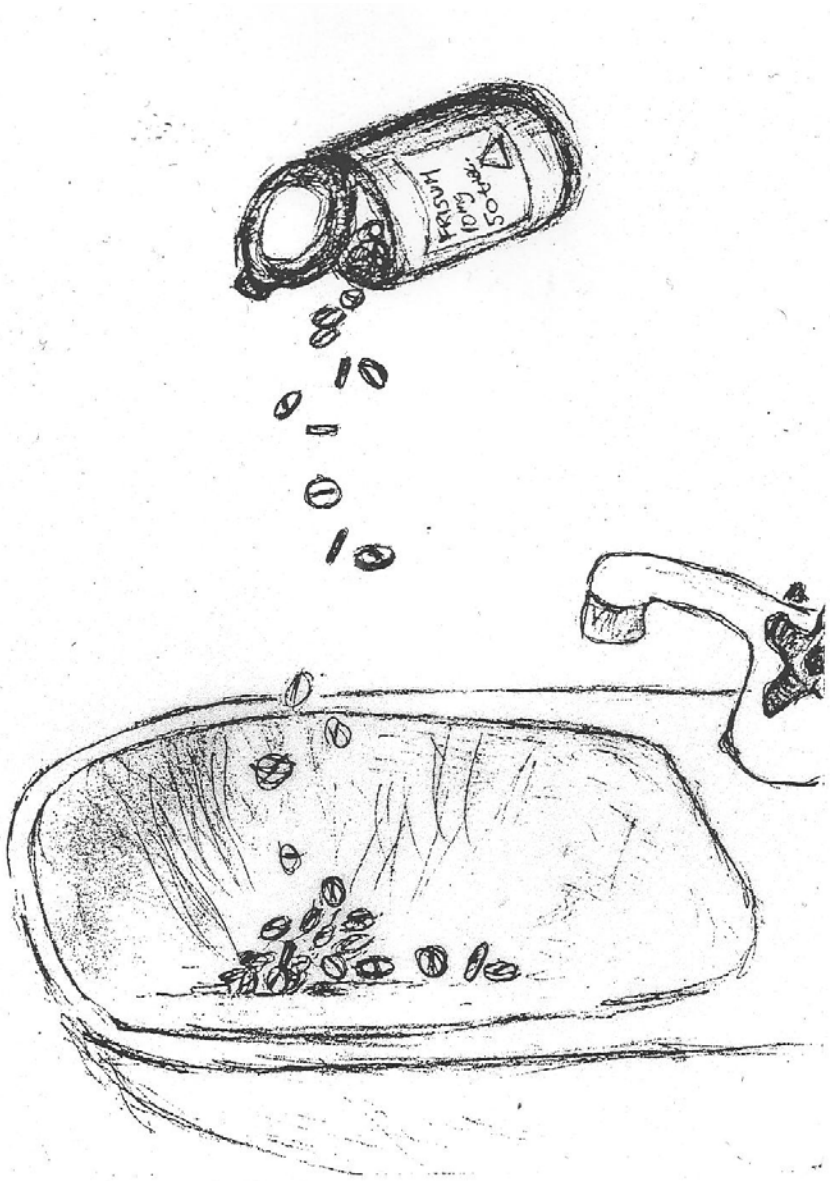
- In an Italian questionnaire study of 228 patients attending epilepsy clinics patients:
  - Considered epilepsy surgery very dangerous (56%) or somewhat dangerous (41%)
  - Were anxious about the possibility of major adverse events: paralysis (47%), brain damage (61%), loss of independance (45%)
  - Considered epilepsy surgery 'a last resort' (73%)

Erba et al 2012

Patients' hopes for epilepsy surgery apart from seizure freedom

- Desire for work
- Driving of motor vehicles
- Independence
- Socialising
- Freedom from drugs

Taylor et al 2001



’If I didn’t have epilepsy….:
patient expectations of epilepsy surgery

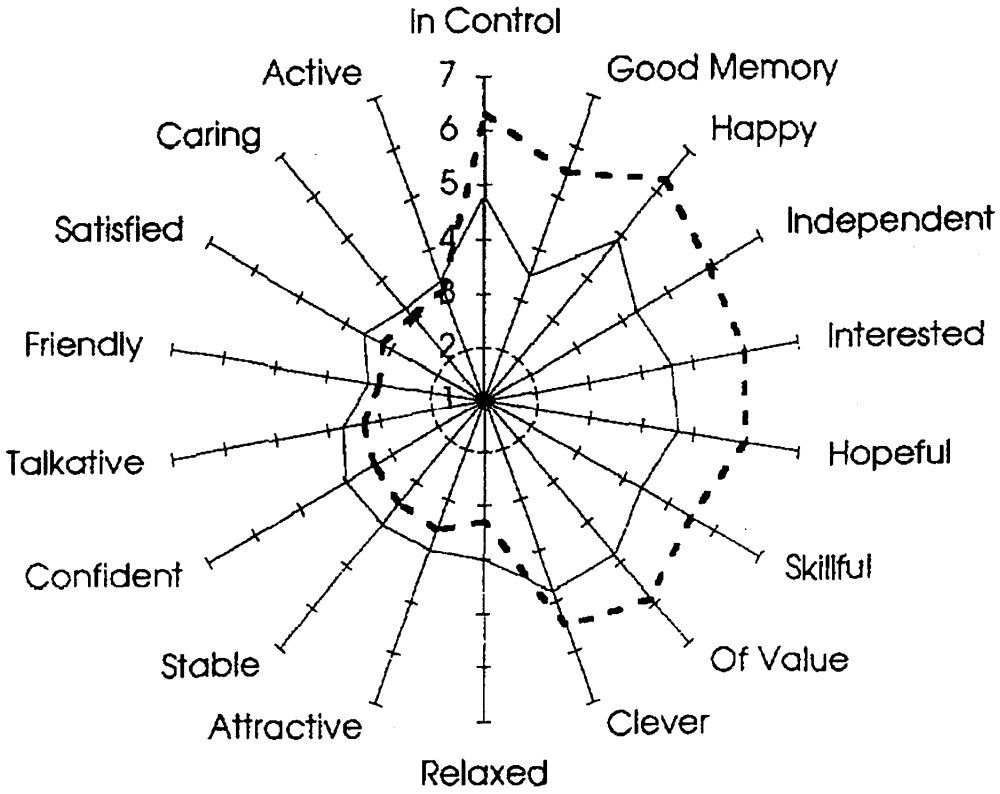


Figure 1. *Diagrammatic representation of preoperative self-ratings versus expectations after successful surgery (n = 70). The scales are presented clockwise in the order of greatest/least magnitude of difference. Preoperative self (solid line); expectations of surgery (heavy dashed line).*

Baxendale and Thompson 1996

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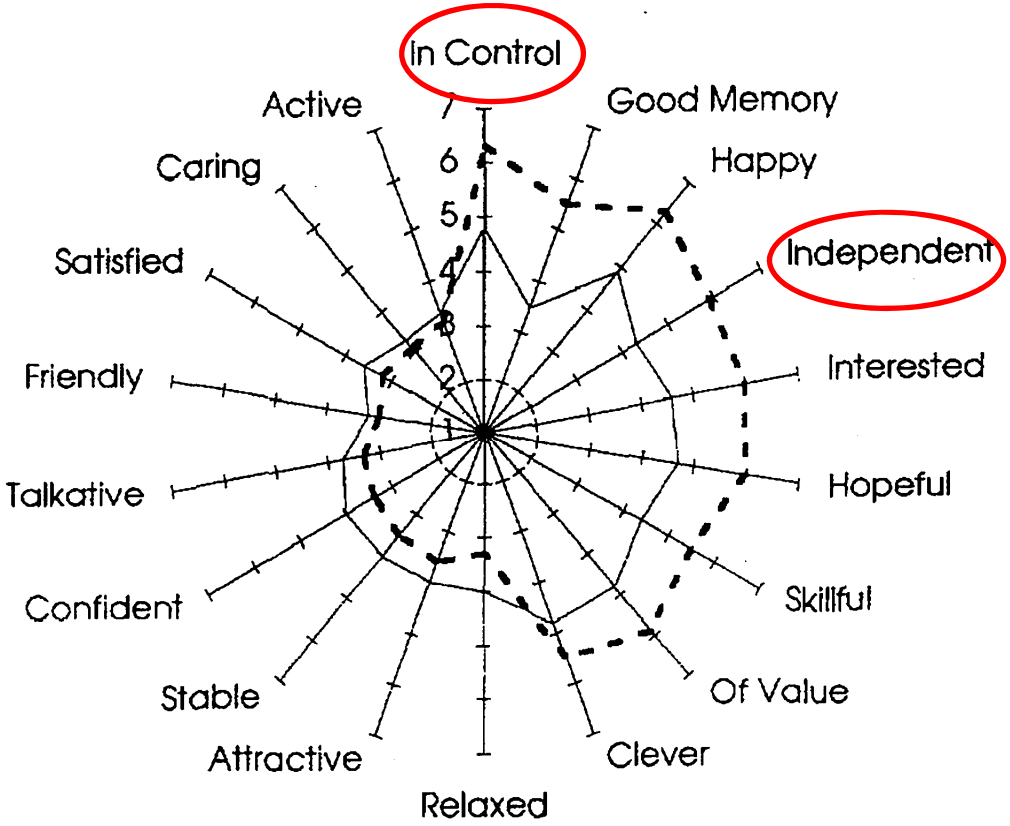

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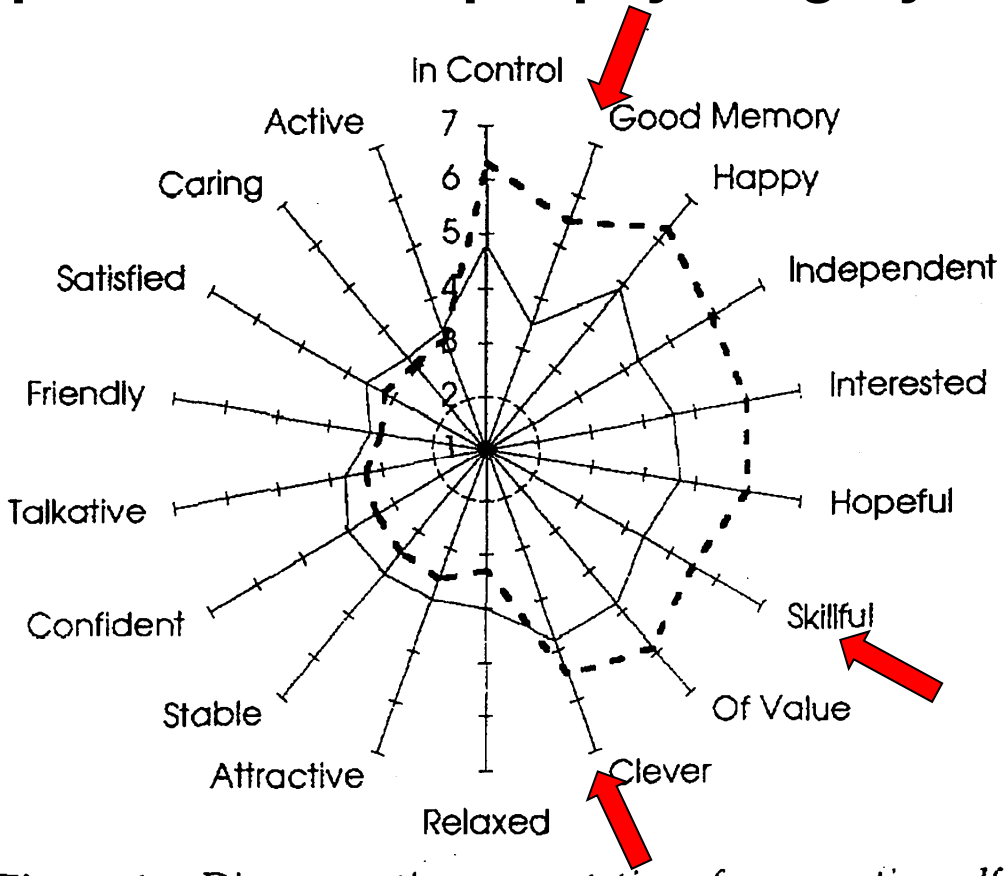

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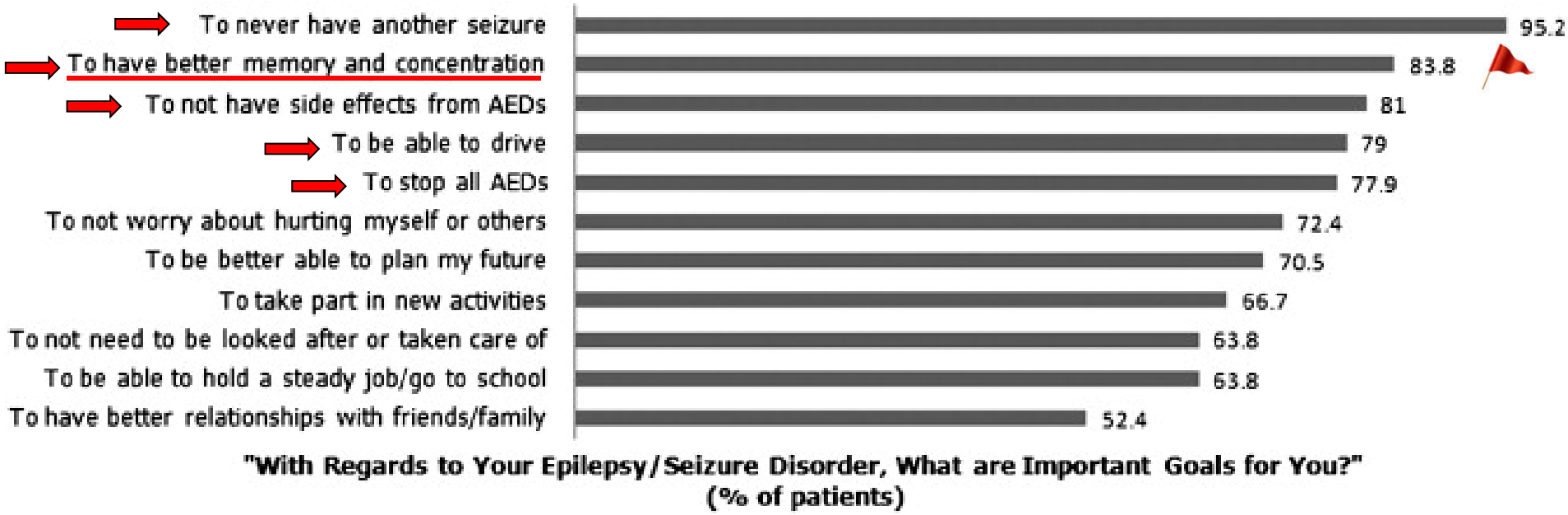
“With regards to your epilepsy/seizure disorder, what are important goals for you?”



Hrazdil et al: Epilepsy &Behavior, Volume 28, Issue 1, 2013, 52 - 6

Patient expectations

So, some patients may fear too much…

…while others may hope too much

We need to provide reliable and good counselling in both these settings

Individualised counselling

- The more our counselling can be individualised, the more understandable and useful it is for the patient
- This pertains both to risks and benefits

Why do patients want surgery for epilepsy?

- Because they suffer so much from having severe epilepsy which has a devastating impact on all aspects of life
- Because epilepsy surgery is a safe treatment with prospects of good seizure outcome and low risk for complications
- But also because they may have unrealistic hopes about what will change in their lives and because they have not adequately considered the risks

Addressing fears and hopes

- When counselling we have to be aware both of fears and hopes
- Often patients don’t word their hopes, you have to explore them in order to discuss in a realistic way what can be achieved

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