# Pre and Post Operative Neuropsychiatric Evaluation and The Measure of Outcome of Epilepsy Surgery

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#### INTRODUCTION

It is said that most people with epilepsy are well adjusted and can lead full lives. This is because, firstly, many of the people who suffer from epilepsy only suffer it for a brief period of their life. Either the seizures remit or the treatment rapidly brings them under control. Secondly, many such people have grown to maturity without epilepsy and they have established themselves in work, in their families, and in society before their life was affected by epilepsy. Thirdly, "epilepsy" is a large category and it is possible to suffer from forms of epilepsy that do not disrupt life much. Finally, some people seem able to cope well with problems that overwhelm others.

It is also said that epilepsy is a serious and chronic illness that can be associated with many other problems. The epilepsies that start in childhood and persist into adult life are among those that are particularly liable to be associated with other difficulties. This is because the epilepsy and the disorders that underlie them can impair important developmental processes. There is a marked increase in mortality as well as morbidity. There are also certain, intractable, focal epilepsies, arising at any time in the life span, that are more likely to be associated with social and psychiatric problems.

The treatment of epilepsy, whether by medication, or surgery, or other intervention, is designed to stop seizures or "usefully" reduce the frequency of seizures. The questions then are; in what way it is "useful" to stop seizures and, does reducing their frequency have an effect similar to stopping them? Doctors and patients have shared a belief that the-

For many years the surgical treatment for epilepsy was confined to a few specialist centres. It has had critics who fear it as a form of psychosurgery or see it as an unproven, expensive intervention. Outcome studies that were designed to show the wider benefits of surgical treatment have been helpful in increasing the wider acceptance of epilepsy surgery. The wider use and the wider application require continued audit and continual improvement of assessment of outcome. In recent years the construct "Quality of life" has been applied to people with epilepsy as a way of measuring the effects of illness and the impact of treatment. In this paper I shall argue for the value of individual, skilled interviewing and for diagnosis of psychiatric disorder both before any proposed surgical treatment and afterwards in follow up. I shall outline the technique we are developing in London and Dublin to meet the needs of auditing the newer forms of epilepsy surgery that cover widely differing degrees of handicap and large age ranges. The process covers the needs of patients and doctors to provide for (i) Care, (ii) Audit and (iii) Neuroscience. These components are at different stages of development and can be independent of one another.

#### PSYCHIATRIC INTERVIEW

The three components Care, Audit, and Neurosci-

re was benefit. It is possible that the benefit arises only from the more extreme cases. The justification for a treatment that is unpleasant or perilous has to come from measurement of the effect that stopping seizures has on other aspects of life or from its effect upon the natural prognosis of the illness. Despite the fact that epilepsy has been treatable both medically and surgically for over a hundred years these sorts of considerations are relatively new.

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ence are each contributed to by the psychiatric interview which is part of the pre-surgical assesment. In Dublin, working with adults, this is also supported with on additional SCID (Epilepsy) interview (made by Dr Paul Moran). For Neuropsychiatry, the important data are the biography of the patient and the context of their life in the family and in their local social structure. This is in part psychosocial (strictly, "psychosocial" means the interaction of behovioural and social factors and the influence of social factors upon the individual mind or behaviour). It is also in part neuropsychiatric in that cerebral dysfunction is given much consideration as a possible cause in the sequence of the causation of behavioural problems.

In London I conduct a psychiatric interview with parents and children without the use of schedules. The aim of the interview in children is to review, with both parents as far as possible, the development of the family and the quality of family functioning and the impact upon it of the sickness of the patient. The family background and the supports available to the parents should be known. Their occuptations and their levels of education will probably influence the sort of expected levels of performance. The birth and development of the patient are considered with a review of the effect of any early illnesses or separtions. The birth and the health of other siblings, miscarriages, and deaths are considered as is the impact of the illness of the patient on them. By exploring these aspects of the history it is possible to come to some understanding of sources of psychopathology which originate from outside the sickness of the child and are part of the psychopathology of everyday life. These aspects are likely to remain independent of the process of epilepsy surgery. It is important to the oucome if much of the disability of the child comes from this source since it is not likely to alter after treatment.

The history of the epilepsy too is reiewed from a psychiatric perspective with particular emphasis on the impact of the sickness on the occasion of the first, and the "worst" ever seizures. The first because of the shock sensation of believing one's child to be dead, and the worst similarly but also as a measure of the family's perception of severity. It is also worth asking about dangerous events in rela-

tion to seizures, wandering in the road, falls from bicycles, fits in the bath or the swimming pool, since it is a measure of the real extent of the child's danger and so our willingness to operate, but also a measure of the style of parenting.

The developmental history should be reviewed for both before and after the onset of epilepsy. Mother may have had serious concerns about the child that she was unable to persuade her medical advisors about before the onset of the epilepsy. For example she may have thought that the child had an infantile hemiplegia. She may even have had difficulty getting recognition of the seizures. This information will be of importance when considering the likely nature of the lesion but it could also influence the family's attitude towards medical practice. The developmental history will reveal the deficits (whether global or specific) which contribute to the problems of the child and cause distress to their family.

The behavioural history of the child should be taken from the parents with additional information being gathered from teachers and from admission to the wards or special institutions Much of what is required will come spontaneously in the list of the parents concerns. Further questioning follows standard techniques of psychiatry and questionnaires can provide adjunctive information. The aim is to pursue the complaints until it can be established wether a DSM or an ICD diagnosis can be sustained. The advantage is that these are a more certain measure of the pre-operative state so that postoperative changes can be more readily codified. However there are many other problematic children whose disorders are not easliy classified but whose behavioural problems are a motivating factor for parents seeking help through epilepsy surgery. These behaviours must be listed and described.

In adults the estimation of psychopathology has been simplified by devices such as the SCID (Epilepsy) but they require skill, time, and persistence. The concern is with predicting possible post-operative changes in mental state which are disabling and which make or keep the patient as handicapped as they were before surgery. Careful attention to the family history and the behavioural history to

date should allow some suggestions, from research, that certain types of pathological changes in certain locations might be associated with increased risk to later psychopathology. These data are still too weak to be the basis of absolutely excluding people from treatment but they can suggest advice and caution.

The study of the neuropsychiatry of epilepsy surgery has suggested the following associations.

#### (i) in Adults

#### (a) Personality Disorders

These are described in DSM IV as "an enduring pattern on inner experience and behaviour that deviates markedly from the expectation of the individual's culture". It is manifest in the way of perceiving and interpreting the world. It is evident in the range intensity lability and inappropriateness of emotional responeses, in problems of interpersonal functioning and impuls control. The enduring pattern is inflexible and pervasive. It leads to significant distress and impairment. It can be traced back to early childhood.

The most consistently reported psychiatric problem in people with epilepsy is a problem of personality. Many was have been attempted to describe the varieties of personality malfunction. "Epileptic Personality", "Ixoid", "Organic Personality Problem". "Personality Change" due to "....." is the current DSM IV label. It has been hard to capture the essence in a few words but "aggressive, impulsive, argumentative, imitable, rude, over-sensitive" are frequently used. The sort of phenomenon to described is best understood from seeing the effects of Phenobarbitone, or Diazepam, or lately Gabapentin or Vigabatrin on certain children. They become intolerable to live with.

The "personality disorder of this sort associates, in adults, with male sex, early onset epilepsy, lower Verbal I.Q., left-sided lesions especially M.T.S. (Mesial Temporal Sclerosis). It is of interest that male sex, reduced verbal I.Q. and early scholastic failure characterise delinquents generally. What is interesting about the epilepsy group is the fact that they can change after surgery. This is different from what psychiatrists might expect.

#### (b) Mood Disorders

Depression is a common disorder and mania relatively rare. There are no reports to suggest that the ratio is significantly increased in mood disorders associated with epilepsy. Depression is more prevalent perhaps because is borders closely on normal serious distress and sadness and is an understandable reaction to a severe plight. Reactive mania is rare. Secondary manias are reported as reactions to drug ingestion and withdrawal (CBZ in particular). There is a relationship between structural damage to the right brain and secondary mania. In the initial studies of lateralisation in relation to mental states, depression was found to be associated with right-sided lesions in temporal lobe epilepsy. More recent studies hae demonstrated an association between left temporal lobe damage and epilepsy and surgery.

# (c) Schizophrenia

It is likely that there is a real increase in the rates of schizophrenia in patients with T.L.E. (Temporal Lobe Epilepsy) Those vulnerable to this berakdown may not reveal it for many years. The association that is usually looked for is when epilepsy begins first. There is very little evidence for the sequence: Schizophrenia -> Epilepsy -> discovery of lesion. An important paradigm case was of a girl with T.L.E. diagnosed by age 2 years who had a left lobectomy for a tumour [then called an oligodendroglioma but which would now probably be described as a Dysembryoblastic Neuroepithelial Tumor (DNET)] at 21/2 years. She was then only mildly dysfunctional until her 17th year when she developed schizophrenia. An association between schizophrenia and left temporal lobe was established, recent papers have queried this and there are some late onset, "post-operative," "psychosis", associated with right brain pathology.

#### (d) Childhood

Recent activity in epilepsy surgery has brought to attention children with severe morbidity. There has been a well-established relationship between epilepsy and childhood autism and autistic spectrum disorders or P.D.D. (Pervasive Developmental Disorder). In a centre where we deal with severe fo-

cal epilepsies of childhood onset new data are emerging which link P.D.D or 'Autism' to focal cerebral pathology. In our preliminary figures we can show an association between Autism/PDD and Male Sex, Right Brain Lesion, Early Onset epilepsy (before 2 years), and lesions of the DNET type.

Most of the children in our trials have no codifiable psychiatric diagnosis. In many the diagnosis is obscrued by severe learning disorders.

The other salient finding in our material is the prevalence of a disorder best codified under Oppositional Disorder. There is an absence of Conduct Disorder. Both Oppositional Disorder and Attention Deficit Hyperactivity Dysorder (ADHD) and its variants have significant contributions from the manner of parenting. This is the manner in which the behaviour deviation is handled. This confirms other studies of the relationship between childhood epilepsy and psychopathology.

In summary, the morbidity of childhood epilepsy is an extension of its significant mortality. The changes of behaviour coming from successful surgery - that is surgery that meets its aims - are likely when M.T.S. exists, or when hemispherectomies for preterm vascular damage or post-natal hypoxic damage is present. Psychopathology associated with mass lesions may tend to persist, as indeed it may in adults, and we have no guarantee that eventually the adult psychopathologies will not supervene.

# A NEW FORM OF EVALUATION OF OUTCOME

#### **Features**

- 1. A tretment is a test of an hypothesis. Most treatment hypotheses are not specifically stated, but they could be. Audit is a retrospect on the success of the hypothesis. Audit should be replaced by testing a previously stated treatment hypothesis. The advantage, in terms of power, of hypothesis over audit is that it is stated **prior** to the treatment rather than claimed afterwards.
- 2. Outcome needs to be measured multifactorially

so as to avoid claiming spurious benefits, or replacing one problem by another and not addressing the key issue.

- 3. The issue of whether the relationship between seizure relief and overall outcome is dimensional, as implied in Penfield and Steelman (1947) and subsequently or categorical has to be addressed. Claiming degrees of success on a scale of reducing seizure frequency could be erroneous with only total seizure freedom making a real difference.
- 4. A method of analysis of outcome which can withstand great variation in the levels of functioning of its individuals, differences in age, and severity is required.

The technique suggested here does not prevent the application and development of specific measures of psychological functioning, cognitive levels, quality of life, occupational status, family functioning or mental state. This is a change in the application of these measures.

# (i) Individual contract for individual aims.

For each individual person being operated a contract can be created representing the patient's aims (or as interpreted by their carer) in precise terms. For example, it could state what changes are desired to follow total relief of seizures or various lesser degrees of seizure control; what would constitute success in behavioral, scholastic, or cognitive terms for that individual.

Deriving this contract will clarify all sorts of important issues. For the parent or carer it is a chance to really think through and come to understand the clinical issues and the real prognosis. For the clinical team it ensures that they have clarified their own views on prognosis. It allows them to know how well they have prepared their patient to understand their proposed treatment. Issues can arise, out of creating the contract that, reveal great dependence upon achieving total seizure freedom. The team might wish to suggest that this outcome cannot be presupposed and would not agree to a contract that required it. In our experience the hopes of parents for their children sometimes conflict with the child's cognitive capacity, or any forese-

eable postaperative improvement in that. Usually seizure freedom is the first item required. A more realistic outcome must be negotiated in each of the areas of life usually considered; schooling and occupation; self sufficiency; marriage and reproduction; mental state and behavior. This is probably an artifact of the way in which epilepsy surgery is proposed. But it has also been shown that improved performance in almost any area of life depends on seizure freedom. We do not know to what extent this relates to a physiological or to a psychological process. Even though a successful outcome may require total seizure freedom, in itself it may not allow all that the patient would wish for. It is wise to be aware of this beforehand so that unrealistic expectations can be modified.

#### (ii) Creation and use of prognostic categories

Surgical teams have aggregated their cases according to procedure (for example Collosotomies or Hemispherectomies) when reporting outcome results. In that way cases with excellent prognosis are mixed in with those where the team was aware that they were making the best of a difficult job. The results are consequently hard to interpret. One team may be taking on many difficult cases, another team not. Their results are hard to compare. Most teams are probably accepting a 'fair share' of harder cases.

It would be better if we recognized as one category cases where there was a high expectation of outcome success based on what as been learned over 50 years. Another category would include more marginal or doubtful cases. A third would include difficult and 'experimental' work. These categories may eventually be shown to be based on clinicopathological substrates underlying the seizure disorder.

As a result of this type of classification, the make up of any team's case load could more easily be known. So could their outcomes within categories. In each category the contract, the aims of surgery in each individual case, would be agreed before operation. Outcome would be determined by the extent to which those aims were realized. Such a contract can be agreed whatever the type of operation is proposed and it can cover wide variations in age, cognitive level, mental state and social circumstances which now characterise the population coming to epilepsy surgery in childhood.

Audit would entail looking at the categories the team worked with, the types of contract they made, and the extent of their success.

# SUGGESTED CATEGORIES FOR EPILEPSY SURGERY

These are global or holistic prognostic outcome categories. They can be arrived at from considering the broad range of data available to the team before embarking on surgery. It is recognised that excellent seizure relief or relief of distress can be obtained in some instances without much effect on life overall. This would be made clear in the Individual Aims. The categories are about the probability of achieving aims and, to an extent, the level of expected function after surgery.

#### Category A

This category includes those procedures that have contributed most to our knowledge of epilepsy surgery outcome. These are temporal lobectomy and hemisherectomy. The techniques are well-established resective operations. Experimental approaches are excluded. Lesionectomy and partial resections are excluded (see Wyler et al., 1995).

### Includes

- (a) Conventional temporal lobectomy
- (b) Hemispherectomy on the basis of cerebral damage sustained to a normally developed brain i.e. not developmental abnormalities.

#### Requirements

- (i) A fixed pattern of seizure semiology which is consistent with the location of the lesion to be resected.
- (ii) A single seizure type though this may have various degrees of expression.
- (iii) Clear evidence of a discrete structural abnormality that has a coherent aetiology (encephalomalacia, gliotic, vascular, etc.).
- (iv) No inexplicable conflicts in the data from investigations; EEG's, imaging, semiology, psychological testing.
- (v) Cognitive and behavioral normality. Or, given behavioural problems, they are compatible

- with the history, the lesion, and treatment vicssitudes and not indicative of widespread dysfunction.
- (vi) Competent consistent living place for rehabilitation after surgery.
- (vii) No foreseeable, late coming, psychiatric disorder which would invalidate the outcome.

#### Aims

The team would be prepared to negotiate a contract which supposed the achievement of seizure relief; growth in congnitive and behavioral functioning, and the realization of personal goals.

# Category B

There are a number of situations where surgical treatment is considered worthwhile even though there are factors, known to exist before operation, which reduce the outcome prognosis.

The seizure relief outcome is generally reduced in all extra temporal, compared with temporal lobe, operations and in hemispherectomies where developmental pathology predominates. Certain temporal lobectomies with reduced Category A features would be rated B.

In this category could also be placed those proceddures where the aim is to make an initial limited approach with the possibility of later extension and revision if it proves necessary.

Surgical approaches in this category could be standard, or could be hopeful applications of conventional techniques. (There may be certain techniques such as amygdalo-hippocampectomies that have specific limited applications which require special sub-categories). Techniques may move from category to category in individual teams depending upon their experience e.g. hemispherotomy).

#### <u>Includes</u>

- (i) Temporal Lobe Resections without Category A features.
- (ii) Lobectomies: frontal, occipital lobe resections.
- (iii) Hemispherectomies for developmental anomalies.

#### Requires

- Seizures which currently have consistent semiology but which may have varied in expression over development.
- (ii) Current attacks may be of more than one type (beyond a range of expression of a given seizure) and secondary generalization may be common.
- (iii) The lesion regarded as causal is clear but it may extend beyond a resectable area and be diffuse whether this is visualised or suspected. The cause and origin of a lesion may not be clear.
- (iv) Conflicts in the data provided by investigations as to the locus of a major area of cerebral dysfunction but which allow an agreed conclusion eventually on the balance of evidence.
- (v) Rehabilitation after surgery in less than optimal conditions. Post operative supervision by the team may not be feasible. Locus of rehabilitation may have low concern or interest; or over expectation; or high expressed emotion.
- (vi) Cognitive and/or behavioral problems are thought likely to impair outcoma even if seizure freedom is achieved. There should be a good prospect of improvement though reduced from Category A.

#### <u>Aims</u>

The team could agree a contract of seizure relief in some cases though secondary gains might be limited. Growth towards improved cognitive and social functioning should be looked for or at least deterioration avoided. Aims would be restricted but these should be achieved. Rehabilitation towards improved functioning.

## Category C

This category is for those operations on highly problematic patients with very poor natural prognoses whose severe level of sickness has demanded investigation and which has revealed that a surgical intervention is conceivable and might help the child and its carers. The child may be too young to have had long trials of medical treatment. The duration of drug therapy may not be long in

real terms though it will occupy a large proportion of the life to date.

Also to be considered are those older patients with relentless epilepsy and a high level of sickness and losses of skills encourage the team to do their utmost to "try to help." Neurosurgeons may need to modify standard techniques, use procedures that are palliative, and go to the limits of current surgery in their ambition to relieve distress.

#### **Includes**

- (i) Neocortical EEG focus but no identifiable lesion on structural neuroimaging.
- (ii) Nonstandard surgery
- (iii) Trials of partial resection of abnormal tissue
- (iv) Trial procedures on epilepsies of a probable viral basis
- (v) Callosal section
- (vi) Subpial transection

#### Requires

- (i) Acknowledgement that the natural prognosis is very poor with severe morbidity or mortality.
- (ii) Seizure patterns of variable sort some including focal seizures but not excluding generalised seizures or frequent secondary generalisation.
- (iii) Severity of seizures and high seizure frequency will be a large factor in a decision to operate.
- (iv) Careful collection and collection of data in these cases will be crucial to refining future decisions in this category.
- (v) There may be no discrete lesion and various tractotomies might be tried. Lesions will be only partly resectible or several lesions may coexist.
- (vi) Social and cognitive performance may be very low or young age preclude conventional psychological testing.

#### <u>Aims</u>

The contract should primarily be aimed at reduction of distress as experienced by the patient and by carers. This will come mainly from reduction of frequency of seizures of a distressing sort. Some amelioration of severe behavioral problems may be possible. Life might be more comfortable for all concerned.

#### SAMPLE CATEGORIES AND AIMS

#### (i) Category A

Austin was fifteen at the time of surgery. An acute illness associated with fever at 2½ years led to prolonged convulsions and left hemiplegia. Subsequently, troublesome partial seizures occurred with frequent generalisation. He sustained a normal school career and played several sports. From the age of 12 onwards he had lost friends, slipped in his classwork at school and became irritable. Seizures would sometimes incapacitate him for days on end. He was subject to depressed moods and had experienced a drug induced hallucinosis. His excellent caring parents had made many changes in their lives to accommodate to his best interests. The results of investigations were all entirely consistent with the history and physical finding.

#### Parents aims

- (i) Better management of fits but not necessarily to stop all seizures.
- (ii) To grow up "more normally" that is unrestricted by provisions made for sudden emergencies due to seizures.
- (iii) To be able to leave his parents for recreation, for private social interactions, and for friendships and marriage.

#### Austin's Aims

Austin felt unwilling to foresee much beyond his operation and denied any interest in that process. He agreed that there were certain issues.

- He found drop attacks particularly humiliating.
- (ii) He wanted more friends and freedom to explore on a bicycle.
- (iii) He wanted to become a businessman selling computer software.

#### Follow up - one year

He was entirely seizure free and medication was being weaned. He had resumed his sporting and outdoor activities. His educational programme was adapted to enable him to compete in school leaving examinations in which some success was expected.

#### Category B

Belinda was seven at the time of surgery. The onset of epilepsy had been a form of infantile spasms at the age of 6 months. These responded for a while to treatment with ACTH. Later, the seizures changed to "absences." These were spells of being out of contact and puzzled for a minute or two. There were also tonic attacks that were an extension of her former spasms but preceded by a warning sensation. MRI confirmed a static mass lesion in the posterior aspect of the left temporal lobe and EEG data was consistent with this and other investigations. The child was behaviorally and developmentally within the normal range and her parental and social support was excellent.

It was unlikely that full resection of the lesion would be possible and entry via atypical spasms was anomalous and so she was Category B

#### Parents aims

- (i) To be free of fits. This was a marvelous possibility.
- (ii) This, or even a marked diminution could reduce their need for constant invigiltion.
- (iii) The arrest of (or even recovery from) cognitive decline.
- (iv) To guard against some unspoken future danger from leaving the lesion (a fear of cancer?).

#### Follow up

At one year post operative there was a question of whether auras persisted. There was also a question of emergence of Tourette syndrome. EEG's were normal. A new sibling had been born. It was difficult to elicit satisfaction though many of the contracted benefits had been achieved. Cognitive skills

had not improved. The unspoken future danger had receded.

## Category C

Charlie was five at the time of his left temporal lobectomy. At that time his carer was neither his mother nor his father who were unable to cope with him and had separated. The seizures started at 5 months with generalized seizures, some of these were described as febrile convulsions. Several different types of attack including absences, myoclonic attacks, and focal seizures sometimes involving the left side subsequently occurred. His cognitive development was severely retarded (around 2½ years) and his behavior was overactive to a degree with prolonged tantrums at times. His management was very taxing although his father figure was very dedicated to his care.

A large left arachnoidal cyst was present in the left anterior temporal region. This was associated maaldevelopment of the temporal lobe. On the premise that the cyst could be a prime cause of some seizures, it was removed.

#### Carers aims

- To reduce the most desperate seizure episoodes.
- (ii) To try to reduce his behavioral problems.
- (iii) To have tried everything possible.

#### Follow up - 1 years

Seizures continued but took a more sporadic form and were reduced in frequency. His problematic behaviour with episodes of frantic tantrums was abated.

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