PERSONAL PRACTICE

A psychiatric perspective of epilepsy

D C Taylor

'A botanist, a forester, an artist, and a carpenter will not see the same tree'.

Martti Siirala

Doctors who have trained in the last decade should have had first hand experience of taking a psychiatric history. It is useful because in any situation of medical complexity it is advisable to move from the medical tradition of focusing on the history of the present disorder to the psychiatric tradition of coming to know the predicament of the family through a systematic exploration of it.¹ This perspective of epilepsy comes from working with children at various special centres for epilepsy, in tertiary consultation about learning and behavioural problems, and looking at child and adult candidates for operations for epilepsy. It depends on an acquaintance with the biography of the child.

The comforting popular nostrum is that most people with epilepsy have no behavioural problems and respond well to treatment.² Such people would, presumably, attend hospital rarely and hardly affect my experience. An alternative view ('reframing' is the psychiatric term) is that no less than one in five people with epilepsy have persistent difficulties that create therapeutic challenges: a fairly large number. This is certainly a better view for childhood onset epilepsy, where the more usual story is that, behaviourally, things were not too good before treatment began and have been worse since.³ It is more consistent with epidemiological studies,⁴ which find that up to 75% of children with epilepsy will have behavioural problems, depending on whether there is a structural disorder above the brain stem.

The behavioural aspects of an illness may not engage the attention of doctors. It depends on what the sociologists call the beholder's location, or what writers call their narrative convention. It is a matter of what the purpose of being with the child is thought to be. As Siirala points out, our perception, our concept of what is in front of us, is heavily determined by our purpose. I believe that I should have common cause with paediatricians in wanting the 'best possible' child to emerge or re-emerge. Perhaps paediatricians have become used to children being tiresome? A lot of children are tiresome at the best of times and paediatricians rarely see them at their best. Their tolerance of tedious behaviour is often greater than that of parents, teachers, nurses, and care staff. Perhaps adult tolerance of children is inversely proportional to the duration of their enforced

engagement with them? There is little point in knowing the sorts of psychiatric problems associated with epilepsy if they are not actually perceived, or not responded to when they are perceived.

Paediatricians seem to feel more sanguine about the outcome of epilepsy than I do, again because of the different nature of our engagements with it. Acute convulsions, whether febrile or punctuating the course of a chronic disorder, constitute medical emergencies. They have usually arrested by the time the patient is seen on the ward or in the outpatient department. So reassurance is implicit for the doctor even though the convulsions had been experienced as frightening and a serious setback for the family. Then there are the many syndromes that prove, eventually, to be benign in the sense that they remit or are not associated with deterioration, although they may not feel so benign while they are first seen. The more chronic, intractable epilepsies tend to be associated with other developmental limitations. When the gamut of investigations and treatments has been run through, the scope for change seems to be limited. Sustaining hope and the moves towards the management of chronicity gradually ensue. It might be helpful to have a framework for reconsidering patients as part of the annual audit of recurrent attendees. How best should one listen for the problems other than the seizures? How might the paediatrician respond? Consider the following headings.

Psychopathology of everyday life

Child psychiatric disorders can be diagnosed in between 10 and 20% of the child population. Even where there is no connection with the epilepsy, the behavioural disorder is a complicating factor. It will add to management difficulties for parents and doctors. They are likely to be seen by parents as caused or aggravated by treatment or as a neurological issue. Conduct disorder, as characterised by aggression, destruction of property, theft, and a serious violation of rules is rarely seen in children with epilepsy except as a familial characteristic.

RESPONDING

It is worth discovering whether problems pre-exist before starting treatment. This requires a little extension of the history taking by inquiry into the family structure and culture, which is in any case a wise precaution for a

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chronic sickness. Exclusion from school, many moves of school, involvement with the police, and sequences of parental cohabitants, are the sorts of events that are associated with conduct disorder.

In addition, consider separation problems in the past, current anxiety or failure related to school, and ask directly about mood. Help with the intercurrent psychiatric disorder can facilitate the general management of the child. When attributing the disorder to social and situational factors it is important to remember the added effect of the other sources of psychopathology.

Psychopathology of chronic illness

Any chronic illness has the potential to alter relationships. To be sick is to enter an unwanted categorisation (such as 'the divorced' or 'the bereaved'). To be sick is to have lost 'perfection'. Fear and anxiety are engendered in patients and their parents. Demands on time and resources are increased. The sense of reduced physical wellbeing is linked to low mood. The trend has been towards a 'non-categorical' approach to the study of the behavioural aspects of chronic illness because many of the factors held in common between chronic illnesses are well known to paediatricians. Collaborative work with psychiatrists, encouraging in patients with renal disease and diabetes, has, however, been limited for epilepsy. The salient findings are of increased rates of disorder, in particular of depression in children older than 7 years. Younger children show aspects of separation anxiety, which are often shared with an anxious mother.

RESPONDING

The burden of chronic illness can be managed amazingly by robust, determined parents or those gifted with serene temperaments. Those less well adjusted can be helped by careful listening and an exchange of information in a session set aside for the purpose. This can save the same issues from arising in every subsequent session or the frustration of never mentioning them. Parents who are found to be only marginally coping themselves will need help and support from specialist units, schools, and psychiatric and social work departments.

Psychopathology of brain disease

Brain disease associated with epilepsy may be static or progressive. Developmental changes make it less easy to be certain whether a deterioration in performance implies a progressive process or an age determined impairment resulting from an essentially static process. The factors that trigger the onset of epilepsy associated with static lesions, such as small occult lesions or hemiatrophy, at any given age, are unknown. Evidently such lesions can exert a bias on cerebral organisation or set limitations on skills before the epilepsy starts. In the same way it seems probable that similar influences are exerted on the behavioural repertoire. Thus the emergence of unwanted behaviours during development is not determined entirely by concurrent influences, but is an expression of

prior errors or compensations in cerebral organisation. They are also clearly related to qualities of parenting and experience, particularly in respect of oppositional disorders.

RESPONDING

The investigation and management of the brain disease are mandatory and should involve neuro-paediatricians and referral to specialist centres. Very difficult oppositional or overactive behaviour will require the most careful manipulation of anticonvulsant regimens, bearing in mind that the aim is to assist in helping the child and family rather than obliterating the epilepsy at any cost. Paediatricians need to become skilled in the use of psychoactive drugs if they find themselves without useful psychiatric liaison. All persistent focal epilepsies should be considered to be based in potentially remediable focal lesions unless shown otherwise. These may be evident early in life and expressed initially as infantile spasms. Observation can show these to have unilateral emphasis. About 40% of cases of temporal lobe epilepsy treated surgically in childhood prove to have sclerotic damage from early onset fits with fever. Although this outcome of febrile fits is relatively uncommon,⁵ the high frequency of such fits provides about 200 new cases each year in the UK.

Psychopathology of epileptic dysfunction

The onset of epilepsy is often seen as a clear watershed for behavioural deterioration. This is particularly true of the regression associated with early onset epilepsy. It is also true of the disturbances after the onset of the Landau-Kleffner syndrome. Hyperkinesia is classically associated with the onset of epilepsy. A rarer, more regular, association is the emergence from catastrophic epilepsy into behavioural states in the autistic spectrum, often accompanied by significant hyperkinesia. Some states, often referred to as transient cognitive dysfunction, consist of episodes of 'electrical' status which can be 'transient', but can also persist for months or years. Awareness is reduced and, though the child may appear superficially to be doing not much more than functioning below par, they can be shown to be seriously obtunded if they are studied carefully. These states are, strictly, dementias even though they may be reversible. They form the most obvious part of the broad spectrum of organic losses of function that afflict children with epilepsy. They are also evident in both specific and general learning difficulties. It is nowadays more or less routine that they are under investigated or overlooked in schools.

RESPONDING

Prolonged and overnight electroencephalography is mandatory. The best evidence of the effect it was having comes when the status is stopped. Behavioural problems in reaction to unrecognised learning difficulties will be apparent to observant paediatricians. They will be the basis of many of the most easily remediable behavioural problems. Psychological man-

Key messages

- What are you treating?
- Write down what you think things will be like in two and five years' time
- Are you helping? Or are you making things worse?
- Who might make them better?

agement has little to offer and may distract from the need to control the epilepsy.

Psychopathology due to treatment

All cerebroactive substances can impair cognition and behaviour. The substances used to attempt to control epilepsy are cerebroactive. Ethyl alcohol is a paradigm cerebroactive drug. Its well known potential range of effects on human behaviour, from tedious overactivity to psychosis, from promoting mild social inappropriateness to serious vandalism, from depression to delirium, are reflected in the profile of the unwanted effects of many anticonvulsant drugs. Alcohol also models age dependent responses and human variability in metabolising a drug. Anticonvulsant drugs are handled by brains that are often already severely compromised.

All treatments strike a bargain with potential harm. The harm may emerge in another system and at a later time. The harm may make the treatment a bad bargain. The more drugs that are combined, the worse the potential for harm. In the particular cases of behavioural syndromes caused or aggravated by anticonvulsant drugs, the price to be paid for the antiepileptic effects may be prompt and obvious, or slow and insidious. They can be attended to provided that advice is on offer and readily available. Parents are, too often, asked to tolerate behavioural effects for which, if they were psychiatric disorders arising *de novo*, they would demand immediate treatment. The powerful drive towards treatment at such cost is clearly the fear of death or serious injury and the medicolegal import of that. The evidence for such a fear is not easy to find. Deaths of children with epilepsy are either clearly related to high risks in deteriorating disorders or relentless intractable syndromes, or they are strangely unpredictable, capricious, stealthy, and not apparently closely related to obvious failures of management.

Inadequate medical treatment is the other kind of failure that can have deleterious effects on performance. In addition, surgical treatment must now be considered for a wide range of epileptic disorders where troublesome behaviour, regression, or cognitive decline are evident. The development of surgery depends on the work of special centres, but the use of the treatment depends on the knowledge of paediatricians and their willingness to exploit it on behalf of their patients. They should be asking themselves why they have children with hemiplegia, or with focal epilepsy, causing management problems, who have not been considered for surgical treatment. They should be thinking about the Morrell procedure for the patients with Landau-Kleffner syndrome, and seriously considering callosal section for those with intractable drop attacks. There is increasing evidence that children with infantile spasms, especially those with evidence of lateralisation, should be scanned for evidence of focal pathology with a view to referral for an operation. The aim, in all these cases, is to create the greatest possible benefit for the child. This means the avoidance of cognitive and behavioural decline and the ensuing further negative effect on relationships.

RESPONDING

The responsibility for providing a child with substances that are powerfully cerebroactive is serious at any time. When it is planned that they should be used for a long time, or for all time, the matter deserves highly informed opinion. Long term clinic attendees may find themselves seen by doctors whose experience does not match the weight of the decisions that they are asked to take.

One down side of treatment for any disorder is that treatment is an affirmation of the reality of the problem. This will account for some of the ambivalence that obtains and a lesser degree of enthusiasm for treatments than doctors might think proper.

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- 3 Taylor DC. Psychiatric aspects in epilepsy in children. In: Wallace S, ed. *Epilepsy in children*. London: Chapman and Hall, 1996.
- 4 Graham P, Rutter M. Organic brain dysfunction and child psychiatric disorder. *BMJ* 1968;3:695-700.
- 5 Verity CM, Ross EM, Golding J. Outcome of status epilepticus and lengthy febrile convulsions: findings of a national cohort study. *BMJ* 1993;307:225-8.