

A socio behavioural perspective for understanding and managing behaviour problems in children with epilepsy

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In this paper, reasons for the occurrence of interictal behaviour disturbance in children with epilepsy, and the management of such problems, are considered. The search for a direct relationship between epilepsy related variables and behaviour disorders is far from conclusive. While such a relationship may exist with respect to ictal behaviour problems, this line of investigation is of limited value in respect of its implications for the management of interictal problems. In the latter case it is proposed that organic factors may be considered to be a risk factor. In addition, the negative psychosocial sequelae of a diagnosis of epilepsy can result in conditions which are likely to foster the development of inappropriate behaviours. Learning theory would further suggest that environmental contingencies have a role to play in the shaping and maintenance of such behaviours. This broader framework for conceptualising the development and maintenance of interictal behaviour disorders has clear management implications. Clinical examples of the successful application of this approach to the management of persistent behavioural problems in two young people with epilepsy are presented.

INTRODUCTION

Children with epilepsy are at risk for developing behavioural disorders, and show more behavioural disturbance than age matched control groups (Rutter *et al.*, 1970; Bagley, 1971; Mellor *et al.*, 1974; Hackney and Taylor, 1976; Stores, 1977; Hoare, 1984; Epir *et al.*, 1984), their own siblings (Richardson and Friedman, 1974; Long and Moore, 1979; Epir *et al.*, 1984), and children with other chronic disorders (Hoare, 1984).

Estimates of prevalence rates of behaviour disorder vary from 12 to 95% depending on the sample studied, that is, mainstream schools, general practice, out-patient epilepsy clinics, or specialist residential centres (for review, see Cull, 1988).

Given the extent of the problem, much attention has been paid to investigating whether there is any relationship between behaviour disorder and epilepsy-related variables, that is: aetiology; seizure type; seizure frequency; age of onset and duration of the seizure disorder; EEG type, and medication. However, the literature is conflicting, and while all these factors may have a role to play, there is little conclusive evidence of any one exerting a primary function with respect to the development of behaviour disorder (for review, see Cull, 1988).

As yet, the issue of the management of behaviour problems in children with epilepsy has not been adequately addressed. Exploring the nature of the association between

epilepsy and behaviour implies that the course of any behavioural problem is intimately linked with the course of the seizure disorder itself. From such a perspective, the management of behavioural problems is seen to hinge on controlling the epilepsy and manipulating medication. When this option has been explored, however, there are no indications as to what steps can be taken in the face of a persistent disturbance. A further problem is that the literature fails to distinguish between behavioural phenomena that are ictally related, and inter-ictal disorders of behaviour. While medically based treatment strategies may be appropriate with regard to ictal events, this may not necessarily be the case for interictal behaviour problems.

At the David Lewis School there is residential provision for 96 children, on a term time basis. Even when optimal seizure control is achieved, using behaviourally non-toxic drugs in monotherapy where possible, we are still faced with a substantial number of children presenting with socially inappropriate and/or unacceptable inter-ictal behaviours. Indeed, in an increasing number of cases, it is the nature and severity of the behaviour disorder that is responsible for the students being maintained in a specialist centre.

Psychosocial factors in the development of behaviour disorders in children with epilepsy have received relatively little attention. Yet in terms of the management of

the child with epilepsy, the most effective interventions are likely to be those that take into account the broader psychosocial sequelae and implications of such a diagnosis, hand-in-hand with the medical management. From such a perspective, epilepsy is a multifaceted problem, and we would like to consider how some of these factors might foster the kind of conditions that are not conducive to the development of effective and socially appropriate behaviour.

In this paper, we would like to offer a socio-behavioural perspective on the development of behaviour disorders in children with epilepsy and consider the management implications. We will start with a brief review of what we consider to be the relevant psychosocial issues, highlighting those aspects that may predispose to inappropriate behaviours.

PSYCHOSOCIAL SEQUELAE OF A DIAGNOSIS OF EPILEPSY

Stigma

Bagley (1986) has reported that "epileptics are the most rejected of all the supposedly handicapped groups", and showed, in a study of teachers attitudes, that children with epilepsy were described more "adversely" than controls.

In similar vein, West (1986) reported on a study of 20 families containing 22 children with epilepsy. Evidence of "felt stigma" was apparent, from interview, for the parents of 15 children. "For them, having a child with epilepsy meant a disvalued identity with potential or actual consequences for stigmatization ranging from rejection, being 'put away', to . . . losing friends" (p.255). A number of parents also referred to the pervasive nature of stigma in that his "disvalued status" was seen as tarring the entire family unit.

Parental expectations

More specifically, parents expect that their child with epilepsy will be more likely to have emotional problems, to be unpredictable and highly strung than their siblings. In contrast, parents have greater expectations for their children without epilepsy with respect to: performance at school; involvement in sporting activities; ability to concentrate; and in the choice of occupation available to them (Long and Moore, 1979).

Parental management and family coping strategies

That the diagnosis of a seizure disorder has some considerable impact on the family unit cannot be denied; "epilepsy exists simultaneously as an individual disease and a family problem" (Ziegler, 1981). In response to their anxiety and uncertainty about handling the child with epilepsy, parents may overreact and become overprotective (Mulder and Suurmeijer, 1977; Munthe-Kaas, 1981).

In his survey of stigma, West (1986) also explored approaches to child management. For all parents the focus was on keeping the child "normal" and avoiding stigmatization. For some, this meant minimizing the child's participation in outside activities such as going out with friends, staying away from home overnight and supervising the child in public. Indeed, restricting the child's social activities is a common finding of other investigators (Richardson and Friedman, 1974; Long and Moore, 1979; Munthe-Kaas, 1981).

Parents also rate themselves as being more dominant and strict when dealing with their child with epilepsy than with his/her siblings (Long and Moore, 1979). Families may adopt a rigid and autocratic system of management which effectively excludes the young person with epilepsy from problem-solving and decision-making processes (Ritchie, 1981). At the same time parents may be less demanding of their child for fear of provoking seizures.

Effect on the child

Parental attitudes have been found to be significantly correlated with social development. Thus poor socialisation in the child is associated with parental strictness and egalitarianism (Hartlage and Green, 1972). Restrictive practices are also associated with deviant behaviour, and rob the child of crucial opportunities for engaging in social interactions, and for identifying with his peers. His life is controlled by others and he has little opportunity for developing decision making and interpersonal skills, and begins to feel different from, or inferior to, his peers. Further, an autocratic and dominant parent may not be providing the best role model for the child. A number of authors have also commented on the relationship between family variables and behaviour disorders. In particular; a disturbed home and family discord (Pond and Bidwell, 1959/60; Ounsted *et al.*, 1966); maladaptive or negative family and parental attitudes (Price *et al.*, 1948; Pond, 1952); overanxious parents (Bidwell, 1952); inappropriate child management practices (Stores, 1982), and parental disturbance (Rutter *et al.*, 1970), have been associated with behaviour problems in the child with epilepsy. In controlled studies, similar factors were also found to discriminate between disturbed and non disturbed children with epilepsy (Grunberg and Pond, 1957; Bagley, 1971; Hoare, 1984).

It would seem that those management practices aimed at keeping the child "normal" may have quite the opposite effect. Thus, children with epilepsy score significantly lower on a measure of self-esteem than matched control groups of healthy children and children with diabetes, such that they see themselves as being less intellectually/academically able than their peers, more anxious, and less popular (Matthews *et al.*, 1982). They were also significantly more likely to perceive the source of control over

events in their lives as unknown than children in either of the previously mentioned control groups. They attribute their own successes to unknown sources; their social functioning is similarly attributed to unknown sources and perceived as being controlled by powerful others (Matthews *et al.*, 1982). The investigators proposed that an external locus of control was related to the apparently unpredictable nature of seizure occurrence. However, it can be seen from the foregoing discussion that it may be a very real reflection of what is going on in the child's life, and partly a response to restrictive parental management practices.

Matthews and Barabas (1986) suggest that an external locus of control is implicated in the development of poor social interactions and inappropriate and unacceptable behaviours. It can affect the motivation to engage in appropriate social interactions and the situation may be further complicated and exacerbated by the fact that the response of others may well be influenced by demeaning attitudes and expectations held about people with epilepsy. Overall, an external locus of control may result in feelings of helplessness. The child fails to see himself as being responsible for his/her own behaviour, and may blame others for making them angry or for upsetting them. While such a perception is maintained the child is unlikely to modify his/her behaviour, or even appreciate why this is necessary.

In summary, the conditions arising out of the effects of stigma, parental expectations, parental and family coping strategies, and the child's self-image, are ripe for the development of inappropriate behaviours. The child may withdraw or act-out in some way in an attempt to make his/her presence felt and meet his/her needs.

This now brings us full circle, so for some children the "prophecy" may be fulfilled, they learn how to behave in ways that may have been initially feared and expected, and subsequently enter into a vicious circle of increasing inappropriate behaviours, matched possibly by increasing rigidity and restrictiveness in parental management, and rejection.

IMPLICATIONS FOR MANAGEMENT

In view of this, we would like to suggest that while organic variables may influence the predisposition towards behaviour disorder, this is not a sufficient explanation for the exhibition and maintenance, of that behaviour, and treatment aimed only at these factors is unlikely to be wholly effective.

From our clinical experience, we would like to suggest that interictal behaviour disorders, which remain in the face of appropriate and effective intervention at the organic level, need to be treated as an associated but very separate entity from the seizures themselves. It is our view that this can most usefully be done from a learning theory

perspective. Thus, in the presence of a predisposition towards disturbed behaviour, we propose that environmental contingencies shape and maintain the behaviour, often in association with a failure to have learnt socially acceptable and appropriate alternatives. Such a view on the genesis of behavioural problems has clear implications for their management in children with epilepsy.

We would like to illustrate the application of this approach with examples of our own clinical practice at the David Lewis School.

PROCEDURE

The first step is to monitor the frequency and extent of the target behaviour and to explore and analyse the environmental contingencies, that is, antecedents and consequences. The antecedents for inappropriate behaviour vary from child to child, but are often fairly innocuous (e.g. being told no, being criticized, being asked to do a job, being called names, not getting attention), whereas the consequences or outcome of the behaviour are fairly uniform. At the David Lewis School the general response to such behaviours had been for a caring concerned adult to counsel the individual about this, having removed the child from the situation if necessary, while trying to find out what it was all about. Thus, typically, the child would manage to get out of something (e.g. school or cleaning the kitchen), and gain a lot of staff attention. Similarly, at home, many children used their behaviour as a way of manipulating their environment to their own benefit. With such powerful reinforcers operating, it was highly unlikely that the children would change their behaviour, even assuming they knew what the alternatives were. In addition, there was a tendency to punish misdemeanours, for example by loss of pocket money or other privileges, whilst not acknowledging the occurrence of appropriate and acceptable behaviours. Thus we have been concentrating on manipulating the child's environment such that inappropriate behaviours are not reinforced, while a lack of these behaviours and the use of acceptable alternatives are positively reinforced or rewarded. Here are some examples of how this has worked in practice.

EXAMPLES

A. Christopher is a 17-year-old young man, who experienced a prolonged febrile convulsion at 9 months, which was not treated, and subsequently had more frequent afebrile convulsions. He has mild learning difficulties, and is described as being hyperactive and prone to temper tantrums and aggression. He was admitted to the David Lewis School in April 1978.

His seizure frequency is relatively low with current treatment. In the year prior to referral only one complex partial seizure was observed, on a medication regimen of

sodium valproate 100 mg per day, haloperidol 2 mg per day (to control behaviour), and procyclidine 5 mg per day (to counteract side effects).

Clinical psychology referral was prompted by Christopher's transfer to a house with other boys of his age and older. He did not settle well, his behaviour was immature and disruptive. For example he would throw himself on the floor in front of visitors, enter other people's rooms uninvited, run around with very exaggerated limb movements, refuse to do his chores, and would kick or hit others with no provocation. In general, he was making life very difficult for everyone. His mother was also very concerned about his aggressive behaviour at home, particularly directed towards his 3-year-old brother.

Risk factors for the development of behaviour problems include: an early age of onset of the seizure disorder; the use of sodium valproate, which may exacerbate an already existing hyperkinetic disorder, (Barnes and Bower, 1975); and the family situation (mother had divorced and re-married, and there is no contact with Christopher's natural father).

An incentive based programme was devised whereby Christopher would be rewarded for refraining from physical aggression, and other inappropriate behaviours. Tokens earned at the end of each week could then be exchanged for some tangible object of Christopher's choice. The initial response was positive, but not maintained. Modification of the programme to include a tangible daily incentive, such as a favourite snack, or breakfast in bed, subsequently proved more successful. Christopher's behaviour improved dramatically and he is now able to sustain appropriate behaviours over longer periods of time for relatively less reward. This approach has also been followed at home, and improvements reported. The change in behaviour has been so impressive that haloperidol and procyclidine were completely withdrawn within one year of starting the programme.

B. Martin is 14 years old, and was born at 7 months gestation, the 6th child of 10, of who only 4 are living, and he is the youngest. Developmental milestones are reported to have been considerably delayed. His epilepsy followed febrile convulsions at 2.5 years, thereafter consisting mainly of tonic clonic seizures. His seizures are few and tend to be self induced tonic clonic seizures, by sitting too close to the television. He is currently maintained on sodium valproate 1000 mg per day.

He was admitted to the David Lewis School in 1985, at which time he was described as an extremely disruptive and disturbed boy. He used to gobble his food using his hands, making himself sick at the table; he would defaecate on the floor, urinate in his bed, and rip and tear at books, clothes, wallpaper etc. He was also obsessed by fire and fire engines.

An opinion from a child psychiatrist in 1985 described Martin as having "a number of psychopathic traits in a severe conduct disorder" and "that there would be little point in trying any specific behavioural issues or treatments with this boy".

He proved to be quite difficult and his behaviour settled with 30 mg of thioridazine, but was showing signs of deteriorating again in early 1988.

Martin was referred to the Psychology Department because of disruptive and inappropriate behaviours, including: destroying other people's belongings; not settling at night and waking the other children; not following instructions; temper tantrums, and behaving in such a way that he was putting himself and others at risk, including fire setting.

An incentive based programme was commenced whereby weekly tangible rewards of Martin's choosing were available contingent upon minimal occurrence of the inappropriate behaviours. His behaviour improved slowly, such that 6 months later there were still a few incidents of stealing, disturbing others, and spoiling others belongings. Thioridazine was withdrawn at this time. One year later, the weekly report about Martin consisted of superlative adjectives such as "wonderful", and "marvellous". Only one minor temper tantrum occurred throughout this time. Two years later, the improvement is maintained with no further significant behavioural problems at all.

This improvement is seen, in spite of developmental delay, seizure onset at an early age, psychopathic traits, and an extremely disturbed and disrupted home background.

CONCLUSION

We suggest that while the organic contribution to interictal behaviour disorders of childhood epilepsy may be important with respect to predisposition, this is by no means the whole story. The role of environmental contingencies is of equal if not greater importance, and offers a much more positive and constructive treatment model.

A socio behavioural perspective has much to offer in terms of understanding the development and maintenance of behavioural problems in children with epilepsy and further, provides a positive and constructive approach to the management and modification of these difficulties.

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