Problems for the child with epilepsy

Aicardi’s presentation on epilepsy at the 1998 International Child Neurology Association conference in Ljubljana, Slovenia, started dramatically by using the iceberg, with larger amounts of ice below the surface, as an analogy for epilepsy. He then talked about the phenomena associated with epilepsy – the learning and behaviour problems.

Beckung and Uvebrant titled their 1997 paper on epilepsy ‘Hidden dysfunction in childhood epilepsy’1. ‘Hidden’ and ‘under the surface’ maybe, but hidden from whom? I suspect young people with epilepsy and their parents have been well aware for many years of some of these associated problems. But health professionals presented with children with epilepsy have concentrated too much on the convulsive episode itself and ignored the broader spectrum. About a third of children with epilepsy have another easily recognizable pathology, such as severe learning disabilities (mental retardation) or cerebral palsy (CP)2. But the number of children who have specific learning disabilities (for example, dyslexia) and behavioural problems is less clear. I think most practitioners would feel that children of the latter group are at least equal in number to those of the former, but we simply lack information about the epidemiology.

In this issue, the exemplary study by Schoenfeld and his colleagues3 examines neuropsychological and behavioural status in a group of children with epilepsy who have complex partial seizures, which is not always an easy diagnosis to make. These children are compared with a proper control group. The sample size is satisfactorily large. The children underwent a comprehensive neuropsychological assessment which covers a wide range of cognitive domains. For behavioural data the authors have depended on the Achenbach checklist, although a broader range of such data may have been preferred. However, the outcome is very clear-cut and their discussion draws attention to four significant findings. Firstly, there are significant cognitive impairments in the children even when social and familial factors are controlled for. Secondly, the authors note that the profile of cognitive dysfunction has specific features, namely both expressive and receptive language are particularly impaired. This profile is, of course, specific to this group of children with epilepsy. The pattern in other (well defined) epilepsy syndromes may be different. Thirdly, the authors find impaired function in behavioural and social adjustment. And again a profile emerges for this particular group of children. The children do not have aggressive and delinquent behaviours, but the patterns include social withdrawal, somatic complaints, anxiety, and depression. Again, a different pattern might be observed in a different epileptic subgroup. The final findings highlight the predictors of neuropsychological status and behavioural adjustment. A finding of interest is that the frequency of seizures within the last year partly predicts the behavioural and social problems, but not the cognitive problems which are more associated with an early onset of the disease. It is tempting to hypothesize that the latter findings represent a more severe pattern of disease. Equally, it is important to remember that after brain surgery, and indeed sometimes after effective pharmacological therapy, quite marked improvements in cognitive function can be seen. Therefore, caution should be taken in directly relating the frequency of the seizure to the behavioural phenomena and perhaps a loop exists to account for these findings. Naturally, there are other issues which we would like to see analysed, most importantly the role of drugs and their undesirable side effects, which may affect both cognitive and behavioural issues.

Another issue to arise from these studies is the amount of work needed to produce the data collected, but this information is invaluable for anyone involved in education and management of the child. However, in my own child development centre, such detailed studies on an individual basis would present problems, given the volume of patients we have to see. In addition, if the children with epilepsy are to be studied, what about the children with ADHD, who we have to see. In addition, if the children with epilepsy are to be studied, what about the children with ADHD, who equally need examining with extreme care4. Psychologists, too, need to study carefully the children with CP severe learning disabilities, autism, and so on. This is all time-consuming and difficult work, and any study which highlights areas of particular importance is helpful in directing attention to specific domains but does not eliminate the need for comprehensive neuropsychological studies in virtually every child with a disability.

These hard facts should be presented to service managers and providers, because simply ‘dishing out the drugs’ to the child with epilepsy will no longer do. Children with epilepsy must be carefully studied and carefully followed up, and then provided with appropriate support to help them with their neuropsychological and behavioural problems, problems not hidden but often ignored.

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References