The identification of educational problems in childhood epilepsy

The Children with Epilepsy in Sussex Schools (CHESS) Study - report summary
**Introduction**

Epilepsy is the most common neurological disorder in childhood. It affects an estimated one in 200 children but is widely misunderstood and misdiagnosed. It is known that children with epilepsy have learning and behavioural difficulties, but the severity and extent of the problems are unknown and the challenges children face are often missed because of the pressing medical needs of the condition. Crucially the impact of their learning and behavioural difficulties on their academic progress and quality of life in school often remains hidden.

**Aims**

This study was designed to:

- Comprehensively examine the school-based difficulties of children with ‘active’ epilepsy in a defined population in the UK.
- Use the results of the assessments as a basis for discussion with the child, parents and school staff to identify possible support for each child.
- Explore whether the current epilepsy guidelines need to include an increased emphasis on the assessment of cognition, behaviour and a consideration of educational issues.

By undertaking this study, we hoped to bring the medical and educational aspects of epilepsy together.

**Methodology**

The research, led by Professor Brian Neville, was carried out by a group of investigators from Young Epilepsy, Crawley Hospital, Gothenburg University - Sweden, UCL – Institute of Child Health, Great Ormond Street Hospital, Dartmouth College - USA and University of Edinburgh.

An Educational Psychologist visited 40 schools in the Crawley and Horsham catchment area of West Sussex to screen and subsequently assess children with ‘active’ epilepsy (on antiepileptic drugs (AEDs) or had a seizure in the last year) for learning and behavioural difficulties. Parents and teachers completed measures of behaviour and the children completed measures of cognition and academic achievement (e.g. reading and mathematics).
Findings

This table presents results from the initial assessments.

<table>
<thead>
<tr>
<th>Initial assessments</th>
<th>Parent report</th>
<th>Teacher report</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulties with academic progress</td>
<td>79%</td>
<td>67%</td>
</tr>
<tr>
<td>Display more behavioural difficulties than peers</td>
<td>73%</td>
<td>40%</td>
</tr>
<tr>
<td>Difficulties with attention and concentration</td>
<td>64%</td>
<td>37%</td>
</tr>
<tr>
<td>Difficulties with activity levels</td>
<td>31%</td>
<td>18%</td>
</tr>
<tr>
<td>Difficulties with oppositional behaviour</td>
<td>22%</td>
<td>14%</td>
</tr>
<tr>
<td>Difficulties with verbal aggression</td>
<td>29%</td>
<td>9%</td>
</tr>
<tr>
<td>Difficulties with physical aggression</td>
<td>24%</td>
<td>14%</td>
</tr>
<tr>
<td>Difficulties with other behaviours</td>
<td>12%</td>
<td>6%</td>
</tr>
</tbody>
</table>

- Difficulties with school attendance were reported by 49% of parents.
Detailed assessments

Cognition:

- Global cognitive difficulties (IQ score below average) were found in 55% of the children and 40% of the children were functioning in the learning disabled range (IQ score below 70).
- 58% of the children were underachieving on at least one of four memory tasks.
- 42% of the children with epilepsy were underachieving in the area of processing speed.

Academic achievement

- 42% were underachieving in at least one area of academic achievement, with greatest difficulty in mathematics and sentence comprehension.

Behaviour

- In total 60% met diagnostic criteria for at least one behavioural or motor disorder (i.e., Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Developmental Co-ordination Disorder (DCD), depression or anxiety). However, only one-third of the participants who met criteria had previously received these diagnoses (see graph 1).

Graph 1: Diagnosis of behavioural disorders
Extent of the problem

• Difficulties were not confined to children with identified special educational needs.
• 95% of the children had significant difficulty in at least one area of cognition or behaviour.
• Of the children in the study, 28% were not on the special educational needs register. Of these:
  o 50% displayed ‘academic underachievement’ in at least one area.
  o 63% displayed ‘memory underachievement’ in at least one area.
  o 46% met diagnostic criteria for a behavioural disorder.
• Children often presented with more than one school-based difficulty; 60% of the children with a cognitive impairment also had a behavioural disorder.

Conclusion

• This study provides clear evidence that children with epilepsy have a high rate of difficulties in cognition and behaviour.
• Difficulties were often not recognised prior to psychological assessment but were clearly having an impact on academic progress and were leading to frustration on the part of the young person, parents and school staff.
• Children were not receiving treatment for, or being helped with, these difficulties. This gap in provision is likely to contribute to further difficulties with academic progress and has a significant negative impact on the quality of life of these children and their families.
Recommendations

The following recommendations should be considered in order for school-aged children with epilepsy to reach their potential in educational settings:

• The current guidelines for the management of childhood epilepsy should be updated to reflect the high likelihood of cognitive and behaviour problems in the condition.
• Epilepsy should be recognised as a special educational need. Accurate records need to be kept of all children who have the condition by schools and local education authorities.
• Guidelines on the management of epilepsy in school-aged children need to include the need for comprehensive psychological assessment. Psychological assessments should be offered to all children with epilepsy to identify any difficulties as soon as is practicable, after diagnosis so effective support can be put in place.
• There is a need for on-going monitoring of children with epilepsy in school-based settings after initial psychological assessment.
• Epilepsy training for schools should include both medical management and training focussing on common learning and behavioural difficulties associated with the condition.
• Communication between the young person, parent, school staff and medical staff needs to be facilitated in order that the young person’s condition is understood by all responsible for their care.

Future work

• There is a need for research into the efficacy of interventions to manage the school-based problems of children with epilepsy.
• The trajectory of learning and behavioural difficulties in childhood epilepsy, over time, needs to be investigated.
• Research is needed to identify how best to support the informational and emotional needs of parents, and families, affected by the condition.
• Young people with epilepsy often reported a lack of contact with others with the condition. The support needs of young people with epilepsy should be recorded and possible support mechanisms systematically evaluated.
• The best methods of staff training in schools need to be evaluated so that knowledge, attitudes and practices reflect the best available evidence.
Acknowledgments

We would like to thank the young people, their parents and all the school-based professionals who participated in, and facilitated, this study.

We are also extremely grateful to the Esmée Fairbairn Foundation and the Roden family who funded this project.

About Young Epilepsy

Young Epilepsy is the national charity working exclusively on behalf of the 112,000 children, teenagers and young people aged 25 and under living with epilepsy. With over 100 years expertise it provides world class diagnosis, assessment and rehabilitation for children and young people with epilepsy. The charity also carries out research into the condition and how it can be treated.

It has a unique blend of specialist services including St Piers School and College and residential services providing education and healthcare for children and young people with epilepsy, autism and other neurological conditions. The charity provides a range of support and information for parents, children and young people, and training for professionals. It campaigns for better access to, and quality of, health and education services.