

# Behaviour in children with cerebral palsy with and without epilepsy

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The aim of the study was to describe behavioural problems in children with cerebral palsy (CP) with and without epilepsy. The children were sampled from the Western Sweden CP register and were part of a European Union project. The Strength and Difficulties Questionnaire and questions on epilepsy were answered by one parent of each child. Medical records were reviewed. Parents of 83 children (44 males, 39 females) age range participated: 30 at Gross Motor Function Classification System levels I and II, and 53 at levels III to V; 60 had spastic age range 8 to 12 years (bilateral 42, unilateral 18) and 23 dyskinetic CP; 34 children had active epilepsy. The proportion of children with normal behaviour on the total difficulties score (TDS) of the Strength and Difficulties Questionnaire was significantly lower than normative data (57% vs 80%,  $p < 0.001$ ). Parents of 21 children (25%) considered their child's behaviour to be abnormal. Children with CP and epilepsy had a significantly higher median TDS ( $p = 0.03$ ) than seizure-free children. In children with aided or no walking ability, the TDS was significantly higher in those with epilepsy ( $p = 0.04$ ). Parents of 32 children (39%) considered their children's behaviour to have an impact on themselves and others. We conclude that behavioural problems are common in children with CP, and even more when epilepsy is present. Parents identify these problems, and professionals need to address them.

Children with cerebral palsy (CP) frequently have associated impairments, such as epilepsy, reduced cognitive function, visual impairment, and neuropsychiatric problems.<sup>1</sup> Up to 60% of the children with CP have epileptic seizures,<sup>2</sup> whereas the prevalence in the general child population is 0.4%.<sup>3</sup> Severe learning disability\* in Sweden is present in 0.3% of children, and mild learning disability in 0.4%,<sup>4</sup> but learning disability is present in 23 to 44% of children with CP.<sup>5</sup> In a Swedish study, 46% of those born preterm and 37% of children born at term had learning disability.<sup>6</sup> In children with both CP and epilepsy, learning disability\* is present in more than 50%.<sup>7</sup>

Mental health problems such as conduct, emotional, and hyperkinetic disorders are present in about 10% of 5 to 15-year-old children in the UK.<sup>8</sup> In children with epilepsy, mental health problems were present in 37% of children, and in 56% of those with additional impairments such as CP, learning disability, muscle disease, difficulties with coordination or speech and language problems.<sup>9</sup> Psychiatric disorders were present in more than half the children with hemiplegic CP, but one-fifth of those had no contact with child mental health services,<sup>10</sup> suggesting that these problems may be overlooked in clinical practice. Yude and Goodman<sup>11</sup> reported that two-thirds of children with hemiplegia aged 9 to 11 years had peer problems. Behavioural problems may lead to great distress, and it is important to identify these problems so that assistance can be provided as needed.

The children in this study were the Swedish sample in the cross-sectional study Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE) in which the participation and quality of life in 8 to 12-year-old children with CP were ascertained and compared across seven countries in Europe.<sup>12</sup>

The aim of the study reported here is to describe and compare behavioural problems in a group of children with CP, with and without epilepsy, further separating them by walking ability, to test the hypothesis that epilepsy in children with CP implies a higher risk of additional behavioural problems and an increased impact on the family.

## Method

CP was defined according to the Surveillance of Cerebral Palsy in Europe (SCPE) as a motor disorder of movement and posture, permanent but not unchanging, due to a lesion to the immature brain.<sup>5</sup> Epilepsy was defined according to the International League Against Epilepsy as at least two unprovoked seizures.<sup>13</sup> Active epilepsy was considered when seizures had occurred within the previous year. Cognitive level was divided into normal (IQ > 70), mild learning disability (IQ < 50–70), and severe learning disability (IQ < 50). Cognitive level was estimated from current school performance and, where it had been performed, psychological assessment. Table I shows the testing and evaluation that had been performed before this study. The 12 children estimated as having normal cognitive level without clinical evaluation attended normal schools without learning problems. In two 8-year-old children with severe physical impairment, psychological assessment had not been performed and the cognitive level could not be estimated.

See end of paper for list of abbreviations.

\*North American usage: mental retardation.

Motor function was classified by the Gross Motor Function Classification System (GMFCS),<sup>14</sup> in which levels I and II are independent walkers, level III walks with aids, and levels IV and V are wheelchair users. The first two levels were combined to form a group of independent walkers, and levels III to V were combined to be a group with aided or no walking ability.

In the SPARCLE study the Strength and Difficulties Questionnaire (SDQ) was administered. It assesses behaviour and mental health problems in children and adolescents, and was developed from a revised Rutter questionnaire.<sup>15</sup> The psychometric properties of the SDQ have been tested and found satisfactory, with reliability coefficients of 0.57 to 0.85 and a validity of 0.57 to 0.72 for the domains of SDQ.<sup>16</sup> The Swedish version has also shown adequate validity.<sup>17</sup> Parents are asked to disagree, agree to some extent, or agree (0–2 points) with 25 attributes in the five domains: emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behaviour. On the basis of 20 items of four domains (not including the prosocial behaviour domain) the points are added together to generate a Total Difficulties score (TDS) with a maximum of 40 points. A score of 17 points or more is considered abnormal behaviour, between 14 and 16 borderline, and below 14 points normal behaviour. Each domain can be assessed separately, but the cutoff levels for abnormal, borderline, and normal differ. About 10% of a community sample scores in the abnormal band, with a further 10% scoring in the borderline band.<sup>16</sup>

In addition, the Impact Supplement of SDQ was used with questions about distress, burden, and social impairment due to the child's behaviour at home and at school, with friends and in social activities. This Impact Supplement gives another set of scores between 0 and 10 points, where a score of 2 or more is considered abnormal, 1 borderline, and 0 normal.

The first author administered the SDQ to one parent and interviewed the parents in their homes or in the regional habilitation centre between June 2004 and April 2005. The SPARCLE interview includes a question on the occurrence of epilepsy, but in our study we chose to do a more thorough analysis of epilepsy with questions about the type and frequency of seizures, the use of antiepileptic drugs (AEDs), and when the last seizure had occurred, and a more in-depth analysis of cognitive level. Medical records were reviewed.

#### PARTICIPANTS

The children included in the study were sampled from the population-based CP register of western Sweden.<sup>18,19</sup> The diagnosis of CP had been confirmed at the age of 4 years. In line with the SPARCLE protocol, a stratified randomization by

GMFCS level was undertaken to include 30 children from each level except levels I and II, which were combined. There were 290 children aged 8 to 12 years; 180 were at GMFCS levels I and II, and 110 at levels III to V. Of the 110 children at GMFCS levels III to V, six were not eligible. The parents of the remaining 104 were asked to participate in the study, 53 of whom accepted. Of the 180 children at GMFCS levels I and II, randomly selected families were contacted until 30 had agreed to join the study, by which time contact had been made with 114 of them. Thus, there were 83 families who agreed to take part in the study and 135 families who declined participation. A comparison between responders and non-responders in terms of sex, gestational age, CP type and learning disability showed no differences.

Medical records of 82 children were reviewed, with one family refusing access to the medical records. This child did not now have epilepsy according to the parents, or at age 4 years according to the CP register. The children were allocated into either (1) epilepsy (seizures within the last year) or (2) no epilepsy (seizures previously but not within the previous year, one single seizure, or never had seizures).

#### STATISTICAL ANALYSIS

Descriptive statistics were used. Binomial distribution was used for comparison between proportions, the Mann–Whitney U test was used for comparison between two independent groups, and the Spearman's rank coefficient test was used for correlation analysis. The level for statistical significance was set to  $p \leq 0.05$ .

#### ETHICS

Ethical approval was obtained from the Ethics Committee at Göteborg University. Written informed consent for participation and publication was obtained from all the parents in the study.

#### Results

One parent of each of 83 children with CP was interviewed. There were 39 females and 44 males. The children were between 8 and 12 years old at the interview; 10 children were 8 years old, 20 were 9, 21 were 10, 14 were 11, and 18 children were 12 years old (median 10y). All GMFCS levels were represented: 14 in level I, 16 in level II, 10 in level III, 17 in level IV, and 26 in level V.

Sixty children (72%) had spastic CP: 42 bilateral (eight tetraplegia and 34 diplegia) and 18 unilateral (nine right-sided and nine left-sided). Twenty-three children (28%) had dyskinetic CP.

Thirty-four children with CP had active epilepsy, 13 had previously had epilepsy, four had had a single seizure, and 32 had never had seizures. These last 49 children did not

**Table I: Cognitive evaluation in children in study population (n=83)**

<i>Method</i>	<i>Normal (IQ&gt;70), n=29</i>	<i>Mild learning disability (IQ 50-70), n=23</i>	<i>Severe learning disability (IQ&lt;50), n=29</i>	<i>Unclear cognitive level, n=2</i>
Psychological testing	17	21	12	0
Clinical evaluation	0	2	17	0
No clinical evaluation	12	0	0	2

meet the criteria for epilepsy and therefore formed a group without epilepsy.

In 13 of the 34 children with epilepsy the seizures had begun before age 1 year. Five children had autism, all in the epilepsy group. Table II shows epilepsy characteristics and TDS in children with epilepsy and in children with previous seizures. One child with previous epilepsy was considered to have abnormal behaviour; this child was still on AEDs.

Parents of 21 of the 83 children (25%) rated their child's behaviour as abnormal according to the TDS. In another 15 children (18%) behaviour was borderline, and in 47 children

**Table II: Characteristics of active or previous epilepsy in children with cerebral palsy (n=47)**

Characteristic	Active epilepsy (n=34)	Previous epilepsy (n=13)
No AEDs	1	8
AEDs at present	33	5
AEDs ≥2 at present	16	1
Type of seizure		
Partial	7	2
Partial+GTCS	13	5
Partial+other generalized	13	2
Only generalized	1	2
Infantile spasms	5	2
Seizure frequency last 3mo		
No seizure	7	13
<1/month	8	
1/month	7	
1/week	3	
Daily	9	
Long seizures (>10min)	24	5
GMFCS level		
I and II	8	3
III	6	1
IV	5	3
V	15	6
Cognitive level		
Normal	4	5
Mild learning disability	10	2
Severe learning disability	18	6
Uncertain	2	
TDS		
Normal	14	10
Borderline	8	2
Abnormal	12	1

AED, antiepileptic drug; GMFCS, Gross Motor Function Classification System; TDS, total difficulties score.

(57%) it was normal. The proportion of children with normal behaviour on the TDS was significantly lower than the normative data (57% vs 80%,  $p<0.001$ ). The median TDS for the whole group was 12 (range 1–29). Children with epilepsy had a significantly higher median score (15) than those without epilepsy (10),  $p=0.03$ . There was no significant difference in TDS by sex.

Table III shows the TDS by domain in children with and without epilepsy. The proportion of children with epilepsy and a normal TDS was significantly lower than in children without epilepsy (difference 26%, 95% confidence interval [CI] 15–32%,  $p<0.01$ ). The difference in the proportion of normal domain score between those with and without epilepsy was significant in the domain of hyperactivity/inattention (difference 22%, 95% CI 0–44%,  $p<0.05$ ) and close to significance in the domain of peer problems (difference 19%, 95% CI –3 to 41%,  $p<0.10$ ).

Parents of 32 children out of 83 (39%) considered their child's behaviour to have an impact on themselves and others; the parents of children with epilepsy to a slightly higher, but not statistically significant extent (44% vs 35%). Children with a normal TDS more often had normal cognitive function and no epilepsy (19/46; 41%) than those with a borderline or abnormal TDS (6/35; 17%).

The numbers of children with epilepsy by cognitive function, TDS, and Impact score for GMFCS levels I and II, and III to V respectively, are shown in Tables IV and V. In children with independent walking (GMFCS levels I and II; Table IV), the presence of epilepsy was significantly related to increasing cognitive deficit. In children with aided or no walking ability (GMFCS levels III–V; Table V), the presence of epilepsy was significantly related to increasing cognitive deficit and increasing TDS, although no difference in TDS was found in GMFCS level V. In neither of the two groups of walking ability was a significant correlation found between the presence of epilepsy and Impact score. Significant correlation was present between TDS and Impact score ( $\rho=0.58$ ,  $p<0.001$ ).

## Discussion

The aim of the study was to describe and compare behavioural problems in children with CP, with or without epilepsy. We found that TDS and Impact score were high in the whole group, and the median TDS was significantly higher in the group with epilepsy. In children with epilepsy, the hyperactive/inattention domain score was significantly higher than in those without epilepsy. Children with aided or no walking ability and epilepsy had a higher TDS than those without epilepsy.

**Table III: Results from the total difficulties score (TDS) and its four domains in children with CP with or without epilepsy (n=83)**

TDS and domains	Epilepsy (n=34)			No epilepsy (n=49)		
	Normal	Borderline	Abnormal	Normal	Borderline	Abnormal
TDS	14 (41)	8 (24)	12 (35)	33 (67)	7 (14)	9 (18)
Domain						
Emotional symptoms	22 (65)	3 (9)	9 (26)	33 (67)	3 (6)	13 (27)
Conduct problems	23 (68)	4 (12)	7 (21)	37 (76)	5 (10)	7 (14)
Hyperactivity/inattention	14 (41)	4 (12)	16 (47)	31 (63)	9 (18)	9 (18)
Peer problems	15 (44)	5 (15)	14 (41)	31 (63)	7 (14)	11 (22)

Results are presented as n (%). CP, cerebral palsy

Thirty-four children had epilepsy and 13 children had previously had epilepsy. All children except one with epilepsy were on AEDs, as were five of the 13 children with previous seizures. Half the children with epilepsy were on polytherapy.

The children in this study were part of the SPARCLE project in which GMFCS levels I and II and levels III to V were to be equally represented through stratification. This meant the inclusion of more children with severe motor impairment than in the CP series. In Sweden, GMFCS levels I and II comprise 61% and III to V 39%,<sup>6</sup> in comparison with 36% and 64% in the present study. There were many families who did not wish to participate. An analysis of missing data on CP type and cognitive level, however, showed no difference from reported data. Thus, the study was considered to be representative for children with CP and GMFCS levels I and II and III to V respectively. In addition, the distribution of CP types within each GMFCS group was similar to that in the Western Sweden population-based study by Himmelmann et al.<sup>6</sup> The proportion with learning disability (70%) in GMFCS

levels III to IV was identical in both studies. Mild learning disability of 33% in GMFCS levels I and II was higher than the 20% in the study by Himmelmann et al.<sup>6</sup> This difference might be explained by the age difference, because the children in the Himmelmann study were 4 to 8 years old at the estimation of cognitive function, whereas the children in this study were 8 to 12 years old. There may be a tendency in younger ages to emphasize the physical disability and overlook the actual cognitive function.

Lower cognitive level was associated with the presence of epilepsy. Cognitive level had been assessed in most children (83%), but 12 children considered to have normal cognitive level and attending mainstream schools had not undergone assessment. This is surprising, considering that an assessment is usually needed for the child to receive appropriate school support.

The study was based on the answers from the SDQ from one parent. The answers might have been slightly different had both parents participated. The SDQ assesses behaviour and mental health in children and adolescents.

**Table IV: Association between the presence of epilepsy in 30 children with cerebral palsy with independent walking ability (Gross Motor Function Classification system levels I and II) and cognitive function, Total Difficulties score (TDS) and Impact score**

<i>Cognitive TDS and Impact</i>	<i>Epilepsy, n</i>	<i>No epilepsy, n</i>	<i>Difference in proportions (95% CI)</i>	<i>Spearman <math>\rho</math></i>	<i>p</i>
<b>Cognitive function</b>					
Normal	2	16	0.29 (-0.03 to 0.61)	0.48	0.007
Mild learning disability	4	6	0.89 (0.30 to 1.47)		
Severe learning disability	2	0			
<b>TDS</b>					
Normal	3	14	0.07 (-0.35 to 0.50)	0.26	<i>ns</i>
Borderline	1	3	0.27 (-0.09 to 0.63)		
Abnormal	4	5			
<b>Impact score</b>					
Normal	3	12	0.13 (-0.38 to 0.65)	0.14	<i>ns</i>
Borderline	1	2	0.13 (-0.20 to 0.47)		
Abnormal	4	8			

Difference in proportions contrasts normal outcome with not normal outcome. The Spearman's rank correlation coefficient ( $\rho$ ) tests for a trend for increasing scores across disability groups. CI, confidence interval; *ns*, not significant.

**Table V: Association between the presence of epilepsy in 30 children with cerebral palsy with independent walking ability (Gross Motor Function Classification system levels I and II) and cognitive function, Total Difficulties score (TDS) and Impact score**

<i>Cognitive TDS and Impact</i>	<i>Epilepsy, n</i>	<i>No epilepsy, n</i>	<i>Difference in proportions (95% CI)</i>	<i>Spearman <math>\rho</math></i>	<i>p</i>
<b>Cognitive function<sup>a</sup></b>					
Normal	2	9	0.28 (-0.10 to 0.66)	0.31	0.029
Mild learning disability	6	7	0.41 (0.06 to 0.76)		
Severe learning disability	16	11			
<b>TDS</b>					
Normal	11	19	0.27 (0.07 to 0.61)	0.28	0.044
Borderline	7	4	0.30 (-0.03 to 0.63)		
Abnormal	8	4			
<b>Impact score</b>					
Normal	15	16	0.48 (-0.02 to 1.20)	0.14	<i>ns</i>
Borderline	0	2	0.07 (-0.21 to 0.35)		
Abnormal	11	9			

Difference in proportions contrasts normal outcome with not normal outcome. The Spearman's rank correlation coefficient ( $\rho$ ) tests for a trend for increasing scores across disability groups. <sup>a</sup>Not possible to estimate in two children. CI, confidence interval; *ns*, not significant.

It can be used as a screening instrument, to study effects of treatment or for research. For diagnostic purposes, however, it can be used only in conjunction with clinical assessment. The SDQ identifies 70% of behavioural problems, hyperactivity, depression and anxiety, but only 50% of phobias, separation anxiety, or eating disorders.<sup>20</sup> Nordin and Gillberg<sup>21</sup> found that four out of 38 children with CP had autism spectrum disorders, and the SDQ was not developed to identify such conditions. A recent study by Hermann et al.<sup>22</sup> showed high rates of ADHD (31%), anxiety disorders (36%), and depression (20%) in children with epilepsy; when CP is also present these disorders might be even more prevalent. We did not address the occurrence of psychiatric diagnoses in this study because the information is not always available in the medical files, and these conditions may be underdiagnosed.

The Swedish version of SDQ has adequate validity and is 'a useful tool for mental health screening in children and adolescents'.<sup>17</sup> SDQ scores can only be an indicator of possible behavioural problems. However, it is essential that children with a high TDS in conjunction with an elevated Impact score are properly assessed to elucidate possible mental health problems.

Behavioural problems are more common in children with neuroimpairments<sup>9</sup> and in children with CP.<sup>10,23</sup> The median TDS in this group of children with CP was 12, in comparison with a mean of 8.4 for a general UK population,<sup>16</sup> and 6.3 for a Swedish population of 7-year-olds.<sup>24</sup> As many as 25% of the parents in this study rated their children's behaviour as abnormal. In the complete SPARCLE data set, 24% of the parents considered their child's behaviour to be abnormal, and the median TDS was 12 for the whole group.<sup>25</sup>

In the four domains of the SDQ included in the TDS, the children in this study scored more highly than over 10 000 UK 5 to 15-year-olds.<sup>16</sup> This was also found in a study by McDermott et al.<sup>23</sup> The percentage of children in the abnormal group in the hyperactive/inattention domain was high, and significantly higher in children with epilepsy than in those without epilepsy.

A study by Carlton-Ford et al.<sup>26</sup> showed that children with previous epilepsy fare worse behaviourally than children who have never had seizures, but we found no difference in TDS between those with previous epilepsy and those who had never had seizures, which might be due to a lack of power as a result of small numbers.

Diagnostic predictions from questionnaire data are likely to be more accurate if both symptoms and impact scores are given. According to the American Psychiatric Association,<sup>27</sup> the definition of many psychiatric conditions includes both symptoms and impact, and thus the Impact Supplement gives valuable additional information. As many as 39% of the parents scored in the abnormal range in the Impact score, which indicates abnormal distress and burden on others caused by the child's behaviour, not only to the family but possibly also at school, in leisure activities, and in peer relationships.

In the Davies study<sup>9</sup> of behavioural problems in children with epilepsy, the SDQ was used to assess peer relationship and impact, but the children with 'complicated epilepsy' had a variety of additional neuroimpairments, not only CP. To our knowledge, the SDQ has not been used in studies of children with all types of CP. In a study by Goodman and

Graham,<sup>10</sup> the SDQ was used in a group of children with hemiplegic CP. Psychiatric problems were associated with greater neurological severity, lower IQ, special schooling, and family adversity (parental depression, high level of parental criticism of the child). The most consistent predictor of psychiatric problems was IQ. Once this had been taken into account, the neurological severity was not a significant predictor of psychiatric problems. We found that behavioural problems were more frequent in children with CP and epilepsy, and even more so if cognitive function was low. According to Goodman and Graham,<sup>10</sup> IQ is primarily a marker for underlying neurobiological factors that influence psychopathology rather than being the main risk factor in itself. Epilepsy could also be a marker of neurological injury and could therefore increase the risk of psychiatric conditions, which is consistent with the report from Davies et al.<sup>9</sup> We chose to use walking ability as a marker of neurological injury, because motor impairment is still the core feature of CP and has been found to correlate strongly with learning ability, visual impairment, and epilepsy.<sup>6</sup>

Should SDQ be used in children with CP? We think that it is an adequate instrument for children with milder motor impairments and communicative skills. There was no difference in TDS between children with and without epilepsy in GMFCS level V compared with the other levels. Some of the questions might not be applicable to children with severe physical impairment. Despite that, borderline or abnormal behaviour was high (43%) in children in GMFCS level V.

## Conclusion

Behavioural problems are common in children with CP, and are more common when other neuroimpairments such as epilepsy are present. It is important to identify and address such problems. Parents identify behavioural problems, but they may be overlooked by professionals. Behavioural problems have an impact not only on the child but also on the everyday life of the family.

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#### List of abbreviations

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AED	Antiepileptic drug
SDQ	Strength and Difficulties Questionnaire
SPARCLE	Study of Participation of Children with Cerebral Palsy Living in Europe
TDS	Total Difficulties score

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