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The effects of perceived stigma and psychological over-control on the behavioural problems of children with epilepsy

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This pilot study finds that parents who think that their child will be stigmatized and who perceive that epilepsy limits their child, report higher levels of four child behavioural problems than reported by other parents of children with epilepsy. Those children with epilepsy who report that their parents use an over-controlling psychological approach to parenting report higher levels of four behavioural problems than those children with epilepsy who do not report over-controlling behaviour from their parents.

The effects of simple partial seizures and of seizure severity on children's behavioural problems are completely mediated by perceived stigma, perceived limitations, and perceived parenting. Seizure frequency, absence seizures, and treatment with ethosuximide have direct effects on three children's behavioural problems; the effects of these medical variables are generally unaffected by control for parent's and children's perceptions.

Key words: children; stigma; parenting; behaviour problems; epilepsy; seizures.

INTRODUCTION

Childhood epilepsy appears to have three general sociopsychological effects: (1) children with epilepsy have more behavioural and emotional problems (depressed mood, low self-esteem, and high levels of behavioural problems at home and at school) than other children; (2) parents of children with epilepsy may think that their child will be stigmatized; (3) families which have a child with epilepsy appear to function differently from other families. However, perceived stigma and disrupted family dynamics can also cause problematic behavioural and emotional outcomes in children. One may reasonably ask then, to what degree epilepsy produces poor behavioural outcomes directly, and to what degree are these outcomes related both to the parents' fear of stigma and to concomitant changes in parenting? This paper examines these issues in a pilot study of children with epilepsy and their parents.

BACKGROUND RESEARCH

First, previous studies have found that children with epilepsy are at risk from a variety of behavioural and emotional problems. Regardless of the comparison sample (siblings¹, children with asthma^{2,3}, children with diabetes⁴ or children from a random sample of the population^{1,5,6}), children with epilepsy appear, prior to control for other relevant variables, to fare worse—emotionally and behaviourally—than those with whom they are compared. Studies consistently find that children with epilepsy have poorer self-esteem, are more likely to be depressed, have higher levels of behavioural problems at home, and find it more difficult to interact with their peers and adults at school^{2,3,5}.

Sometimes these outcomes are related to characteristics of the epilepsy itself. Generally, children whose epilepsy began early in life, has been relatively long lasting, or is characterized by frequent seizures,

have more negative outcomes^{7,8}. Sometimes specific seizure types are associated with higher levels of psychological problems. For example, complex partial seizures have been found to be associated with higher levels of psychological problems⁷. Similarly, children taking phenobarbital tend to have more severe problems than children taking other medications; children being treated with multiple anticonvulsants often fare more poorly than other children with epilepsy⁷. Results for seizure and medication variables⁹ are, however, often inconsistent from study to study and across different outcomes.

Secondly, although public attitudes towards epilepsy appear to have become less stigmatizing since the 1940s¹⁰, adults with epilepsy believe that they are stigmatized^{11,12}. The feeling of being stigmatized is not, however, directly related to experiences of being stigmatized¹³. For example, about one-third of adults with epilepsy can cite an instance of discrimination against themselves, but nearly all (90%) report feelings of being stigmatized¹⁴. Parents of children with epilepsy may, similarly, think that both other adults and their child's peers stigmatize their child; such parents appear to introduce the issue of stigma to their children¹¹. These fears revolve around the potential for social rejection that comes with a publicly witnessed seizure¹⁵. The probability of a seizure being witnessed will probably be related to seizure frequency, type, and severity. So, perceived stigma may be related to these seizure variables as

Thirdly, the families of children with epilepsy appear both to function differently compared with other families and to change over time. Again consistently, the dynamics change for the worse; families of children with epilepsy are less creative in handling problems, using a more rigid interactional style ¹⁶; they also have less-well-developed interactional resources^{2, 17}. These differences appear to develop over time and affect other family members as well. Siblings of children with newly diagnosed epilepsy do not score particularly high on measures of psychological disturbance⁴; when length of time since diagnosis is not considered, however, siblings of children with epilepsy score worse than members of control families¹⁸.

Changes in family dynamics appear to take place at the level of the parent-child dyad. Both mothers and fathers of children with epilepsy have been found to reject their children more than parents of 'healthy' children. Parents of children with epilepsy generally believe that the epilepsy has an adverse affect and hold lower expectations for their child than for their other children the problem-solving efforts of children with epilepsy 1. In experimental situations mother-child

interaction exerts effects on problem behaviour at least as strong as medical variables²². Clinicians have suspected that parental over-control may be a problem^{23,24}, and too much parental worry and control is cited in retrospective studies of childhood epilepsy¹⁵. In general, children whose parents believe that their child will be stigmatized and who attempt to control their child too strongly will probably fare worse behaviourally and emotionally.

The three general sets of variables discussed above—seizure and medication variables, perceived stigma, and parenting—could be independent causes of behavioural and emotional problems. Alternatively, parental reactions could mediate between medical and seizure variables and behavioural and emotional outcomes. Based on previous research⁵, we suspect that the effects of epilepsy on children's behavioural problems are, at least in part, mediated by parental perceptions and behaviour. Variables, like perceived stigma and parental over-control, should be more extreme the more severe and observable the epilepsy; these parental variables should, in turn, predict worse behavioural problems.

In order for mediation to occur in a way consistent with the hypothesized causal ordering, three conditions must hold: (1) medical and seizure variables must be related to behavioural and emotional problems; (2) seizure and medical variables must be more strongly related to perceived stigma and parenting than they are to behavioural problems; and (3) perceived stigma and parenting must be more strongly related to behavioural and emotional problems than are medical variables. If these three conditions hold, then the effects of medical and seizure variables on behavioural and emotional problems should be reduced (or even eliminated) when we control for perceived stigma and parenting. By examining both mediated and unmediated effects we gain a better understanding of the complete web of relations involved in the behavioural problems of children with epilepsy.

METHODS

Sample

We identified children with epilepsy through the Department of Pediatric Neurology at a local hospital. With the aid of each child's neurologist, we introduced the study to the parents of children who met our inclusion criteria. Children had to be between the ages of 6 and 13 (average age = 10.04 years), to have non-degenerative epilepsy as their primary diagnosis, to be on medication, and to be free of other complicating factors (e.g. severe mental retardation). Fol-

| Medication | n | Seizure t | уре | n | |
|-------------------|--------|-------------------------|---------|---------|--|
| Carbamazepir | ie 17 | Complex | partial | 20 | |
| Valproic acid | 16 | Absence | | 9 | |
| Phenytoin | 4 | Tonic-cl | onic | 9 | |
| Ethosuximide | 2 | Simple p | artial | 5 | |
| Acetazolamid | e 2 | Secondarily generalized | | 4 | |
| Phenobarbital | 2 | Unclassi | fied | 1 | |
| Seizure variables | Mean | Median | Minimum | Maximum | |
| Seizure frequency | | | | | |
| (per year) | 732.43 | 12.00 | 0 | 21,900 | |
| Seizure severity | 3.46 | 3.00 | 1 | 7 | |

Table 1: Characteristics of medication, seizure type, and seizure-related variables.

lowing procedures approved by the human subjects review board, over the course of a year we identified and contacted the parents of 73 children who were eligible and consented to participate in the study. In slightly over half of these families (n=37), we obtained simultaneous but separate interviews with both the adult responsible for coordinating medical care (for 31 families this was the mother) and with the child. Interviews were scheduled for times separate from the child's neurological evaluation, but were conducted at the hospital where the child received neurological care.

We attempted to minimize self-selection by providing child care for siblings during the interview and by providing taxi vouchers for families who needed transportation. The median family income was approximately \$30,000 per year; approximately two-thirds of the parents had had more than a high-school education. The sample was evenly split between females and males (17 vs. 20, respectively). The racial split was roughly proportional to our metropolitan area (27 white, 10 African–American).

Measures

Information about medications and seizure type were coded from patient records by a trained medical researcher and double-checked with the primary neurologist when necessary. Other measures, as indicated below, are based on either parent or child reports. If not reported in the text, the exact wording of the questions for all scales is available from the first author.

Medications. As indicated in Table 1, children were taking one or more of the following medications: acetazolamide (n = 2); carbamezepine (n = 17); ethosuximide (n = 2); phenobarbital (n = 2); phenytoin (n = 4); or valproic acid (n = 16). Although as reported below, we do find some individual medication effects, we find no additional effect of polytherapy.

Seizure type. Table 1 also shows the classification of children by seizure type: absence (n = 9); complex partial (n = 20); secondarily generalized (n = 4); simple partial (n = 5); tonic-clonic (n = 9); unclassified (n = 1). There was no evidence of any effect of having multiple seizure types (n = 7) above and beyond the effects of individual seizure types. As a result of our sample selection process (described above), all of our subjects have idiopathic seizures, not epilepsy syndromes.

Seizure frequency. The child's parent was asked two questions. Were seizures occurring daily, weekly, monthly, or yearly? How frequently were seizures occurring within that period? These two pieces of information were then converted to create a single variable indicating the number of seizures per year. As shown in Table 1, children averaged 732.43 seizures per year or about two per day. As indicated by the comparatively low median seizure frequency (12.00 per year), however, most children in our sample have relatively few seizures. Slightly less than one-third of the children (n = 11) were seizure free during the previous year.

Seizure severity. Using a seven-point scale from 'not at all' to 'extremely' severe, each parent was asked: Overall, how would you describe the severity of your child's seizures? On this scale a 4 indicates 'moderate' control, which is only slightly higher than the average (mean = 3.46).

Perceived limitations. Parents were asked four questions (adapted from Ryan et al¹²) about how seizures directly affected their child (alpha = 0.75). Each of the questions was answered using a seven-point scale where 1 indicated 'almost never' limited and 7 indicated 'almost always' limited. The average (mean = 11.95) corresponds to a report weighted slightly towards the end of the scale indicating less limitation.

Perceived stigma. In addition, parents were first asked six questions about how other people behaved towards their child (adapted from Ryan et al^{12}) and then 12 questions about how people generally behaved towards a child with epilepsy (adapted from Link et al^{25}). Each question was answered on a seven-point scale with a score of 1 indicating that stigma was extremely unlikely and a score of 7 indicating that stigma was extremely likely. The two sets of questions formed a single scale (alpha = 0.93). The average scale total (mean = 51.97) corresponds to a response of indicating slightly less than a moderate likelihood of stigma for each item.

Child's report of parent's behaviour. Children were asked about the way the parent being interviewed acted as a parent. We used a version of the Child's Report of Parent's Behaviour Index²⁶ the vocabulary of which we modified (with the help of two children's reading and vocabulary specialists) to be more appropriate for the younger children in our sample. We created three scales based on the results of factor analyses from previous research^{26,27}. Only one scale, Perceived Parent's Psychological Over-Control (16 items; alpha = 0.79), predicted any children's selfreported behavioural problems in our step-wise analyses. The other two scales, Rejection (alpha = 0.93) and Lax Control (alpha = 0.80) did not prove predictive in the step-wise analyses, and are not discussed below.

Parallel parent-report measures, with reliabilities ranging from 0.77 to 0.82, were developed and used in analyses. Consistent with previous research that shows a lack of correspondence between parent and child reports of the 'same' phenomenon²⁸, our parent and child reports of parenting share less than 15% of their variance (r = 0.07-0.37). Parents' reports of how they parent the child with epilepsy were included in analyses, but did not predict any reports of children's behavioural problems in our step-wise analyses. As a result, they are not discussed below.

Child's behavioural problems. We used age-appropriate behavioural problem items from the National Health Interview Survey²⁹. The items are very similar to questions used in the Child Behavior Checklist³⁰, which has been used successfully in research on children with epilepsy^{7,31,32}. These 20 items form four factors: home behavioural problems, school behavioural problems, depressed mood, and impulsiveness⁵. Since previous research²⁸ shows that parent and child reports very often diverge, we asked each parent to report on the child's behaviour and asked each child to report on her or his own behaviour.

We then created parallel scales for each of the four previously identified dimensions (see Table 2 for reliabilities and other scale characteristics). Parent reports and child reports of three of the four dimensions share relatively little variance (2% of depressed mood; 14% home behavioural problems, and 14% impulsiveness). In only one dimension do the two reports share a substantial proportion of their variance (29% for school behavioural problems). The average correlation among items was generally lower when parent and child reports are combined; reliabilities for combined reports did not improve despite doubling the test length³³. As shown in our analyses below, different variables predict parent and child reports.

Table 2: Selected characteristics of perceived limitations, stigma, parenting, and child-problem variables.

| | Mean | Standard deviation | Reliability |
|----------------------|--------|--------------------|-------------|
| Adult's reports | | | |
| Perceived limits | 11.95 | 6.26 | 0.75 |
| Perceived stigma | 51.97 | 24.29 | 0.93 |
| Child's home | | | |
| behavioural problems | 17.46* | 4.85 | 0.89 |
| Child's school | | | |
| behaviour problems | 5.30* | 1.53 | 0.77 |
| Child's | | | |
| depressed mood | 6.03** | 2.43 | 0.84 |
| Child's | | | |
| impulsiveness | 8.30 | 2.36 | 0.79 |
| Child's reports | | | |
| Adult's | | | |
| psychological | | | |
| over-control | 29.34 | 6.42 | 0.79 |
| Own home | | | |
| behavioural problems | 18.74 | 4.18 | 0.71 |
| Own school | | | |
| behavioural problems | 4.83 | 1.72 | 0.50 |
| Own | | | |
| depressed mood | 7.11 | 2.36 | 0.67 |
| Own | | | |
| impulsiveness | 8.11 | 2.37 | 0.63 |

Parent reports are based on 37 cases; child reports are based on 35 cases.

Mean differences between adult reports of child behaviour problems and the corresponding child report: * $P \le 0.10$; ** $P \le 0.05$; *** $P \le 0.01$.

ANALYSIS PLAN

Our analysis plan tends to maximize the effects of medical and seizure variables compared with parenting and perceived stigma. First, perceived limitations and perceived stigma were predicted using simple step-wise regressions that allowed demographic background variables, medication type, seizure type, seizure frequency, seizure severity, and other variables to enter if significant.

Secondly, the eight children's behavioural problem variables were predicted using an hierarchical step-wise approach. For each behavioural problem variable, demographic background variables, medication type, seizure type, seizure frequency, and seizure severity variables were allowed to enter into each equation. The variables with significant effects in this second step (i.e. medication and seizure variables) were held in the equation. Thus perceived limitations, perceived stigma, all six parenting variables, and control variables entered each equation; these new variables were retained only if they added significant predictive power.

Subsequent analyses (not shown) demonstrate that, regardless of the order in which sets of variables were entered into the hierarchical step-wise equations, the same variables almost always emerged as significant. Many variables (e.g. demographic background, parent's stigma-coping styles, and child's attitude toward illness) were never significant in the step-wise analyses.

The analyses presented below are based on the maximum number of cases. The results for the variables found in the figures below remain virtually identical regardless of missing data. As with our analysis plan, our handling of missing data tends to minimize the effects of perceived stigma and parenting. Given the small sample size, adjusted *R*-squares are reported.

RESULTS

Patterns of correlation

Table 3 presents correlations among variables that were significant in the analysis of parents' reports of children's behavioural problems. Quite consistently, simple partial seizures are associated with more beneficial outcomes. For parent reports, simple partial seizures are associated with lower levels of perceived stigma, perceived limitations, and behavioural problems. Perhaps this is so since simple partial seizures do not necessarily involve either loss of consciousness or generalized seizure activity²⁴. Seizure frequency and seizure severity are generally, though not always, associated with significantly higher levels of perceived stigma, perceived limitations and with higher levels of behavioural problems. Perceived limitations and perceived stigma are always significantly associated with higher levels of children's behavioural problems as reported by their children. Importantly, where mediation effects appear in the regression results (which are discussed below), the magnitude of the correlations is consistent with viewing stigma or parenting as the variable that mediates between medical variables and behavioural problems. For example, simple partial seizures are more strongly related to perceived stigma (-0.303) than they are to school behavioural problems (-0.236), and perceived stigma is more strongly related to school behavioural problems (0.446) than are simple partial seizures.

Bivariate results for children's self-reported behavioural problems are presented in Table 4. For these variables, we also see a consistent pattern of results. Simple partial seizures are associated with lessperceived parental psychological over-control, and to a lesser degree, with lower levels of self-reported behavioural problems. Perceived parental psychological over-control is consistently, and fairly strongly, associated with higher levels of self-reported behavioural problems. Absence seizures, on the other hand, tend to be related more strongly to behavioural problems than to perceived parental psychological over-control. Treatment with ethosuximide is related only to higher levels of depressed mood. Since absence seizures are generally treated with ethosuximide (r = 0.42 in our sample), these two results probably reflect aspects of the same medical problem.

Effects on parents' reports of their child's behavioural problem

Figure 1 presents the significant results from the last step of each analysis for parents' reports of children's behavioural problems. Results for variables that enter into the analysis early, but fail to remain significant, are discussed below but not presented. The effects of medications and seizure variables that appear to be completely mediated by perceived stigma and perceived limitations are shown on the extreme left of the diagram; medication and seizure variables that appear to have partially mediated or unmediated direct effects on parents' reports of children's behavioural problems are shown at the extreme right of the diagram.

Seizure severity and simple partial seizures (which are not significantly correlated with each other) appear to affect behavioural problems only indirectly through their effects on perceived stigma and perceived limitations. In fact, the bivariate relationship between seizure severity and parents' reports of their child's depressed mood (r = 0.33) appears to be completely mediated by perceived stigma. Having simple partial seizures (compared with other types of seizure) has no significant bivariate relationships with parents' reports of their child's behavioural problems. Parents of children with simple partial seizures (compared with children with other types of seizure) are significantly less likely both to fear stigma (beta = -0.30) and to view their children as limited by their epilepsy (beta = -0.34).

As can be seen from examining the centre of Fig. 1, the most consistent predictor of parents' reports of

Table 3: Parent report models: correlations among significant variables.

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|-----|----------------|----------------------|---------------------|------------------|------------------|---------------------|---------------------|-----------------------|-------------------|---------------|
| | Simple partial | Seizure frequency | Seizure severity | Absence seizures | Perceived limits | Perceived stigma | Home behavioural | School behavioural | Depressed mood | Impulsiveness |
| | seizures | рег уеаг | | | | | problems | problems | | |
| 2: | -0.067 | | | - | | | | | | |
| | 0.347 | | | | | | | | | |
| 3: | -0.012 | -0.095 | | | | | | | | |
| | 0.471 | 0.289 | | | | | | | | |
| 4: | -0.224 | 0.308 | -0.105 | | | | | | | |
| | 1 0.09 | 0.032 | 0.268 | | | | | | | |
| 5: | -0.342 | 0.065 | 0.288 | 0.015 | | | | | | |
| | 0.019 | 0.352 | 0.042 | 0.465 | | | | | | |
| 6: | -0.303 | -0.156 | 0.439 | 0.003 | 0.681 | | | | | |
| | 0.034 | 0.178 | 0.003 | 0.492 | 0.000 | | | | | |
| 7: | -0.071 | 0.243 | 0.094 | 0.209 | 0.410 | 0.513 | | | | |
| | 0.338 | 0.074 | 0.291 | 0.107 | 0.006 | 0.001 | | | | |
| 8: | -0.236 | 0.220 | 0.085 | 0.432 | 0.319 | 0.446 | 0.737 | | | |
| | 0.080 | 0.095 | 0.308 | 0.004 | 0.027 | 0.003 | 0.000 | | | |
| 9: | -0.103 | 0.295 | 0.332 | 0.151 | 0.507 | 0.561 | 0.748 | 0.552 | | |
| | 0.271 | 0.038 | 0.022 | 0.186 | 0.001 | 0.000 | 0.000 | 0.000 | | |
| 10: | -0.221 | 0.284 | 0.166 | 0.144 | 0.491 | 0.471 | 0.616 | 0.562 | 0.542 | |
| | 0.095 | 0.004 | 0.162 | 0.197 | 0.001 | 0.002 | 0.000 | 0.000 | 0.000 | |

Correlations and one-tailed tests of significance are reported. All statistics and analyses are based on 37 cases.

Table 4: Child report models: correlations among significant variables.

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 Depressed mood | 8 Impulsiveness |
|----|-------------------------|---------------------|-------------|--------------------------------------|---------------------------------|-----------------------|------------------------|--------------------|
| | Simple partial seizures | Absence seizures | Ethosuxmide | Parental over-control problems | Home behavioural problems | School behavioural | | |
| 2: | -0.240 | | | | • | | | |
| | 0.082 | | | | | | | |
| 3: | -0.101 | 0.418 | | | | | | |
| | 0.283 | 0.006 | | | | | | |
| 4: | -0.577 | 0.268 | 0.065 | | | | | |
| | 0.000 | 0.060 | 0.356 | | | | | |
| 5: | -0.391 | 0.259 | 0.015 | 0.680 | | | | |
| | 0.010 | 0.067 | 0.465 | 0.000 | | | | |
| 6: | -0.247 | 0.213 | -0.048 | 0.388 | 0.569 | | | |
| | 0.076 | 0.109 | 0.393 | 0.011 | 0.000 | | | |
| 7: | -0.301 | 0.392 | 0.411 | 0.545 | 0.614 | 0.619 | | |
| | 0.040 | 0.010 | 0.007 | 0.000 | 0.000 | 0.000 | | |
| 8: | -0.299 | 0.474 | 0.093 | 0.496 | 0.602 | 0.544 | 0.470 | |
| | 0.040 | 0.002 | 0.297 | 0.001 | 0.000 | 0.000 | 0.002 | |

Correlations and one-tailed tests of significance are reported. All statistics and analyses are based on 35 cases.

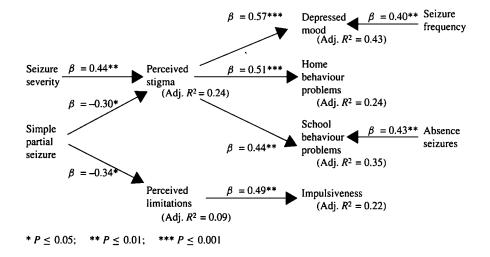


Fig. 1: Effects of seizure severity, seizure frequency, seizure types, perceived stigma, and perceived limitations on parent ratings of children's behavioural outcomes.

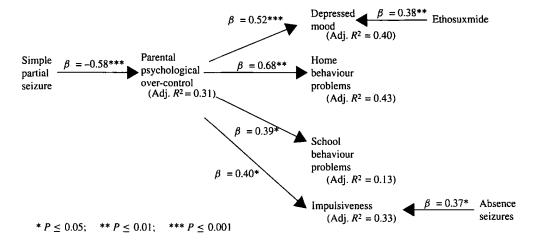


Fig. 2: Effects of simple partial seizures, seizure type, ethosuximide, and children's perception of parent's psychological over-control on children's ratings of their own behavioural outcomes.

their child's behavioural problems is parents' reports of perceived stigma. Parents who believe that their child will be stigmatized also report significantly higher levels of depressed mood (beta = 0.57), home behavioural problems (beta = 0.51), and school behavioural problems (beta = 0.44). Parents who report that their child's epilepsy is limiting are significantly more likely to report (beta = 0.49) that their child is impulsive. In addition, children with more frequent seizures are reported as having worse depressed moods (beta = 0.40) than children with less-frequent seizures. Children with absence seizures (compared with children with other types of seizure) are more likely to be reported as having school behavioural problems (beta = 0.43). These last two effects appear to be unmediated by perceived stigma and limitations.

A large number of potential predictors (e.g. number of seizure types, number of medications, seizure control, perceived clumsiness, parent's stigma management techniques, the child's perception of her/his epilepsy as an illness) are never significant.

Effects on children's self-reported behavioural problems

The significant results from the last step of each analysis of children's self-reported behavioural problems are found in Fig. 2. The figure shows, on the left side, medication and seizure variables which appear to have indirect effects on children's behaviour; medication and seizure variables with direct effects are shown on the right-hand side.

Children diagnosed as having simple partial seizures report significantly lower levels of parents' attempts at psychological over-control than do children with other types of seizure (beta = -0.58). Al-

though the correlation between simple partial seizures and home behavioural problems was significant (r = -0.39), this relationship completely disappears once parental psychological over-control enters the analysis.

This single variable, children's perception of parent's psychological over-control, most strongly and consistently predicts children's self-reported behaviour; children who perceive their parents as psychologically over-controlling report themselves to be more depressed (beta = 0.52), as more of a problem at home (beta = 0.68), as more of a problem at school (beta = 0.39), and as more impulsive (beta = 0.40). In addition, children taking ethosuximide report a significantly more depressed mood than do children taking other medications (beta = 0.40), an effect that is virtually independent of parenting. Similarly, children with absence seizures report being more impulsive (beta = 0.37) than do children diagnosed with other types of seizures. This effect is approximately 20% smaller after controlling for mediating variables than it was before (beta = 0.47). As with parent reports, many potential predictors were never significant in the step-wise analyses of children's self-reported behavioural and emotional problems.

CONCLUSIONS

The results of the study should be interpreted cautiously. Our sample is quite small, and although the pattern of correlations is consistent with the causal ordering we have hypothesized, the data are cross sectional. The results for this pilot study suggest, albeit tentatively, that characteristics of the epilepsy, type of medications, perceived stigma, perceived limitations resulting from seizures, and parenting form a web

of relationships that predicts behavioural problems in children with epilepsy. The effects of seizure severity and simple partial seizures appear to be mediated by perceived stigma and parenting. Since only two children were treated with ethosuximide, the results for that variable are probably not representative.

Consistent with other research³⁴, our results show a lack of strong correspondence between parent's reports and children's reports of the 'same' phenomena. Parallel reports (of both parenting and child behaviour) are positively but weakly related to each other. In addition, similar, but far from identical, sets of variables predict parent's and children's reports of behavioural problems. For example, simple partial seizures, absence seizures, seizure frequency, parental perceptions of stigma, and parent's perceptions of their child's limitations are all involved in the web of relationships that predict parental reports of less-than-optimal children's behaviour. The web of relationships for children's reports of their own behaviour, on the other hand, involves simple partial seizures, absence seizures, ethosuximide, and the child's perception of how he or she is parented. For each web, the effects of simple partial seizures are mediated by a parenting variable; but the parenting variables are different for parent reports compared with children's reports.

What are we to make of the lack of correspondence between children's and parent's reports on parallel measures? Although one might be tempted to discount children's reports, it would be a mistake to do so. Parent's reports about their children, although valid for certain purposes, are not necessarily accurate reports of what their children are doing and feeling²⁸. Reports of behavioural problems call not only for observations of behaviour but inferences about motivation and evaluation of behaviour with reference to cultural standards. As a result, a child's report and a parent's report each represent equally valid, but discrepant, interpretations of the child's behaviour³⁴.

Previous research^{35,36} demonstrates that the individual's interpretation is crucial. In fact, the more internal or private the behaviour or feeling (e.g. depressed mood) the less accurate are parent's assessments of their child's behaviour likely to be; for publicly constructed and enforced assessments of behavioural problems (e.g. school problems) agreement is likely to be more complete. This discrepancy is well understood in the clinical literature where, for example, the most common reasons for identifying an adolescent as depressed is not a parent's report of the child's depressed mood but behavioural problems. Our results, with the lowest agreement for reports of depressed mood and the highest agreement between reports of school behavioural problems mirror the degree of private vs. public construction and

enforcement of what count as problems.

Future research should attend to both children's and parent's reports in examining the relationship between parenting and the behavioural problems of children with epilepsy. Studies should focus on carefully assessing both congruences and differences between different family member's reports and not simply focusing either on single individuals or the family as a global system. With larger and perhaps longitudinal samples, researchers could test to see whether statistical relations that apparently differ in magnitude are statistically different³⁷ and implement other more sophisticated dyadic models³⁸. Such research could move beyond prediction to modelling more adequately the causal influences among medical, psychological, and sociological variables.

From a more practical point of view, parents of children with epilepsy should be encouraged to learn more about epilepsy and stigma, and to become involved in parent support groups^{39, 40}. Our results suggest that such groups probably need to focus less on parenting *per se* and more on parent's understandings of and reactions to epilepsy and fears that they may have about the reactions of others to their child's condition. In contrast, programmes for children and adolescents should probably focus on how children understand and interpret their parent's behaviour. In addition, children and adolescents with severe seizure disorder problems may benefit from interventions designed to help them overcome behavioural and emotional problems and to cope with vocational issues⁴¹.

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REFERENCES

- Hoare, P. Does illness foster dependency? A study of epileptic and diabetic children. Developmental Medicine and Child Neurology 1984; 26: 20-24.
- Austin, J.K. Childhood epilepsy: child adaptation and family resources. Journal of Child and Adolescent Psychiatric and Mental Health Nursing 1988; 1: 18-24.

- Austin, J.K. Comparison of child adaptation to epilepsy and asthma. Journal of Child and Adolescent Psychiatric and Mental Health Nursing 1989; 2: 139-144.
- Austin, J.K. Psychiatric disturbance in the families of epileptic children. Development Medicine and Child Neurology 1984; 26: 14–19.
- Carlton-Ford, S. et al. Epilepsy and children's social and psychological adjustment. *Journal of Health and Social Behavior* 1995; 36: 285–301.
- Gortmaker, S.L. et al. Chronic conditions, socioeconomic risks, and behavioral problems in children and adolescents. Pediatrics 1990; 85: 267-276.
- Hermann, B.P. et al. Correlates of behavior problems and social competence in children with epilepsy, aged 6–11. In: Childhood Epilepsies: Neuropsychological, Psychosocial and Intervention Aspects (Eds B.P. Hermann and M. Seidenberg). New York, Wiley, 1989: pp. 143–157.
- 8. Hermann, B.P. and Whitman, S. Psychopathology in epilepsy: the role of psychology in altering paradigms of research, treatment, and prevention. *American Psychologist* 1992; 47: 1134-1138.
- Committee on Drugs. Behavioral and cognitive effects of anticonvulsant therapy. *Pediatrics* 1995; 96: 538–540.
- Caveness, W.F. and Gallup, G.H. Jr. A survey of attitudes toward epilepsy in 1979 with an indication of trends over the past thirty years. *Epilepsia* 1980; 21: 509-518.
- Schneider, J.W. and Conrad, P. In the closet with illness: epilepsy, stigma potential, and information control. *Social Problems* 1980; 28: 32–44.
- Ryan, R. et al. The stigma of epilepsy as a self-concept. Epilepsia 1980; 21: 433-444.
- Britten, N. et al. Sources of stigma following early-life epilepsy: evidence from a national birth cohort study. In: Psychopathology in Epilepsy: Social Dimensions (Eds S. Whitman and B.P. Hermann). New York, Oxford, 1986: pp. 228– 244.
- Scambler, G. and Hopkins, A. Generating a model of epileptic stigma: the role of qualitative analysis. Social Science and Medicine 1990; 30: 1187–1194.
- Schneider, J.W. Disability as moral experience: epilepsy and self in routine relationships. *Journal of Social Issues* 1988; 44: 63-78.
- Ritchie, K. Research note: interaction in the families of epileptic children. *Journal of Child Psychology and Psychia*try, 1981; 22: 65-71.
- Lothman, D.J. et al. Mother-child interaction in children with epilepsy: relations with child competence. *Journal of Epilepsy* 1990; 3: 157-163.
- Hoare, P. and Kerley, S. Psychosocial adjustment of children with chronic epilepsy and their families. *Developmental Medicine and Child Neurology* 1991; 33: 201-215.
- Kitamoto, I. et al. Child-parent relationships in the care of epileptic children. Brain and Development 1988; 10: 36-40.
- Ferrari, M. Epilepsy and its effects on the family. In: Child-hood Epilepsies: Neuropsychological, Psychological, and Intervention Aspects (Eds B.P. Hermann and M. Seidenberg). New York, Wiley, 1989: pp. 159–172.
- Pianta, R.C. and Lothman, D.J. Predicting behavior problems in children with epilepsy: child factors, disease factors, family stress, and mother-child interaction. *Child Development* 1994: 65: 1415-1428.
- Nicholas, K.K. and Pianta, R.C. Mother-child interactions and seizure control: relations with behavior problems in chil-

- dren with epilepsy. Journal of Epilepsy 1994; 7: 102-107
- Dell, J.L. Social dimensions of epilepsy: stigma and response.
 In: Psychopathology in Epilepsy: Social Dimensions (Eds S. Whitman and B.P. Hermann). New York, Oxford, 1986: pp. 185–210.
- Freeman, J.M. et al. Seizures and Epilepsy in Childhood: A Guide for Parents Baltimore, Johns Hopkins, 1990.
- Link, B.G. et al. The effectiveness of stigma coping orientations: can negative consequences of mental illness labeling be avoided? *Journal of Health and Social Behavior* 1991; 32: 302–320.
- Burger, G.K. et al. Estimating factor scores for children's reports of parental child-rearing behaviors. Journal of Genetic Psychology 1973; 121: 107–113.
- Grotevant, H.D. and Carlson, C.I. Family Assessment, A Guide to Methods and Measure New York, Guildford, 1989.
- Gecas, V. and Seff, M.A. Families and adolescents: a review of the 1980s. In: Contemporay Families: Looking Forward, Looking Back (Ed A. Booth). Minneapolis, Minnesota, National Council on Family Relations, 1991: pp. 208–225.
- Adams, P.F. and Hardy, A.M. Current estimates from the National Health Interview Survey, 1988. National Center for Health Statistics. Vital and Health Statistics 1989; 10: 173.
- Achenbach, T.H. et al. National survey of problems and competencies among four- to sixteen-year olds. Monographs of the Society for Research in Child Development 1991; 56: 3, serial no. 225.
- Dorenbaum, D. et al. Use of a child behavior checklist in the psychosocial assessment of children with epilepsy. Clinical Pediatrics 1985; 24: 634–637.
- Mitchell, W.G. et al. Psychosocial, behavioral, and medical outcomes in children with epilepsy: a developmental risk factor model using longitudinal data. *Pediatrics* 1994; 94: 471– 477.
- Carlton-Ford, S. Final report to the Epilepsy Foundation of America. 1995.
- Perrin, E.C. et al. In the eyes of the beholder: family and maternal influences on perceptions of adjustment of children with a chronic illness. Developmental and Behavioral Pediatrics 1993; 14: 94-105.
- Gecas, V. The self-concept. Annual Review of Sociology 1982; 3: 1-33.
- Rosenberg, M. Conceiving the Self Malabar, Florida, Krieger, 1986
- Carlton-Ford, S. A simple method for estimating and testing equality restrictions using OLS regression. Sociological Focus 1993; 26: 165-176.
- Carlton-Ford, S. et al. A longitudinal analysis of depressed mood, self-esteem, and family processes during adolescence. Sociological Focus 1996; 29: 135-154
- Austin, J. and Hernandez, N. Epilepsy parent and family support network development. Mimeograph adapted from Epilepsy Parent and Family Networks Resource Materials Epilepsy Foundation of America, 1991.
- Santilli, N. and Hernandez, N. Access to community support services. In: *Handbook of Pediatric Epilepsy* (Eds J.V. Murphy and F. Dehkharghani). New York, Marcel Dekker, 1992: pp. 341-355.
- Fraser, R.T. and Clemmons, D.C. Vocational and psychosocial interventions for youths, with seizure disorders. In: (Eds B.P. Hermann and M. Seidenberg) Childhood Epilepsies: Neuropsychological, Psychological, and Intervention Aspects New York, Wiley, 1989: pp. 201–219.