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Clinical Research

Negative Emotions in Children with Newly Diagnosed Epilepsy

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Summary: Purpose: To understand the emotional predicament in children with recently diagnosed idiopathic or cryptogenic epilepsy.

Methods: We used the well-tried method of structured projection for the first time in children with epilepsy. Thirty-six children with epilepsy, aged 7–15 years (mean age, 9.5 years) and in 35 control children aged 7–15 years (mean age, 9.4 years), attributed shame and guilt in relation to three types of situation (non-illness related, illness related, and epilepsy related). Children were evaluated twice: shortly after diagnosis, before antiepileptic drug (AED) use and after an interval of 3 months.

Results: Children with epilepsy and healthy controls were similar in their way of attributing shame and guilt. However, the type of situation was of influence: Both children with epilepsy and healthy children attributed more shame to incompetence due to epilepsy than to incompetence due to other illnesses.

Conclusions: Increased affective problems in childhood epilepsy cannot be explained by excessive attribution of shame and guilt, affects known to be important precursors of psychopathology, yet both healthy children and children with epilepsy attribute more shame to epilepsy than to other illnesses. Epilepsy is not like any other disease. Key Words: Epilepsy—Children—Shame—Guilt—Psychopathology.

In epilepsy, affective problems abound (1–4). More than 25% of children with normal intelligence and relatively benign epilepsy have signs of depression, but these are apparently not always recognized by carers (5). We have attempted to understand the affective predicament of children with epilepsy by concentrating on the affects of shame and guilt. Both are negative but normal adaptive affects (6). The question addressed by this study is whether children with recently diagnosed epilepsy differ from healthy matched control children in their attributions of shame and guilt. Currently it is reasoned that psychopathology develops from intrinsically normal affective reactions. Recurring affects induce a proneness to react to these affects (7). Proneness distorts cognition, biases action and perception, and thus leads to maladaptiveness. Maladaptiveness in turn leads to affective distress (8). The relevance of the affects of shame and guilt for later psychopathology has been noted since Freud (cited in 6). In children, proneness to shame and/or proneness to guilt are potent predictors of depression (9–13).

Although related, shame and guilt have relevant distinguishing features (14). Shame is felt when a person, whether child or adult, loses control and suspects that important others consider the person to be what she or he does not want to be. Hence, shame occurs in the context of experiencing an unwanted identity. Guilt, on the other hand, is elicited by violation of a moral rule (e.g., causing harm to others). In feelings of guilt, not so much one’s identity but the responsibility for one’s behavior is at stake (15). Both affects are relevant in epilepsy. The condition is characterized by a transient loss of control (16), which may elicit shame responses. Furthermore, inherent to epilepsy is the fact that the child runs the risk of causing harm to others (e.g., when the child, because of a seizure, spoils social play activities, parties, or lessons), which may elicit guilt responses.

We used the method of structured projection, a technique of which reliability and validity have been established (15,17–21). The child is provided with short stories (vignettes) describing situations eliciting feelings of shame and/or guilt in the protagonist. The child is asked to indicate on a 5-point scale how much shame and how much guilt the protagonist feels in that situation. Advan-
tages of structured projection are that the child itself, and not relevant others, provides the attributions. Inhibitory response tendencies that are frequent in children when tackled directly on matters of affect are evaded by the request to imagine how much shame or guilt the protagonist feels. Furthermore, the responses are not of an all-or-none nature but reflect the intensity of the attribution. Structured projection is a novel procedure in the study of affect in children with epilepsy, and prior reports of affect attribution in children with epilepsy are, to our knowledge, absent.

We explore the attributions of shame and guilt in a well-defined subset of the population of children with epilepsy. Normally developing children with recently diagnosed idiopathic (no underlying cause other than a possible hereditary predisposition) or cryptogenic epilepsy (presumed to be symptomatic, but the etiology is unknown) (22) are compared with healthy matched controls. Illness has been recognized as a condition leading to feelings of shame and guilt (23). Based on the hypothesis that epilepsy-related situations are a separate class of affective elicitors among illnesses, we designed vignettes referring to situations of illness and vignettes referring to situations in which epilepsy in particular is the origin of incompetence of the protagonist. The attributions of shame and guilt are investigated immediately after diagnosis, before use of antiepileptic drugs (AEDs), and 3 months later.

METHODS

The study was part of a multicenter neuropsychological project of the Dutch Study of Epilepsy in Childhood (DuSECh). The study was subsidized by the Dutch Epilepsy Foundation (NEF), JANIVO Foundation, and Peugeot Holland N.V. All children participated on the basis of written informed consent from their parents, and, if 12 years and older, from the children themselves as well. The study was approved by ethics committees of the participating hospitals.

Subjects

Thirty-six children with recently diagnosed epilepsy participated (17 girls: mean age, 10.0: SD, 2.24; range, 7.0–15.8; 19 boys: mean age, 9.1; SD, 2.29; range, 6.1–15.5). The diagnosis of epilepsy implied they had experienced at least two seizures. Epilepsy variables (Table 1) were rated according to DuSECh protocol by the participating pediatric neurologists (22,24). Inclusion criteria were newly diagnosed epilepsy, normal education, and no previous use of AED. Exclusion criteria were acute symptomatic epilepsy, associated neurologic abnormality, other chronic illness, or mental retardation. All children were examined twice, with an interval of 3 months. The time of the first examination was dictated by the interval between diagnosis and initiation of AED therapy of the child with epilepsy. There was no sample attrition.

The control children were medication free, healthy classmates of the patients with epilepsy, matched for age, sex, educational level, and socioeconomic status. Controls were recruited by the patients with epilepsy and their parents. Thirty-five control children agreed to participate (17 girls: mean age, 9.9; SD, 2.30; range, 6.9–15.9; 18 boys: mean age, 8.8; SD, 2.27; range, 6.3–14.9). Only one boy with epilepsy could not find a suitable classmate within the short time span between diagnosis and AED use. Like the children with epilepsy, control children were examined twice, with an interval of 3 months.

Attrition of shame and guilt

The task consisted of 16 situations (eight non–illness related, five illness related, and three epilepsy related). There were small differences between boys’ and girls’ versions of the situations (e.g., when reference was made to boys’ or girls’ toys). Each situation featured a protagonist of the same sex as the child’s. The child was asked to listen to the stories and to imagine how much shame and how much guilt the protagonist would feel. To facilitate answering, the child was provided with a visual analogue, consisting of five, bright blue, size–graduated vertical rectangles drawn on a piece of white

<p>| TABLE 1. Classification of seizures and epilepsies in 36 children |
|---------------------------------|-----------------|-----------------|</p>
<table>
<thead>
<tr>
<th>Seizure classification</th>
<th>Number of patients (at diagnosis)</th>
<th>No. patients (between first and second assessment)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partial seizures</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Simple partial</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Complex partial</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Generalized seizures</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Absence</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Myoclonic</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Tonic–clonic</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>Unclassified seizures</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Number of seizures</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;5</td>
<td>30</td>
<td>15</td>
</tr>
<tr>
<td>6–10</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>&gt;10</td>
<td>13</td>
<td>7</td>
</tr>
<tr>
<td>Epilepsy classification</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Localization related</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Idiopathic</td>
<td>6</td>
<td>Benign childhood epilepsy with centrotemporal spikes</td>
</tr>
<tr>
<td>Cryptogenic</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>Generalized</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Idiopathic</td>
<td>16</td>
<td>Childhood absence</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Juvenile absence</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Juvenile myoclonic</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Epilepsy with generalized tonic–clonic seizures on awakening</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other, not defined above</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7</td>
</tr>
<tr>
<td>&quot; According to the Commission on Classification and Terminology of the International League against Epilepsy (22, 24).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot; In case of multiple seizures, two types were classified (n = 2).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot; Absence seizures or complex partial seizures.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Epilepsia, Vol. 41, No. 3, 2000
The following examples present only label-based questions (only label-based results are presented).

Non–illness-related situation
Last night Eric did not sleep well. He is still very tired when he has to get out of bed in the morning. At school he almost falls asleep. Then the teacher asks him a question. Eric is startled, and he has no idea what the question is about.
How ashamed is Eric?
How guilty does he feel?

Illness-related situation
Tom’s friend Oscar promised his dad he would do some odd jobs. Tom promised to help Oscar. When Tom comes home from school, he isn’t feeling well. His mum says he cannot leave the house to help Oscar.
How ashamed is Tom?
How guilty does he feel?

Epilepsy-related situation
Bart has an illness. Sometimes he drops to the floor, and his arms and legs shake. A few seconds later, everything is back to normal. You can talk to him like you used to.
How ashamed is Bart?
How guilty does he feel?

paper. Each rectangle represented a particular amount (none, a little, some, a lot, and a great deal).

Procedure
Trained psychologists (A.S. and K.J.O.) performed the investigation. Testing started by training the children to use a visual analogue, as elaborately explained in Olthof et al. (15). Subsequently, situations were verbally presented in a fixed random order, during a 20-min session.

Shame and guilt judgments
After describing a situation, the experimenter first asked label-based and correlate-based shame questions and then label-based and correlate-based guilt questions. In correlate-based questions, children are asked to indicate to what extent they would experience experiential correlates of each emotion. The experiential correlates were specifically tailored for that situation. (Shame correlate, e.g., the protagonist’s face is getting red, the protagonist thinks others believe he/she is stupid. Guilt correlate, e.g., the protagonist thinks he/she might get punished for this, the protagonist thinks about what to do to help the other after all.) Correlate-based ratings are often used because discussion exists on whether children are sufficiently aware of the differential meaning of the emotion labels “guilt” versus “shame.” The label-based questions were, “How ashamed (guilty) did [protagonist’s name] feel? Did she/he not feel any shame (guilt), did she/he feel a little ashamed (guilty), did she/he feel some/a lot of/a great deal of shame (guilt)?” When asking these questions, the experimenter pointed to the appropriate rectangle of the scale. Children gave their shame and guilt ratings in response to each of the shame-and/or guilt-eliciting situations (see box).

Statistical analysis
The ratings were averaged across the non–illness-related, illness-related, and epilepsy-related situations. Differences between group means were studied by using a 2 (Medical Status: epilepsy vs. healthy children) × 2 (Gender: girls vs. boys) × 3 (Type of Situation: non–illness- vs. illness- vs. epilepsy-related) × 2 (Type of Affect: shame vs. guilt) × 2 (Time after Diagnosis: shortly after diagnosis vs. 3 months later) mixed design analysis of variance (repeated measures, full factorial) with Medical Status and Gender as between-subject factors. In all cases, averaged F tests were used because Mauchly sphericity tests showed compound symmetry. Unique sums of squares were used for main and interaction effects whereby each significant effect was tested after controlling for age as covariate. All tests were performed with a significance level of alpha = 0.05, two-sided. If a p value was between 0.05 and 0.10, a tendency to significance was presumed and will be reported. Helmert contrasts were used to interpret interaction effects (25). Analyses were carried out using the Statistical Package for Social Sciences (SPSS, version 7.0 for Windows).

RESULTS
There were no clear differences in children’s performances depending on whether label-based or correlate-based responses were used. This is consistent with the findings of Olthof et al. (15) that school-age children’s performance when answering shame- and guilt-related questions did not depend on whether label-based or correlate-based questions were used. Therefore we describe only the label-based attributions. Correlate-based results are available on demand, from the first author.

Gender and age
No statistically significant differences were found between boys and girls (data not shown). Age as a covariant, however, was statistically significant. Shame and guilt attributions decreased with increasing age (r value, −2.89; p = 0.01). The decrease with age was steeper for guilt (r value, −3.17; p = 0.00) than for shame (r value, −2.31; p = 0.02).

Children with epilepsy versus healthy children
No statistically significant differences in attribution of either shame or guilt were found between children with epilepsy versus healthy children (Fig. 1).

Shame versus guilt
The main effect of Type of Affect was statistically significant (F value, 21.29; p = 0.00). In all situations, more shame than guilt was attributed.

Non–illness- versus illness- versus epilepsy-related situations
The main effect of Type of Situation was statistically significant (F value, 27.34; p = 0.00). In non–illness-
SHAME AND GUILT IN CHILDHOOD EPILEPSY

related situations, more shame and more guilt was attributed than in the two illness-related situations.

Interaction effect

The interaction effect of Type of Situation \times Type of Affect was statistically significant (F value, 7.31; p = 0.001). Analysis of variance (repeated measures) with Helmert contrast, conducted to interpret the Type of Affect \times Type of Situation interaction, revealed:

1. Shame and the situational context (Fig. 2). The main effect of Type of Situation was statistically significant (F value, 24.76; p = 0.00). Shame differentiated non-illness-related situations from illness-related situations (collapsed over epilepsy- and illness-related situations; F value, 44.11; p = 0.00). The mean amount of shame was statistically significantly less in illness-related situations. Moreover, shame also differentiated epilepsy-related situations from other illness-related situations, in the sense that epilepsy-related situations accounted for more shame than other illnesses did (F value, 5.46; p = 0.02).

2. Guilt and the situational context (Fig. 3). Again the main effect of Type of Situation was statistically significant (F value, 15.56; p = 0.00). Guilt differentiated non-illness-related situations from illness-related situations (collapsed over epilepsy- and illness-related situations; F value, 32.14; p = 0.00). The amount of attributed guilt was significantly lower in illness-related situations. As opposed to shame, guilt did not discriminate epilepsy-related situations from other illness-related situations.

Effect of time

When compared with the initial attributions, across all situations and in patients as well as in control children, the amounts of attributed affect were lower after 3 months (F value, 5.20; p = 0.03).

DISCUSSION

Current theories of psychopathology hold that depression may develop from frequently occurring but adaptive affective reactions to situations in which incompetence is experienced (10–12). Guilt and shame have been shown to be intrinsically adaptive affects that, when recurring, establish a proneness to experience these affects. Proneness to shame and proneness to guilt have been shown to be important precursors of depression, a mood disorder that is widespread among adults with epilepsy (26–28). The purpose of this study was to examine the attribution of shame and guilt in the earliest stages of epilepsy. In the epilepsy literature, we have not found any study dealing with affect from a developmental perspective.

In normally developing children with recently diagnosed epilepsy, we investigated the attributions of shame and guilt and compared these with the attributions of shame and guilt in healthy classmates. We used the method of structured projection, which required the child to estimate the amount of shame and guilt that a pro-
agonist felt in three types of situations describing his or her incompetence. The incompetence was either not related to illness, related to illness in general, or related to epilepsy in particular.

Two major findings are discussed: First, children recently diagnosed as having epilepsy do not attribute shame and guilt more intensely, more frequently, or to different elicitors than do their healthy peers. Second, less shame and less guilt are attributed if incompetence originates from illness than from non–illness–related situations. Moreover, epilepsy elicits more shame than do other illnesses.

The first finding may be specific to the sample of the children with epilepsy under study. Particularly the recency of the illness process and diagnosis appears to be relevant. This very short history of relatively mild epilepsy prevented the child from developing proneness to shame and/or guilt.

One earlier study points in the same direction; although using different assessment techniques, Stores et al. (29) found only a few inconsistent affective differences in children of similar age and drawn from a similar segment of the epilepsy population as in our study, finding only a few inconsistent affective differences. Studies suggesting affective disturbances in epilepsy (1,5) apply to other segments of the epilepsy population, particularly to children who had epileptic seizures more frequently and for a longer period than those in our study. This would imply a greater chance of developing proneness.

The second finding, that all children attributed more shame to incompetence due to epilepsy than to incompetence due to other illnesses, appears to have far-reaching implications. Shame is felt when a person loses control and experiences an unwanted identity. The finding thus appears to touch on stigma, a notion that reflects the manner in which others perceive a person with deviant characteristics. The unpredictability of failure of control is closely related to epilepsy and repeatedly leads to situations eliciting feelings of shame.

One should recognize, however, that these results are based on a rather small sample. Continuation of prospective and controlled research, under way in our department, will clarify the course of shame and guilt attributions in a larger sample of this segment of children with epilepsy. This will enable us to explore variability within the epilepsy sample based on seizure variables. Extension to children with less benign epilepsies is envisaged. We expect more prominent development of proneness in more severe cases of epilepsy.

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