*Seizure* 1998; **7**: 309–316

# An insight into children's and adolescents' experience of seizures and epilepsy

FRANCO GALLETTI, ANNA RINNA & CELESTE ACQUAFONDATA

*Dipartimento di Scienze Neurologiche e Psichiatriche dell'Età Evolutiva, University of Rome "La Sapienza", via dei Sabelli 108, Roma, Italy*

Correspondence to: Dr F. Galletti, Dipartimento di Scienze Neurologiche e Psichiatriche dell'Età Evolutiva, University of Rome "La Sapienza", via dei Sabelli 108, Roma, Italy.

A qualitative study was performed to investigate the individual experience of seizures and epilepsy in children and adolescents. Forty-one patients aged between 6 and 18 years old and affected with idiopathic epilepsy underwent one or more semi-structured interviews in a hospital day unit. Children aged 7 years or older could describe the experience of partial fits (in one case also of a presumably generalized fit). Seizures which occurred 6–12 months before had often been forgotten. Psychic involvement was reported in 90.3% cases, even when seizures had been classified as partial motor according to the parents' description. Social status and school achievement had no significant influence on the patient's ability to express his or her feelings, but some children had serious difficulty finding appropriate words to describe unfamiliar experiences; other patients used a simile, uncommon expressions or odd names to describe the fit. A poor relationship was found between seizure severity and patient's discomfort, and the image of the disease appeared independent of the experience of the seizures. As regards the epilepsy itself, patients seemed to suffer from generic problems rather than from specific concern about it, but some adolescents inserted their thoughts about the disease into reflections on their existential condition.

*Key words:* epilepsy; childhood; adolescence; qualitative methods; seizure experience; individual feelings.

## INTRODUCTION

Physicians talk about childhood epilepsy, but do they talk with children suffering from epilepsy? In most cases, scientific literature is based on seizure description from parents or by means of 'objective' methods such as videotape recording, EEG or polygraphy[1–3], and/or long-term EEG monitoring[4]. The relevance of these methods has been properly enhanced; besides, neurologists know that many seizures only involve subjective symptoms, and some have shown that 'minor' fits may be underestimated or remain undiagnosed when dialogue with the child is not performed[5,6]. Recent literature focusing on patients' quality of life added more reasons to pay attention to perceptions as well as objective symptoms. This seems to be the first step in alleviating not only social effects, but also, and most importantly, individual discomfort caused by the epileptic experience and condition. Patients' interviews confirm that this is one of their main needs[7].

Indirect and quantitative studies tried to investigate children's discomfort with the epileptic condition[8], and show that children and adolescents with epilepsy often suffer from poor self-esteem[9] and excessive dependency[10]; a tendency of parents to overprotection was also reported[11]; socio-cultural causes seemed to influence the parents' anxiety and negative attitudes toward epilepsy[12]. A recent study showed that families are mainly concerned about childhood epilepsy with respect to their child's future, seizure relapse, and school performance; children are mainly concerned about medication and seizures[13]. Few authors have employed qualitative methodology to explore the individual experience of the epileptic child. Children with epilepsy whose families are members of the British Epilepsy Association underwent a 30-item questionnaire; the 896 respondents described their seizures as making them feel helpless, scared, panicky, frustrated and different from others[14]. The widest qualitative study on this topic was performed, according to our knowledge, by Wilde and Haslam[15] interviewing 48 patients aged from 13 to 25 years. Besides other data, information about feelings and fears related to epilepsy was obtained. Their results cannot be summarized but will be an object of discussion below.

1059-1311/98/040309 + 08 $12.00/0

In our practice at pediatric age we found it useful to question the patient directly about his or her subjective experience and feelings; so we wondered whether such an approach could be systemized to acquire better knowledge of the patient's world. We started to investigate the individual experience of the epileptic seizure and the feelings related to epilepsy in children and adolescents. We assumed that a qualitative investigation would fit our purpose, and established the following methodology.

## MATERIALS AND METHODS

A group of patients was selected, fulfilling the following criteria:

(1) age between 6 and 18 years;

(2) diagnosis of idiopathic epilepsy;

(3) normal neurological and cognitive development;

(4) no other severe comorbidity.

According to international definition[16], idiopathic epilepsies depend on no known cause other than a possible hereditary predisposition. They are characterized by age-related onset, typical clinical and electroencephalographic features, and a lack of brain lesions or neurological signs. This group of epileptic syndromes was chosen to perform our enquiry so that no neurological or psychological factor other than epilepsy could influence the patients' perceptions. For the same reason all patients suffering from cognitive problems or affected with severe comorbidity were excluded from this study. Hollingshead and Redlich's socio-economic categories[17], revised according to an Italian context, were applied to evaluate social background, in order to assay whether social condition could bias the patient's competence to disclose his or her internal world. For the same reason school achievement was evaluated from teachers' reports, as school underachievement has frequently been found even in idiopathic epilepsy[18, 19]. Seizure onset, type, frequency and duration were obtained from patients' records. In particular we considered whether the patient had presented with a recent fit or not (during the 6–12 months preceding the interview), with the idea that remote seizures could be recollected badly.

The study was performed from September 1995 until October 1996 and all patients were at our hospital day unit undergoing periodical examinations. A total of 41 patients was selected (mean age = 12 years). There were 25 focal and 16 generalized cases of idiopathic epilepsy. One patient was classified in socio-economic category 1, two in category 3, 23 in category 4, five in category 5, eight in category 6 and two in category 7. School achievement was good in 27 cases, adequate in 10 and poor in four. Seizure course is summarized in Table 1 and seizure type in Table 2. An epileptic fit had occurred recently in 19 cases, more than 6 months before in seven cases, more than 1 year before in 15. As regards recent seizures, two patients had fits every day, but in two cases they were represented only by eyelid myoclonias, in five cases seizures occurred weekly, in nine sporadically (five had presented only one or two fits), finally, in three cases the occurrence of fits during the last 6 months was only suspected.

Our previous experience had demonstrated that most parents and children were inclined to spontaneous communication of their experience and concern, if doctors had sufficient time and empathy for discussion. So, we thought that conversation was the natural means to obtain an insight into patients' experiences, and conceived a semi-structured scheme of interview, focusing on (1) subjective seizure experience, including possible warnings; (2) fit circumstances and suspected precipitants; (3) spontaneously developed methods of seizure inhibition, if applied; (4) feelings associated with seizure occurrence; (5) impact of fits on daily living and adjustment to epileptic condition; (6) teachers' and peers' reactions to the patient's condition, as perceived by the subject; (7) opinions on drug therapy; and (8) opinions on doctors were considered if the patient spontaneously talked about them.

Interviews took place as an ordinary day unit procedure, and were performed without predetermined time limits. Normally, the patients attended the unit in the morning for at least 3 hours. Blood analysis, if necessary, was performed first. The conversation started with the anamnestic update preceding the execution of the electroencephalogram, and continued after it, when examination result and therapeutic advice was given. Spontaneous verbalization was preferred, and hesitant patients were encouraged to express freely the topics they wished to talk about. We never attempted to force patients who looked reluctant to communicate. Children under 11 years who showed difficulties in verbal description of the seizure experience were invited to 'draw the fit'. One or two parents were present during all the interviews, but if the examiner estimated that a more confident disposition would be achieved by a private talk, parents' permission was obtained to perform it with underage patients.

Particular attention was necessary to obtain the maximum from these interviews. Discretion, savoir-faire and delicacy were obviously essential, as seizure experience is often considered by children as personal and very confidential. For the same reason, a non-dramatic disposition was sometimes appropriate, and several children appeared to be more confident when interviewed by younger doctors or medical students. On the other hand, adolescents showed a propensity for

Table 1: Seizure course

| Patient no. | Admission age (years) | Time since admission (years) 0–5 | 6–10 | 11–14 | 15–18 |
|---|---|---|---|---|---|
| 1 | 18 | sporadic | daily | weekly sporadic | sporadic |
| 2 | 17 | sporadic > monthly | > monthly | **** | *weekly |
| 3 | 11 | sporadic ** sporadic | monthly > | < | |
| 4 | 12 | daily | < | < | |
| 5 | 11 | sporadic | sporadic ** | * | |
| 6 | 11 | sporadic > | ** sporadic *** | * | |
| 7 | 8 | | sporadic ? | | |
| 8 | 6 | sporadic ** daily ** | * ? | | |
| 9 | 10 | sporadic | sporadic ** sporadic | | |
| 10 | 14 | | | sporadic > | |
| 11 | 9 | | daily | | |
| 12 | 15 | sporadic ** | sporadic > | sporadic * | * |
| 13 | 17 | sporadic *** | **** | *** sporadic | *** |
| 14 | 9 | | sporadic | | |
| 15 | 13 | | sporadic * | *** | |
| 16 | 9 | | daily *** | | |
| 17 | 15 | | sporadic daily | daily ** | < |
| 18 | 9 | sporadic | sporadic | | |
| 19 | 10 | | sporadic ** sporadic * | * | |
| 20 | 9 | daily | sporadic * sporadic | | |
| 21 | 15 | sporadic *** sporadic | daily ? | ? sporadic > | * |
| 22 | 17 | | | sporadic *** | * sporadic |
| 23 | 8 | sporadic monthly **** | ** < | | |
| 24 | 7 | sporadic *** sporadic * | sporadic | | |
| 25 | 8 | | daily * ? | | |
| 26 | 10 | daily | * weekly | | |
| 27 | 18 | | sporadic * | *** | * sporadic |
| 28 | 18 | | | sporadic | *** |
| 29 | 7 | sporadic * sporadic | sporadic ** ? | | |
| 30 | 16 | sporadic ** | ** sporadic | daily > ** | * ? |
| 31 | 18 | | | daily monthly | sporadic |
| 32 | 8 | daily | daily | | |
| 33 | 12 | sporadic * | * monthly * | ** | |
| 34 | 9 | sporadic | **** | | |
| 35 | 15 | sporadic | weekly monthly | weekly monthly | weekly |
| 36 | 8 | | sporadic | | |
| 37 | 15 | | | sporadic monthly | ** sporadic |
| 38 | 11 | * | sporadic ? ** | | |
| 39 | 16 | sporadic | daily ** sporadic | sporadic | sporadic |
| 40 | 16 | sporadic **** sporadic | **** | **monthly sporadic | sporadic ** |
| 41 | 16 | | sporadic ? * | **** | * sporadic |

*, 1 year of remission; >, long-lasting seizures (> 5′); <, minor seizures (eyelid mioclonias, etc.); ?, uncertain seizures.

veteran physicians, and sometimes liked discussing the existential aspects of their condition with them. Thus, after a preliminary interview, the following team of examiners was established: one childhood neuropsychiatrist, two young physicians attending postgraduate school and one medical student frequenting the unit. The latter was trained for 6 months before taking part in the study. As a rule, the young doctors and the student performed the introductory interview, that could take the appearance of a play-session with little children. The specialist concluded the consultation in the presence of his younger co-workers, being available to answer questions raised by the issues emerging during the former interview.

Table 2: Seizure type[a]

| Patient no. | Seizure type |
|---|---|
| 1 | A.3.a; b.5; A.1a |
| 2 | B.5; A.1.c; A.2.a.2; A.3.b; A.1.b; A.1.d |
| 3 | B.4; B.6; A.2.a.2; A.1.b.1; A.1.a.1 |
| 4 | B.2; B.1.a.2 |
| 5 | A.1.a.1; A.3.a; |
| 6 | A.3.a; A.1.a.1; A.1.b.1; B.3 |
| 7 | A.1.d; D |
| 8 | A.1.a.3; B.1.b; D |
| 9 | A.1.c; B.4; A.3.a |
| 10 | B.5; A.1 |
| 11 | A.2.b.1; A.1.c |
| 12 | A.1; A.3.a; B.5 |
| 13 | B; B.4; |
| 14 | A.1.a.1 |
| 15 | A.1 |
| 16 | C |
| 17 | A.1.a.3 |
| 18 | B.4 |
| 19 | A.1.a |
| 20 | B.2 |
| 21 | B.5; A.2; A.3; D |
| 22 | A.1; A.1.b; A.3 |
| 23 | B.4; B.2; B.2.a |
| 24 | B.1.a; B.5; A.1.d |
| 25 | B.4; D |
| 26 | B.1.a.1; B.1.a.2 |
| 27 | A.1.a.1; B.4 |
| 28 | A.3.a; A.1.a.1 |
| 29 | A.1.d.6; A.1.d.4; A.1.d.3; D |
| 30 | A.3; D |
| 31 | B.1.a.1; B.5 |
| 32 | A.1.d.5; A.1.b.2 |
| 33 | A.1.a.1; B.5; a.1.b.1; A.3 |
| 34 | B.4 |
| 35 | A.3; A.2.b; B.4 |
| 36 | A.1.b.6 |
| 37 | B.3; B.1.a.1; B.4 |
| 38 | A.1.b.2; D |
| 39 | A.2; A.2.a.2 |
| 40 | B.4; A.1.d |
| 41 | a.1.b.2; A.2; D |

[a] See reference no. 25 for key.

Patients' responses were transcribed into a confidential personal computer file immediately after the interview. Responses to single items were classified into appropriate categories (for instance, the seizure experience was classified as only physical or not only physical) and any eloquent or original expressions were taken into consideration. Correlation of response categories to seizure type, frequency and timing was attempted. We underline that correlation, in this context, must be intended according to logical rather than mathematical meaning. Statistical analysis was not suitable for the results we obtained, on account of the qualitative nature of our material.

## RESULTS

### Subjective seizure experience, including possible warnings

In all, 23 patients described their seizure experience. Merely physical sensations were reported in four cases (nos 5, 9, 10 and 19), and one patient (no. 1) had both physical and non-physical symptoms during different seizures. It is interesting to remark that at age 18 the latter recall fits experienced several years before as 'a feeling of discomfort at my stomach', but we found in her patient's record that at age 11 she had told the doctor: 'I feel a cramp at my head, I feel pulled at my left side'. Other fits had been described at age 12 as 'the sight dims, I feel I'm fainting' (we apologize if some patients' locutions seem too 'literary', but we believe that it would not be correct to translate into a foreign slang informal expressions used by Italian children).

Seven patients (nos 2, 7, 11, 24, 27, 33, and 34) always had not only a physical experience of the fit, i.e. the seizure regularly involved perception, orientation, thought, etc. In particular, patient no. 7 said: 'I don't understand anything any more, I don't know where I am, then I feel a little tickle here [she indicated her belly] and headache starts'. Child no. 11 said: 'I feel like a stone, dazed, then I feel the *tremigio* [a word similar to 'trembling' invented by the child], a little monster turning inside me'. Patient no. 24 said: 'I felt myself on another world and heard a high noise in my head, never heard before; I couldn't move myself any more, then I had headache at my forehead'. A partial fit evolving to generalization was described by patient no. 33 as 'I felt my arm was numb, I was losing control and fainting away, but I heard mommy crying'.

As regards the other 11 cases, no. 17 felt unable to control movement, so that refrained space displacement; no. 35, indicating her breast, complained of 'an internal sensation, like when an arm or a leg gets numb, but I feel it inside'. Patient no. 12 had difficulties in controlling speech; no. 37 complained of 'repeating the same work twice against my will'; no. 38 reported a 'memory gap'. No. 40 'saw non-existent things around, or things different from normal or displaced' or experienced transient discomfort comparable to an unpleasant recollection; no. 41 felt 'stopping at once while I did something', or experienced eye paresthesias associated with an out-of-focus view. A time gap was reported by patient no. 34, who felt himself 'strange' during the fit. A headache on waking revealed the occurrence of nocturnal seizures to patient no. 39, during diurnal fits she experienced 'emptiness around' and was unable to contact people. Some patients displayed seizure localization: at breast level (nos 17 and 35), head (no. 32), head and stomach (no. 7).

Warnings were described by patient nos 13 ('white stars') and 30 ('twinkling lights'). Vague warnings were reported by patient nos 12, 17, 25, 26 and 35. Patient no. 21 remembered only warnings ('discomfort and trouble at my head and belly'). Patient no. 9 considered the first motor symptoms as warnings: 'I feel the fit is coming, because my eye starts trembling: then my lip twists and my face starts trembling'. In case 25

the mother felt able to detect imperceptible warnings not felt by the child; in case 11 the mother affirmed she could feel her child's vegetative symptoms, although the fits had no visible features.

Thus children's narration enriched our knowledge of seizure symptoms, and sometimes a child's description differed from the parents'. Patient no. 6 did not remember her fits, although she had always presented partial seizures, according to her parents. On the whole, if we classify seizure symptoms as 'positive' (i.e. transient involuntary activity of neuropsychic functions) or 'negative' (i.e. transient impairment of neuropsychic function), the former were reported in 11 cases (nos 1, 2, 5, 7, 9, 10, 11, 12, 19, 24, 30 and 32), and the latter in 12 (nos 1, 2, 7, 11, 12, 17, 21, 24, 33, 34, 35, 36 and 37), while six patients experienced both.

In conclusion, most of the patients could report the symptoms of sometimes distant or sporadic partial seizures. It is remarkable that five patients affected only by partial seizures (nos 14, 15, 22, 28 and 29) did not describe their experience. All these patients had only suffered from sporadic fits, and, among them, patient nos 14, 15 and 28 had been seizure-free for more than 1 year, while no. 29 had been seizure-free for more than 6 months. Four patients suffering from partial seizures (nos 1, 3, 6, and 8) did not report their experiences. They had been free from evident partial seizures for more than 1 year, but no. 8 had presented dubious fits during the last year (his father suspected the occurrence of imperceptible facial jerks).

Among patients suffering only from generalized seizures (nos 4, 13, 18, 20, 23, 25, 26, 31 and 37), two reported warnings (case nos 25 and 26), and one (no. 37) was able to describe her absence.

## Fit circumstances and suspected precipitants

In 11 cases children associated seizure occurrence with particular circumstances: patient no. 2 related seizures to a release of emotional strain, when she 'abandoned' herself 'to sleep'. Cases nos 3, 26 and 35 related fits to strong emotions, no. 9 to darkness and 'bad dreams', no. 11 to high level noise or to his mother's expectation, nos 30, 32, 35 and 41 to light stimuli or variations, no. 40 to worries and menstruation and no. 10 assumed she had fits when she was rebuked by her elder sister.

## Spontaneously developed methods of seizure inhibition, if applied

Five patients (nos 1, 11, 26, 30 and 41) had developed methods to inhibit or abort seizures: no. 1 by 'shaking her head', massaging the affected hand and concentrating herself; no. 11 by holding strongly onto a table or distracting themselves and walking; no. 26 by concentrating herself (she had observed that concentration reduces seizure occurrence); no. 30 by distracting themselves during the fit (taking a drink); no. 41 by turning their gaze away from a flashing light and staring at an object.

## Feelings associated with seizure occurrence

The following patients reported feelings and emotions during the fit: nos 27, 32, 35, 40 and 41 reported 'discomfort' or 'trouble'. Patient no. 35, who had related fits to environmental light, discerned she had conceived this causal connection 'to exorcize the fit' and its unpredictable occurrence. No. 30 reported he had been 'upset' by a publicly witnessed fit (publicly witnessed fits had been experienced also by patient nos 1, 11 and 26). No. 37 was 'tired' when she underwent another seizure in spite of therapy; no. 38 felt 'strange, such as sleepy'; no. 39 reported fear, anxiety and confusion, she felt 'strange'. On the other hand, patient nos 7 and 36 said that they 'amused' themselves during the fit. No. 35 could predict the occurrence of the fit by warnings, 'but I don't know whether it's better or worse to recognize it'.

## Impact of fits on daily living and adjustment to epileptic condition

Information about this topic was obtained in 25 cases. Ten patients (nos 4, 9, 12, 19, 22, 29, 34, 35, 39 and 41) communicated their fear (they feared the seizure in itself, its outcome, relapse, etc.); in particular, no. 34 said 'I feared I couldn't wake up any more'. Two patients (nos 11 and 16) reported anxious expectation of the fit and one (no. 38) worried that his condition would be hopeless, as a previous attempt at drug withdrawal had failed. Patient nos 32 and 35 reported generic discomfort; nos 27 and 40 were mostly troubled by the unexpected occurrence of seizures; no. 5 was not particularly worried; no. 10 complained only of a lack of movement control during the fit; no. 17 was 'bothered' rather than frightened. Three patients (nos 8, 10 and 27) complained of feeling diverse from their peers; three (nos 4, 22 and 27) had poor self-esteem; three (nos 3, 16 and 19) were ashamed owing to their condition (although patient no. 19 did not feel himself 'diverse' from peers). One patient (no. 8) complained angrily about his parents' continuous control; another (no. 27) said that 'no one can understand me, my life is marked by my father and by epilepsy'. One (no. 1) who had described herself as 'unlucky', 'unhappy', 'handicapped', spoke about her disease as a past condition after 7 months of remission: 'I grew up, only children have these com-

plexes'. Patient no. 2, who related seizures to a release of emotional strain, felt herself forced into continuous self-control. A girl (no. 3) reported a marked amelioration of her attitude toward life following seizure remission. Another girl (no. 37) did not show any apparent anxiety related to her condition, and had a disordered life. Two patients (nos 16 and 26) considered their condition as a sign of distinction; moreover, no. 16 prided himself on having overcome the dangerous event of the fit. Finally, three patients (nos 3, 13 and 29) confessed to taking advantage of their disease. Although our interviews did not foresee investigating patients' opinions about the nature of epilepsy, one patient (no. 4) spontaneously related her disease to a brain disorder: 'I'm sick, I have a hole in my brain, I'm unable to do anything'.

Further information on patients' daily lives was obtained by observing his or her disposition during the interview. Patient no. 27 looked passive; no. 23 apathetic and unwilling; no. 33 ambivalent; nos 21, 23 and 35 depressed; nos 3 and 25 contrary. Nos 8 and 15 appeared distant from the problem; no. 26 exhibited superiority and no. 31 tried to minimize the problem. Nos 27, 33 and 37 were reluctant; no. 36 looked self-confident; nos 7 and 24 behaved like little adults. The remaining patients seemed co-operative and showed no particular disposition.

### Teachers' and peers' reactions to the patient's condition, as perceived by the subject

Two patients (nos 4 and 5) felt discriminated against by teachers and/or peers. Patient no. 33 felt uneasy with their peers, while nos 21 and 25 were anxious in the same situation; two patients (nos 27 and 35) defined themselves as secluded. Three (nos 3, 11 and 14) complained only of school underachievement. In four cases (nos 6, 17, 31 and 34) relationships with peers were reported as normal.

### Opinions on drug therapy

Answers to this topic were obtained in 13 cases. Patient nos 4 and 27 were tired of drugs which they considered useless; nos 6, 15 and 21 were tired of them because drugs represent a sign and evidence of the disease. Poor compliance was honestly confessed in these following cases: patient nos 3 and 15 refused to be forced by mothers and considered drugs 'a dope'; patient no. 26 indicated their parents as being responsible. In case no. 18 it was not clear whether drugs were taken regularly or not. Poor compliance of an adolescent patient was reported by the parents in case no. 28. Poor compliance of patient no. 38 was reported by her mother, but the patient denied it.

On the other hand, patient nos 1, 17 and 19 declared themselves reassured by drug treatment against seizure relapse.

### Opinions on doctors

In most cases, verbalization and atmosphere during conversation revealed good doctor–patient relationships, but in six cases some previous or actual problems emerged. In case no. 31 both mother and patient had decided to change hospital owing to the doctor's lack of time for discussion. In case no. 9 the mother complained that the previous doctor underestimated the severity of disease in spite of persistent drug-refractory fits. The adolescent patient no. 37 tried to provoke the doctor (while parents showed confidence). Patient no. 27 expressed distrust; in case no. 9 distrust was disclosed by the parents; in the same way the parents of case no. 26 affirmed that doctors 'make experiments on patients', while the daughter declared herself 'annoyed' by controls.

### Correlation with social background and school achievement

No strict correlation was found between social background, school achievement and characteristics of patients' responses; it could be said that patients classified into category 4 and having good school achievement tended to give more responses and to examine more arguments and problems. Low social class and poor school achievement were compatible with verbalization about epileptic experience and condition; anyway it should be stressed that among our patients no-one had a very low social condition.

## DISCUSSION

We found in the literature an article[14] whose author concluded that 42% children did not retain a clear memory of their seizures: this percentage was confirmed by our study, as 56% of our patients reported their fits. We would stress that children aged 7 years and older could describe their experience of the seizure and talk about their condition (one child aged 6 years did not recollect his fits but could describe his condition). In our enquiry, all children and adolescents who described their experiences had suffered from partial seizures, except in one case (no. 37) whose objective symptoms and interictal EEG suggested a diagnosis of generalized seizure. On the other hand, our patients did remember their partial seizures, but often forgot fits after 6–12 months.

As we found no investigation on seizure perception performed in children and adolescents by direct interview, it would be difficult to compare the other issues of our investigation. Summarizing the results, we can say that in all cases the seizure was easily identified and considered as such, and not as a pathology of the involved organ or limb. The head was never mentioned as the site or the starting-point of the fit. In only one patient (affected with partial fits) had the seizure been experienced in terms of a time gap: this never happened in children having generalized fits, although we should expect that in these cases a time gap could represent the only trace of the event. It is interesting that merely physical symptoms were reported by a minority of cases (9.7%), while the majority of patients reported psychic involvement during the attack. As mentioned previously, we cannot compare these results, however, we presume that if direct dialogue with the child is performed, many fits first classified as partial motor should be reclassified.

Seizure experiences were various, dissimilar, and sometimes unusual or singular. Motor fits did not offer any difficulty to description, and were usually reported in objective terms (such as 'my eye starts trembling' and similar). Non-physical and non-motor experiences often required cogitation and encouragement before being described. Subtle, uncommon figures of speech were employed by some children to describe unfamiliar sensations related to the fit. Other children had serious difficulty finding the appropriate words; often they used the adjective 'strange' to avoid the problem; more often they resorted to a simile or they used odd names. They reported seizures as 'feelings', 'sensations' and similar, in subjective rather than objective terms; the word 'seizure' was never employed spontaneously by these patients. Older patients often reported a loss of control.

Emotions were often regarded as seizure precipitants (7/11 cases vs. 4/11 who had discriminated light stimuli); a similar tendency of parents to find an association between stress and seizures in children was reported in a previous research[20]. In all, 11/23 patients (47.8%) had identified precipitating factors, while in a study performed by Cull *et al*[21] on young people with an average age of 17.2 years, a percentage of 63.3% was reported. The same study reported 50.1% of cases (5/23 patients). The disparity of results between the two studies is not explained by the difference in age, as patients who had identified precipitants in our population had an average age of 12.8 years, which does not differ significantly from the average age of all our patients. We believe that the difference depends on the employed methods, as Cull *et al* had used direct questions about seizure precipitants and fit control, while our interview focused on seizure experience. This means that in absence of direct questions such details can escape, even if no time limits are imposed.

While the verbal description of uncommon experience associated with seizure disclosed the creative faculties of our patients, we obtained a prevalent impression that they were only just motivated and capable of focusing on the discomfort related to their condition and rationalizing it. Our patients seemed to suffer from generic trouble rather than from specific concern about their condition, and this impression was confirmed reviewing the responses obtained during interviews. As patients usually wished for a much more co-participatory approach[7,22], and previous studies[14] showed that children often complain that their doctor had never explained about epilepsy, we believed that the context we had set up for conversation should offer them the opportunity to ask questions not asked before, but this did not happen. We received the general impression that the observed patients were not very dynamic, except some adolescents who showed less apathy. Three female adolescents (nos 1, 2 and 27) had inserted their thoughts about seizures into reflections involving the existential condition: for patient no. 2, self-control of fits had become a lifestyle; according to no. 27, both epilepsy and bad relations with her father had contributed to mark her life; patient no. 1 did not consider epilepsy as a primary cause of discomfort, but speculated that her adverse fate included being affected by epilepsy.

It should be very difficult to give an appropriate value to the above reported perceptions, and we do not know whether this psychic trait should be in some way related to epilepsy itself. At present we can only affirm that the narration of the fit rarely involved a marked emotional reaction; so we agree with Layborn and Hill[23] who stated that the negative picture of seizure experience and epileptic condition sometimes presented in the 'expert' literature should be reappraised in comparison with the more positive one resulting from first-hand studies of families' views. Moreover, we found a poor correlation between patients' discomfort and objective severity of seizures (in terms of type, duration and frequency) which confirms a previous study[24] according to which the impact of epilepsy on patient's life may be quite independent from severity and prognosis of the disease. We would stress that the present study involved a selected population, in which epilepsy was the only affection; so we believe that our results allow us to affirm that the image of the disease is quite independent from the experience of the seizure. It seems probable that the image depends to a high degree on the one developed by parents and reflected towards the child, in fact, parents showed more concerned about seizures than their sons or daughters.

In comparison with the study by Wilde and Haslam[15], our study showed the same concerns about the epileptic condition: anxiety, frustration, rage,

worry, seclusion, poor self-esteem, etc.; in any case we did not find as many problems regarding society and the opposite sex. This disparity probably depends on the fact that our methodology was more oriented towards patients' internal worlds; for the same reason, differently from Wilde and Haslam[15], we found that some patients felt themselves to be diverse and alone rather than secluded by their peers. The school was also felt in our experience as the main place of discrimination; prejudice and discrimination in school, when reported by our population, were attributed both to teachers and peers. Having to take medication regularly represented a burden at any age and non-compliance was acknowledged in six cases. We had the impression that little children were poorly motivated to take drugs owing to an insufficient understanding of the need for them, while during adolescence opposition to therapy tended to assume the features of a challenge addressed towards parents. We would stress that in such cases informal advice was easily given to patients and parents during the interview, so that the interview could shift unobtrusively towards a psychotherapeutic session, if the examiner judged that such an approach would fit patient's needs.

## CONCLUSIONS

We believe that the method employed enabled us to enrich our knowledge about seizure experience in childhood and adolescence epilepsy. Listening to children and adolescents expressing their experiences and feelings may be helpful for both clinicians and patients. Physicians can receive direct and new information about seizures, especially about those characterized only by subjective symptoms, and are allowed contact with the patient's internal world. In such a way non-compliance and other similar problems are disclosed more easily. Patients may express emotional maladjustment and may find psychological support in the same context, but above all they can directly converse with their physician: this seems particularly important for adolescents, as a preparation to direct interchanges which will characterize adult relationships with their doctor.

## REFERENCES


1. Mizrahi, E. Electroencephalographic-video monitoring in neonates, infants, and children. *Journal of Child Neurology* 1994; **9** (Suppl. 1): 46–56.
2. Chen, L. S., Mitchell, W. G., Horton, E. J. and Snead, O. C. III. Clinical utility of video-EEG monitoring. *Pediatric Neurology* 1995; **12**: 220–224.
3. Foley, C. M., Legido, A., Miles, D. K. and Grover, W. D. Diagnostic value of pediatric outpatient video-EEG. *Pediatric Neurology* 1995; **12**: 120–124.
4. Donat, J. F. Long-term EEG monitoring for difficult seizure problems. *Journal of Child Neurology* 1994; **9** (Suppl. 1): 57–63.
5. Matricardi, M., Brinciotti, M., Paolella, A. *et al.* Neuropsychological correlates of subclinical paraxysmal EEG activity in children with epilepsy. 2: quantitative aspects of generalized discharges. *Functional Neurology* 1989; **4**: 241–246.
6. Matricardi, M. and Brinciotti, M. Management of subclinical spike-wave complexes in seizure-free epileptic children. *Epilepsia* 1993; **31** (Suppl. 4): 23.
7. Chappel, B. Epilepsy: patients views on their condition and treatment. *Epilepsia* 1992; **1/2**: 103–109.
8. Mitchell, W. G., Scheier, L. M. and Baker, S. A. Psychosocial, behavioral, and medical outcomes in children with epilepsy: a developmental risk factor model using longitudinal data. *Pediatrics* 1994; **94**: 471–477.
9. Viberg, M., Blennow, G. and Polski, B. Epilepsy in adolescents: implication for the development of personality. *Epilepsia* 1987; **28**: 542–546.
10. Hoare, P. Does illness foster dependency? A study of epileptic and diabetic children. *Developmental Medicine and Child Neurology* 1984; **26**: 20–24.
11. Matthews, W. S., Barabas, G. and Ferrari, M. Emotional concomitants of children with epilepsy. *Epilepsia* 1982; **23**: 671–681.
12. Mitchell, W. G., Scheier, L. M. and Baker, S. A. Psychosocial, behavioral, and medical outcomes in children with epilepsy: a developmental risk factor model using longitudinal data. *Pediatrics* 1994; **94**: 471–477.
13. Hanai, T. Quality of life in children with epilepsy. *Epilepsia* 1996; **37** (Suppl. 3): 28–32.
14. Brown, S. W. Quality of life—a view from the playground. *Seizure* 1994; **3** (Suppl. A): 11–15.
15. Wilde, M. and Haslam, C. Living with epilepsy: a qualitative study investigating the experiences of young people attending outpatients clinics in Leicester. *Seizure* 1996; **5**: 63–72.
16. Commission on Classification of the International League Against Epilepsy. Proposal for revised classification of epilepsies and epileptic syndromes. *Epilepsia* 1989; **30**: 389–399.
17. Hollingshead, A. B. and Redlich, F. C. *Social Class and Mental Illness*. New York, Wiley, 1958.
18. Sturniolo, M G., Aliberti, N. and Galletti, F. School underachievement in idiopathic epilepsy. *Seizure* 1992; **1** (Suppl. A): P14/26.
19. Sturniolo, M. G. and Galletti, F. Idiopathic epilepsy and school achievement. *Archives of Disease in Childhood* 1994; **70**: 424–428.
20. Verduyn, C. M., Stores, G. and Missen, A. A survey of mothers' impressions of seizure precipitants in children with epilepsy. *Epilepsia* 1988; **29**: 251–255.
21. Cull, C. A., Fowler, M. and Brown, S. Perceived self-control of seizures in young people with epilepsy. *Seizure* 1996; **5**: 131–138.
22. Schneider, J. W. and Conrad, P. Doctors, information, and the control of epilepsy: a patients' perspective. In: *Psychopathology in Epilepsy: Social Dimensions* (Eds S. Whitman and B. P. Hermann). Oxford, Oxford University Press, 1986: pp. 68–89.
23. Laybourn, A., Hill, M. Children with epilepsy and their families: needs and services. *Child Care and Health Development* 1994; **20**: 1–14.
24. Sturniolo, M. G., Giannotti, F., Maffei, S. *et al.* Benign epilepsy and depression in childhood and adolescence. *Epilepsia* 1991; **32** (Suppl. 1): 42.
25. Commission on Classification of the International League Against Epilepsy. Proposal for revised classification of epileptic seizures. *Epilepsia* 1981; **22**: 489–501.