Psychosocial issues for children with epilepsy

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EPILEPSY is a medical disorder, but for centuries it has also been a social disease. Its medical aspects have been defined in terms of cell membrane instability, excessive firing of neurons, and imbalances of neurotransmitters, but their physiologic essence remains elusive. Its paroxysmal quality led Lennox to describe it as a recurrent tidal wave rather than a continuously rough sea. It is this recurring, overwhelming quality and the periodic loss of control over that which inherently makes us human (the brain) that led ancient peoples as well as our more recent ancestors to equate epilepsy with demonic possession. Children with epilepsy are still battling the remnants of this mythology. They must live lives altered by the intermittent disruption of seizures, altered by therapeutic manipulations, and potentially altered by associated disabilities.

The perception that people with epilepsy have psychosocial problems and difficulties in adaptation is a mixture of myth and reality. Many have difficulty succeeding in school or behaving appropriately, in obtaining suitable employment, in forming and sustaining relationships. But many appear to have no problems and are living full and productive lives. Since most epilepsy begins in childhood, it is reasonable to assume that the underpinnings of these difficulties and these successes also lie in childhood. Successful maturation involves adaptation; the child with epilepsy must adapt to seizures as an element of his biology. This requires the proper tools and understanding. The practitioner who cares for a child with epilepsy must understand its potential psychosocial impact. Each child and family will be different. Many people will be involved with the child, and this interaction must be understood. Many children will have a few seizures, will respond well to medication, and live perfectly normal undisturbed lives; in fact, many children will simply outgrow epilepsy. But unless the physician is sensitive to the possible development of problems, the child who is having difficulties may go unrecognized, and these problems may worsen and be harder to manage. This paper will explore many of the psychosocial issues that have been reported in children with epilepsy. It will explore these problems from the perspectives of the child, and of those who interact with her; it will also address which of these factors can be manipulated in order to help the child achieve a more normal lifestyle.

HOW THE CHILD PERCEIVES HERSELF—HOW SHE RESPONDS

Very little information exists that allows us to look at how a child's perception of herself changes after a seizure. To obtain a more complete picture, we need an understanding of a child's image of herself before seizures started as well as after they have occurred. We presume that this image and possible change in image are dependent on many factors, including the developmental status of the child, the nature of the seizure, sequelae (if any) to the seizure, and how the child and the seizure have been treated by family and friends.

The very young child might not even notice the missing moments of absence seizures; a somewhat older child might realize that she was missing some part of a television program; the school-age child might notice that she was missing instructions from a teacher; and the adolescent might be aware that she was not following a very important telephone conversation. The very young child might be unaware of a tonic-clonic seizure but remember the fright on a parent's

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face; the older child might remember feeling a bit strange and waking to find herself on the floor; the adolescent might also be more aware of this, the embarrassment of incontinence, and the postictal confusion. We presume that children, as well, have difficulty grasping why at one moment they are perfectly fine and then seem to miss something or awaken confused, wet, sore, on the floor or in the hospital. We might suppose that this loss of control would pose problems in a child's search for achievement of independence, since she might wonder if she can depend on her body to do what she wants from moment to moment. There is some evidence that adolescents with grand mal (tonic-clonic) epilepsy have trouble understanding and adapting to such a phenomenon as unpredictably recurring seizures.[1] The study of Hodgman et al[1] identified some very interesting issues. The better the seizure control, the less the adolescent had discussed his condition, or wanted to. Also, those patients neurologically most normal on examination were most negative about their social adjustment and the effect of the disorder on their families. In addition, there is some evidence that adolescents with seizures that have been witnessed in public are better able to adapt to them than adolescents who still fear the day when seizures will occur outside the home and disrupt some activity. It appears that the reality is easier to cope with than the apprehension, and that visibility of the "stigma" may make it easier to deal with.

In addition to the fear of interruption, some data suggest that adolescents frequently are poorly informed about epilepsy, and that this correlates with poorer psychosocial adaptation.[2] In a study of 40 adolescents with seizures who had been exposed to extensive treatment and education, misconceptions were frequent. Almost two thirds still believed they could swallow their tongues during a seizure. One third believed that they could die during a seizure, and 12% believed it was contagious. This misinformation was significantly correlated with dysfunction in adaptation as measured by the Diagnostic Inventory for Children and Adolescents.

In a small study of three groups of children (15 with epilepsy, 15 with diabetes, and 25 with no known health problems), Ferrari and coworkers[3] found that children with epilepsy have lower self-esteem, higher levels of anxiety, and more often perceive events in their lives as caused by unknown sources of control than do healthy or diabetic youngsters. The authors also found that phenobarbital therapy was related to significantly worse scores of self-concept than other medications.

The child frequently reflects the response of her parents. If the parents appear frightened, she will be; she may not even understand why her parents are frightened. If the parents respond by becoming overprotective, the child may either rebel or become dependent. The child may also reflect anxiety by changes in eating, sleeping, or school performance. If the child and parents have a good understanding of the fact that she is normal almost all the time, and that seizures are only brief interlopers, she may be able to get on with the process of becoming an independent and competent person.

The practitioner walks a fine line in exploring these issues with the child. It is important to know what the child has experienced, how she felt, how others reacted, and what they have told her about the seizure. These elements can then be explained and placed in perspective, and it is often necessary to be very concrete. If a child reports that she doesn't know what happens during a seizure, it is probably helpful for the doctor to give an unemotional description. If the child has perceived fear it is important to discuss this, perhaps in the context of saying, "Your mother was worried because it looked like you weren't breathing, but we doctors know that most of the time you were breathing and that even if you stopped for a moment it wouldn't matter; it would be like when you're swimming under water and holding your breath. You'd take that next breath and everything would be fine." Physicians are vital to demystifying seizures for children and parents.

HOW PARENTS PERCEIVE THE CHILD—HOW THEY TREAT HER

When parents first see or learn that their child has epilepsy, they presumably react to both the epilepsy and the child. Epilepsy frightens most people. Parents often have distorted information and worry about a global deterioration and brain damage.[4] They immediately presume a great handicap and extensive limitations. They perceive a stigma—for their child and for themselves. They also must realize, however, that they live with the recurrent tidal wave, not on the rough sea. This is an important analogy since between seizures the sea is calm; their child is normal.

Parents must separate their perception of epilepsy from their perception of the child. It appears that parents of children with epilepsy go through many of the same processes as parents of other handicapped children, many of the same processes, in fact, that people go through in dealing with death. Initially there is the feeling of grief. Their normal child seems lost to them. The life they had envisioned for the child is lost. They wonder if their child will die from the seizures. They wonder how much their child will be able to learn. Will their child ever be able to go to college, find a job, marry, or have children? Parents are saddened; they frequently feel a great deal of guilt, fearing that they may have done something wrong that caused the seizures.

Frequently parents then become angry. They are angry at the unknown—the cause, the future. Often they are angry at health care providers and at the bureaucracy of schools. Husbands and wives may be angry at each other and view each other as unsupportive and lacking in understanding. And they may be angry at the child—angry that the child has disrupted a lifestyle, and angry that the child may require additional care.

The next stage, it is hoped, will be acceptance. Parents need to accept epilepsy for what it is for their child. This may depend on their own earlier experiences with seizures. Obviously, much is dependent on the nature and severity of the seizures. Much also depends on whether there are any additional handicaps. The physician may be crucial in helping parents move to this stage. In most circumstances the physician should be able to communicate an optimism about seizures—that they are not linked to brain damage, that they are very likely to be controlled by medication, and that many kinds of seizure disorders are actually outgrown. It is this sense of being able to control the situation that must be shared and given. The physician must also be able to communicate an understanding of the parents' concern and give guidance as to how to deal with it and channel it appropriately.

It is the ability of parents to move to this stage that greatly shapes how they will treat their child with epilepsy. Overprotection probably develops out of fear and anxiety. An important index of whether parents are overprotective is the extent to which they are able to discuss epilepsy openly with the child. If they are overprotective, they will not allow the child to take the risks necessary to become an independent person.[5] They will presume limitations, and the child will lack confidence. Another aspect of overprotection is overindulgence, which may also be related to feelings of guilt. If the parents are angry, the child will feel the impact. The parents' energy will be dissipated; they will be fighting, not nurturing. It is acceptance, an honest realization of what has happened and how to deal with it, which enables the family to deal with what *is* wrong, not with what is imagined to be wrong.

Obviously there are some children with epilepsy whose seizures cannot be controlled, who experience side effects from medications, who are intellectually or physically limited. Parents of these children must deal with a more pervasive problem. They, too, must come to acceptance and the ability to work from where they are, not from where they would like to be.

Parents are critical to the well-being of any child. This is magnified for the child with epilepsy. If the child perceives fear or rejection in this relationship, she will expect it from others.

HOW SIBLINGS PERCEIVE HER—HOW THEY ACT TOWARD HER

Sibling love, as well as sibling rivalry, is natural. Dependent again on age and developmental stage, there are many possible reactions to a brother or sister's epilepsy. Sometimes the sibling worries, thinking that the little sister has seizures because of the time she got knocked down when they were playing. A young child may simply be jealous of the amount of time and energy sometimes expended on the child with epilepsy. Siblings may have been drawn up into the overprotection cycle, "Don't play so rough, you might bring on a seizure," or "Don't upset her, give her the toy, you might cause a seizure." They may be old enough to realize that some diseases are communicable and be fearful that they may get epilepsy as well. They may also feel a burden of responsibility when asked to watch the child who has epilepsy, or when they are protecting her from the callous remarks of other children. There is some evidence that epilepsy has less impact on the relationship if it begins when the children are older (over 6) and if the child with epilepsy is otherwise normal.[6]

HOW FRIENDS PERCEIVE HER—HOW THEY ACT TOWARD HER

It is the responsibility of the child or the parents to tell friends about the seizures. If friends understand the nature of the problem, they are less likely to perceive the child as simply strange. Friends need to understand that if a child is staring off in an absence seizure, it is not an intentional disregard for what the friends are saying. They need to understand that when a child is having a partial complex seizure and wandering aimlessly about, she has not taken drugs or "gone crazy." Friends of such a child having a seizure can be of great help by preventing her from wandering into a harmful situation. They need to understand that the child will not die during a tonic-clonic seizure, that they should not panic, but should be ready to reorient their friend when it is over, and get on with whatever they were doing together.

HOW TEACHERS PERCEIVE HER—HOW THEY RESPOND

Parents frequently wonder whether to tell a teacher about a child's seizures for fear of altering the teacher's perception of the child. This ought not to be a dilemma since such information is very important and should be communicated. A teacher who knows what to expect can be prepared to deal with a seizure in the classroom, both in terms of helping the child and in terms of helping her classmates to understand what has happened.

Teachers may be aware of the data indicating that children with epilepsy, in general, may have more difficulties in school. It is important to remember that there are many problems involved in reporting information about people with epilepsy; there are biases, particularly in how such children are identified. Many children who are doing well, who have their seizures controlled, and who are not having problems with medication are never identified to the school system or to clinics that might be involved in studying these psychosocial issues. Were teachers biased by knowing that a child had seizures when they noted increased restlessness, fidgetiness, poorer concentration, greater irritability, and more fighting?[7] In another study, teachers had not viewed the children with epilepsy as more socially visible in their early school years; however, as young adults, they had lower educational achievement than expected and an increase in emotional disturbance.[8] Achievement difficulties have been documented frequently. Sixteen percent of children with epilepsy in the Chicago school system were in special education programs.[9] Holdsworth and Whitmore[10] found that only one third of children with epilepsy in a public school program were making satisfactory progress; and Rutter et al[7] showed that almost 20% were reading two or more years behind their grade placement. Again we must ask whether there were many children never identified by the researchers as having seizures because they were doing so well.

Teacher cooperation and expertise are essential. Teachers can be keen observers of whether a child is continuing to experience seizures, whether there are side effects from the medications, and whether a child is having difficulty learning. In addition, they can design appropriate educational strategies to help prevent academic failure. Several studies have indicated that success in school is more predictive of adjustment than other factors.

HOW OTHER CONCERNED INDIVIDUALS PERCEIVE HER—HOW THEY ACT

Many other individuals interact with a child who has epilepsy; they, too, help fashion that child's psychosocial adjustment. It may be difficult for the child's parents to change the perceptions of the grandparents, who may be operating under an old mythology. Frequently the parent must exert greater effort to convince relatives that normalcy must be fostered, that the child must not be allowed to use epilepsy to manipulate, and that overprotection is harmful.

Babysitters should be aware of what a child's seizures encompass. They should know what to do in case of a seizure. They may be fearful and dread the perceived additional responsibility, but if the child is pleasant, their early fear can usually be overcome through experience.

Most children with epilepsy want to participate in a wide range of activities. These should be encouraged. How this is handled depends upon the type and frequency of seizures and what the child wants to do. Appropriate persons should understand about the child's epilepsy and what to do if a seizure occurs. A swimming coach and a buddy should be knowledgeable if a seizure occurs in the pool. The gymnastic coach should make reasonable decisions about which activities are permitted and have a spotter available, but these are safety precautions that all children should experience. A child with seizures needs to understand that he is really not so different.

The world in which a child with epilepsy lives *should* be a large one. Many people will need to be educated. If the child and his family are open and without anxiety, they can explain epilepsy and what should be done, thereby increasing the number of people who have been desensitized and exposed to those who are living full lives with epilepsy.

HOW THE MEDICAL COMMUNITY PERCEIVES THE CHILD WITH EPILEPSY

Our medical literature has attempted to describe the psychosocial problems of children with epilepsy. Again we must realize the biases of ascertainment. Little epidemiologically sound information is actually available. We study the children who have already been identified as having problems, or children treated in seizure clinics—children whose seizures are probably more difficult to control.

There is a vast heterogeneity of function seen in children with epilepsy. Sillanpää[11] has reported that almost 40% had a significant degree of retardation, although half had normal intelligence. Many researchers would stress that decreased intelligence is associated with other organic factors, not simply with the seizures themselves. Rodin[12] has reported the association between organic brain damage and lowered intelligence, and recently showed that both recurrent (or uncontrolled) seizures and phenobarbital therapy were associated with impaired intellectual performance.[13] Ellenberg and colleagues[14] also stressed this concept of underlying brain damage in their recent analysis of 98 children with seizures who were compared with siblings and carefully matched controls. Mental retardation (IQ < 70) was more common among children with seizures, but this was accounted for by children who were known to have had neurologic abnormalities before the first seizure, implying that it was the underlying "brain injury" that was responsible for the dysfunction. These authors have also documented that recurrent seizures in this population, followed until age 7, were not related to IQ. Other studies have reported decreasing function over time,[11,13,15] but much of this may be related to anticonvulsant effect.

Physicians are becoming increasingly aware of the potential impact of anticonvulsant medication upon learning and behavior.[16,17] Studies have implicated the drugs in memory and learning problems,[18,19] but few have been well controlled from the point of view of seizure frequency, therapeutic levels, and patient variability. Vining and coworkers[20] controlled for this, using a double-blind, counterbalanced crossover design comparing phenobarbital with sodium valproate in children with epilepsy. Each child was treated with both drugs for 6 months. Levels were maintained within the therapeutic range, and seizure control was equivalent in both arms of the study. While taking phenobarbital, children had lower performance and full-scale IQs, as well as difficulties with paired associate tasks and other areas requiring symbol manipulation. They did not seem to have problems concentrating or performing other tasks that required rote responses (continuous performance reaction tasks), and they were not apparently sedated. In addition, behavior measured by blinded parental response to questionnaires was significantly worse in a number of areas while the child was on phenobarbital.

Because it is often difficult to quantitate and assess behavior problems, studies reporting on the frequency of such problems in children with epilepsy are quite variable. From 10% to over half the children are reported to have behavioral problems or personality disorders.[21–23] Again we face the biases of ascertainment. Hyperkinesis and poor academic achievement have been reported by Ounsted et al.[24] The study by Rutter et al[7] on the Isle of Wight found that more than 30% had a psychiatric disorder, compared with 6.8% in the general population. Those who had complicated epilepsy were even more likely to have a psychiatric disorder (58.3%); but we must understand how "psychiatric disorder" was defined: as an abnormality of behavior, emotions, or relationships which was sufficiently marked and sufficiently prolonged to cause a handicap to the child and/or distress to the family and community, and which was continuing up to the time of assessment. This is a very open-ended definition, and lacks objective clarification. In attempting to identify causes for psychiatric disturbance, Rutter and colleagues found that it did not correlate with frequent seizures, age at onset of the seizure disorder, visibility of the handicap, or social prejudice. There did appear to be a correlation with lower IQs, psychomotor (partial complex) seizures, demonstrable brain lesions, and malaise in the mothers of children with epilepsy.

A longitudinal British study found that at age 26, 18% of those with epilepsy had been in "psychiatric" treatment for more than one year *v* 6.8% of controls.[8]

A series of very interesting studies by Hoare[25–27] compares three groups of children: children with newly diagnosed epilepsy *v* those with chronic epilepsy, children with newly diagnosed diabetes *v* children with chronic diabetes, and controls—tabulated by age and sex, and identified in their schools. Children with epilepsy did have a higher rate of psychiatric disturbance (again using what appear to be the very broad-ranging criteria of the Rutter scales), but there was no significant difference in rate between newly diagnosed and chronic epilepsy (48% *v* 45%), implying that there may be a proportion of children with epilepsy who are disturbed at the onset of the illness and that this may be

TABLE 1
THE PHYSICIAN'S ROLE IN PREVENTING PSYCHOSOCIAL PROBLEMS

Diagnose correctly:	explain what epilepsy is, what not to fear
Individualize choice of medication:	monitor its full impact
Be—or find:	an outlet for parents' grief, guilt, anxiety
Counsel:	on overprotection, how to deal with others
Monitor the child:	maturation, relationships, emotions, school
Refer for additional help:	to EFA, local groups, for evaluation, counseling

related to the actual brain dysfunction. Partial complex seizures, treatment with two or more drugs, and increased frequency of seizures were associated with increased disturbance. There are many problems in interpreting this research, in particular a paucity of description as to the nature of the seizure disorders, the frequency of seizures, and even how long the children with newly diagnosed epilepsy may have been having seizures prior to diagnosis.

Hoare also looked at the impact of the disorder on the family. Siblings of children in the chronic epilepsy group were more disturbed than the siblings of children whose epilepsy had been newly diagnosed. Children with epilepsy, both newly diagnosed and chronic, were more dependent than either the controls or children with diabetes. The author points out a relationship between dependency and psychiatric disturbance.

The role of medication in influencing behavior is not fully established, but is increasingly recognized.[16,17,19,20] Brent and coworkers have recently stressed the relationship of phenobarbital therapy to major depressive disorder and suicidal ideation, especially where there is a personal or family history of depression.[28,29]

Physicians, we hope, are aware of this information as they treat a child with epilepsy. It is useful to them as a mechanism for understanding the breadth of problems a child may or may not experience. It should shape their management of the total child, which is outlined in *Table 1*.

WHAT FACTORS CAN BE MANIPULATED TO IMPROVE PSYCHOSOCIAL ADJUSTMENT?

Both the child and the family must understand epilepsy. Greater effort must be expended by the physician or the person designated to insure that the family truly understands what epilepsy is, what may or may not have caused it, what is involved in therapy, what restrictions are necessary, and what lies ahead. Material must be individualized and relevant. It is reasonable to give a family literature, but it should be discussed in the context of their child and their family. Physicians must be comfortable in dealing with these matters, or they need to find someone who will work with them to accomplish this.

Families often find it helpful to join with others and share concerns. The Epilepsy Foundation of America (EFA) and its affiliates provide a variety of services. An excellent source for additional information is the Information and Referral Service or the National Epilepsy Library and Resource Center run by the EFA, which can be reached through a toll-free number, 800-EFA-1000. Their address is 4351 Garden City Drive, Suite 406, Landover, MD 20785.

The physician will set the course but must monitor carefully what is happening. This goes well beyond simply ascertaining if seizures have been controlled or if there are changes in any of the blood tests. Baseline and follow-up psychological testing may be helpful in understanding a child's resources and in knowing if there has been any deterioration which might be related to ongoing neurologic problems, the medication, or psychological problems such as anxiety or depression. Several scales are now becoming available that allow us to monitor behavior and psychosocial adaptation routinely in the clinical setting.

CONCLUSION

Although we stress the potential for normalcy to both child and family, we must realize that there are hurdles to be overcome. Seizures are disruptive at best and frightening under some circumstances. Successful therapy involves constant medication even when there is no apparent evidence of malfunction, and medication may have side effects. Compliance may become an issue. Cognitive, behavioral, and psychosocial dysfunction must be dealt with. Medications can be altered, educational strategies can be changed, and psychological therapy can be initiated. If these problems are dealt with early, a child has the potential to mature more successfully and become a more independent and healthy adult.

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