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Pediatrics 1994;94;471

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Psychosocial, Behavioral, and Medical Outcomes in Children With Epilepsy: A Developmental Risk Factor Model Using Longitudinal Data

Wendy G. Mitchell, MD*; Lawrence M. Scheier, PhD†; and Sherryl A. Baker, PhD§

ABSTRACT. *Objective.* We studied factors predicting the risk of adverse long-term psychosocial, behavioral, and medical outcomes in children with epilepsy.

Methods. Children (N = 157, 4.5 to 13 years) were enrolled in a prospective longitudinal study when first seen. Potential subjects were excluded if they were moderately or severely mentally retarded, had motor or sensory handicaps interfering with testing, or did not speak either English or Spanish.

Measures. To develop risk predictors, we collected information regarding the child's medical and seizure history, cognitive functioning, and behavior problems, and family functioning. Children and their families were followed for a minimum of 18 months, then underwent reassessment of medical status, parent's attitudes toward epilepsy, and the child's behavioral and cognitive functioning. Data were analyzed by confirmatory factor analysis to develop baseline factors (Sociocultural Risk, Seizure Risk, and Behavior Problems) and outcome factors (Medical/Seizure Problems, Parent's Negative Attitudes Toward Epilepsy, and Behavior Problems), followed by structural equation modeling to determine across-time causal effects. Eighty-eight subjects completed all baseline and outcome measures.

Results. Among significant across-time effects, Medical Outcome was predicted by Seizure Risk. An increased number of stressful life events predicted better Medical Outcome. Low acculturation increased Parent's Negative Attitudes and was associated with increased Behavior Problems at baseline. Behavior Problems were stable across time. It is interesting that IQ did not affect any of the outcomes, although its effect may have been mediated through other baseline measures.

Conclusions. Seizure history was the best predictor of ongoing medical difficulties, whereas the most important causes of ongoing parental anxiety and negative attitudes toward epilepsy were sociocultural. Variation in medical or attitudinal outcomes was not influenced by either the child's IQ or reported behavioral problems. These findings suggest that to alter attitudes toward epilepsy, programs should be tailored to the sociocultural background of the family. Studies of quality of life of children with epilepsy should include appropriate sociocultural measures. *Pediatrics* 1994;94:471-477; *epilepsy, social*

functioning, acculturation, structural equation modeling, behavior problems, outcome.

ABBREVIATIONS. SEM, structural equation modeling; CHLA, Childrens Hospital Los Angeles; CFA, confirmatory factor analysis; CFI, comparative fit index; *df*, degrees of freedom; LES, Coddington Life Events Scale for Children.

Epilepsy is one of the most common chronic medical problems in childhood. Despite advances in epilepsy diagnosis and treatment, many children with epilepsy function poorly, with an excessive incidence of psychosocial difficulties and behavioral problems.¹⁻⁴ Disability may be related to social stigma, school failure, or emotional problems, rather than to seizures, which may be infrequent or fully controlled. Parental anxiety about the child's condition may contribute to excessive dependency, social disability, and family dysfunction.⁵ Parents may unnecessarily or excessively restrict their epileptic child's activities and may lower their expectations for the child.⁶ Negative family perceptions of the epileptic child may adversely influence psychosocial development.⁷ It has long been recognized that even with normal intelligence in the child, epilepsy increases the chance of school failure.^{3,8} However, we previously reported that indicators of social and economic status were more important than severity, duration, or treatment of seizures in determining academic achievement of children with epilepsy.⁹ Socioeconomic and family status may influence other aspects of the child's functioning as well.

Social disability may be unrelated to the severity and controllability of seizures. For example, Hodgman et al¹⁰ found that good seizure control and normal intelligence were associated with poor self-image, low achievement, and low expectations for the future in adolescents with generalized seizures.

Researchers have attempted to link stress to illness since the introduction of the Life Events Scale by Holmes and Rahe.¹¹ Stressful life events seem to increase health care utilization and psychosomatic and behavioral complaints.¹²⁻¹⁶ However, prospective studies have not supported the idea that stress alone is a strong determinant of chronic illness or poor functioning.¹⁷ The more important effect of stressful life events may be their influence on the family's ability to cope with and their attitudes toward illness.

Cultural background, social power, and family resources may be important determinants of a child's

From the *Neurology Division, Departments of Neurology and Pediatrics, University of Southern California School of Medicine, Childrens Hospital Los Angeles, Los Angeles, CA; †Cornell University Medical Center, Institute for Prevention Research, New York, NY; and §Biometry Division, Department of Preventive Medicine, University of Southern California School of Medicine, Los Angeles, CA.

Received for publication Apr 6, 1993; accepted Feb 25, 1994.

Reprint requests to (W.G.M.) Neurology, Box 82, Childrens Hospital Los Angeles, 4650 Sunset Blvd, Los Angeles, CA 90027.

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medical and behavioral outcome, as well as of family attitudes. Acculturation is not adequately measured by simply assessing ethnicity, race, or national origin. For instance, there are large and important differences between newly arrived and United States-born Hispanic families in terms of their attitudes and behaviors regarding health care.¹⁸ Accordingly, we used several indicators of sociocultural stress, including the child's nativity status and primary language and the mother's education and length of residence in the United States.

In the current study, our goals were to determine which child and family characteristics predict long-term psychosocial and medical outcomes. Most published studies of the psychosocial aspects of epilepsy have been cross-sectional and thus limited their examination of risk factors to contemporaneous associations, rather than across-time causal effects.¹⁹ In addition, most studies have not examined both medical and psychosocial risks in a single comprehensive model. Medical, behavioral, and sociocultural risk factors may interact. For example, ongoing seizures may exacerbate behavior problems or family anxieties, or vice versa. Unless these influences are considered simultaneously, such relations may go undetected.

The current study differs from most previous studies in several important ways. The design is longitudinal, with at least 18 months separating the initial and final assessments. A wide array of potential risk factors and multiple outcomes were included in a single comprehensive model. The data were examined using structural equation modeling (SEM), sometimes called path analysis. The use of SEM enables a researcher to state explicitly and test theoretical assumptions and causal hypotheses. For a more complete discussion of the use of SEM in clinical psychosocial research with children, the reader is referred to a review by Morris et al.²⁰

METHODS

Subjects

Children with epilepsy (43% boys, 57% girls), aged 4.5 to 13 years (median age 7.7 years), were enrolled in the study at the time of their initial contact with the Childrens Hospital Los Angeles (CHLA) Seizure Clinic, regardless of the duration of epilepsy. Subjects with moderate or severe mental retardation or significant motor or sensory handicaps that would interfere with testing were not enrolled. Subjects were also excluded if the child and parent did not speak either English or Spanish. Informed consent was sought at the time of the first clinic visit if the family indicated that they planned to continue to obtain their child's neurologic care at CHLA. Enrollments continued over a period of four years from 1984 through 1988. Subjects were followed for a minimum of 18 months (mean 23.5, range 18 to 30 months), then reevaluated.

The clinic serves a diverse population, which is reflected in the subjects enrolled. Although most families are low-income, ethnic minority residents of inner-city areas, middle- and upper-class subjects were enrolled as well. Forty-five percent of the families identified languages other than English, most commonly Spanish, as the primary language spoken in the home. Korean, Chinese, and Armenian were represented as well. Maternal education also reflects the diversity of the subjects and ranged from no formal education through postgraduate degrees. Immigrant Latin-American parents generally completed fewer than 6 years of formal education.

Baseline Measures

Standardized psychometric tests, questionnaires, and home visits were performed within 1 month of the child's first visit, and information was obtained from medical and school records. In addition to standardized questionnaires, several brief questionnaires were developed to supplement published psychometric instruments. All parent questionnaires were administered in the parent's preferred language by a bilingual research assistant. Mothers were generally the respondent unless the child routinely came to the clinic with another family member. Component variables of each risk and outcome factor are detailed in the Table.

Seizure-Related Risk Factors. Indicators of seizure-related risk included the type(s) of seizure and current and maximum seizure frequency, age at onset, duration of the seizure disorder, prior treatment (successful or unsuccessful), number of medications used in the past, and reasons for previous medication changes. All were determined from information provided by the parent to the examining physician. We hypothesized that children whose seizures began at a young age, who had not responded to treatment, or who had a prior adverse behavioral reaction to medication were more likely to do poorly at outcome.

Developmental/Cognitive Risk Factors. Depending upon age at enrollment and primary language, IQ was measured with either the McCarthy Scale of Childrens Abilities,²¹ the Wechsler Intelligence Scale for Children—Revised,²² or the Spanish version of the latter, the Escala de Inteligencia por Niños Wechsler.²³ The McCarthy General Cognitive Index, the Wechsler Intelligence Scale for Children—Revised, and the Escala de Inteligencia por Niños Wechsler Full Scale IQ, although not identical, are very highly correlated.²¹ As the standard deviations are slightly different, IQ was converted to standardized scores for analysis. Children with intellectual deficits were expected to have poor outcome compared to children with normal cognitive function.

Behavioral Risk Factors. The CHLA Behavior Questionnaire was used to measure the parent's perception of the child's attention span, behavior, and activity level. The Childrens Hospital Behavior Questionnaire, available in both English and Spanish, was developed for use in clinical research at CHLA and was used in a prior study of anticonvulsants.²⁴ We hypothesized that a history of behavior problems, hyperactivity, or attention deficit disorder predicts poor functioning despite adequate seizure control and contributes to inappropriate family responses to the child's epilepsy.

Family Structure and Socioeconomic Risk Factors. Socioeconomic and cultural status was determined by questionnaires assessing parental education, occupation, nativity, length of residence in the United States for immigrants, and primary language. We hypothesized that children with fewer social supports were at higher risk of adverse psychosocial outcome. In addition, we hypothesized that immigrant, non-English-speaking, and minority families would have greater fears, difficulty coping with epilepsy, and the tendency to attribute more of the child's behavioral difficulties to epilepsy.

Stressful Life Events. The Coddington Life Events Scale for Children (LES)²⁵ was used to assess life stresses during the year before enrollment. The LES has available both unweighted (counts of the total number of events) and weighted scoring. Unweighted scores were used because the weights were developed on a demographically different population. We hypothesized that a high LES score was a risk for poor outcome.

Outcome Measures

Outcome was assessed 18 to 30 months after enrollment. The child underwent repeat psychometric testing, the parent was interviewed, and medical records were reviewed. The outcome profile was divided into three areas: medical/biological, parental attitudes/family functioning, and behavioral/emotional. Each dimension comprised several indicators (see Table).

Medical/Biological. Items were determined by physician review of the medical record. Seizure control, objective drug side effects (eg, ataxia, gum disease, or organ toxicity), adverse behavioral reactions to medications, other illnesses (eg, asthma, eczema, abdominal pain, headaches), medications used, and serum levels were recorded. The primary neurologist provided a global rating of the child's medical status.

TABLE. Descriptive Statistics for Risk Factor and Outcome Measures

Latent Construct or Measured Variable	Mean	SD	Range	Skew	r_{ptb}
Baseline assessment					
Sociocultural risk					
Mother's education, y*	10.32	1.60	0-17	-0.16	-.03
Primary language†	0.45	0.50	0-1	0.21	-.01
Mother's years in the US‡	0.27	0.44	0-1	1.09	-.03
Child's nationality§	0.17	0.38	0-1	1.75	-.03
Seizure risk					
Maximum frequency*	0.57	0.50	0-1	-0.28	-.03
Duration*¶	2.13	0.91	1-3	-0.25	.13
Age at first seizure**	2.14	0.79	1-3	-0.25	-.12
Prior treatment failure**	0.83	0.76	0-2	-0.29	.04
CHLA Behavior Problem Questionnaire					
Activity	2.19	1.75	0-7	0.58	.10
Attention	2.25	1.83	0-7	0.67	.14
Discipline	2.36	1.72	0-5	0.02	.06
IQ	89.6	17.66	50-126	-0.52	-.07
Life Events	4.99	2.46	0-12	0.19	.02
Outcome measures					
Medical/Seizure					
Seizure control††	1.36	0.48	1-2	0.57	-.08
Global health ‡‡	1.82	0.96	1-5	0.97	-.15
Adverse effects§§	0.24	0.43	0-1	1.23	-.06
Current medications	0.86	0.35	0-1	-2.12	-.05
Parent's Attitudes Toward Epilepsy					
Anxiety	6.24	2.80	0-13	-0.25	.11
Child's emotions	1.45	1.17	0-4	0.22	-.04
Family functioning	3.13	2.51	0-12	1.08	.20
Achenbach Behavior Problems					
Internalization	61.23	9.79	39-81	-0.32	.06
Externalization	57.95	10.28	34-80	0.31	.18
Somatization	63.64	8.81	44-86	0.46	.04

Abbreviations: SD, standard deviation; CHLA, Childrens Hospital Los Angeles. r_{ptb} = point-biserial correlation with gender.

* These continuous variables were converted to categoric variables because of markedly skewed distributions or outliers: maternal education, mother's years of residence in the United States, maximum seizure frequency, duration of seizure disorder, and age at first seizure.

† 0 = English; 1 = other.

‡ 0 = 10+ years or US-born; 1 = <10 years.

§ 0 = US-born; 1 = immigrant.

|| 0 = new onset; <1 convulsive seizure/month or <1 nonconvulsive seizure/week; 1 = at least 1 convulsive seizure/month or 1 nonconvulsive seizure/week.

¶ 1 = <1 month; 2 = 1 month to 1 year; 3 = >1 year.

1 = birth to 3 years; 2 = 3 to 6 years; 3 = older than 6 years.

** Three variables were dichotomized (1 = risk; 0 = no risk) and combined to form a unit-weighted risk index of prior treatment failure (one point each): (1) greater than 6 months between first treatment and seizure control; (2) any anticonvulsant medication stopped; (3) episode of anticonvulsant intoxication.

†† 1 = no seizures in >1 year; 2 = any seizures in last year.

‡‡ 1 = excellent through 5 = poor.

§§ 0 = no systemic or behavioral adverse effects; 1 = any adverse effects.

|| 0 = none or antiepileptic monotherapy; 1 = polytherapy.

Behavioral/Emotional. The Achenbach Child Behavior Checklist²⁶ was administered to the parent, and summary scores applicable across age and gender were used to assess ongoing behavioral and emotional problems. Three broad-band factors used included externalizing, internalizing, and somatic complaints. Support for the psychometric soundness of these factors is provided by Achenbach and Edelbrock²⁷ and Bund et al.²⁸

Family Attitudes. A parent questionnaire was used to examine negative attitudes toward the child's epilepsy: the parent's fears about epilepsy, knowledge of the condition, precautions for and management of seizures, and perception of the effect of the child's epilepsy on the family's functioning and the child's emotional status. Higher scores indicate more negative attitudes and fears. Of particular interest were the parent's perceived competence to manage the child's condition, restriction of the child from normal activities, avoidance of disciplining the child for fear of causing seizures, and the family's view of the child's epilepsy as interfering with the family's activities.

Data Analysis and Modeling Strategies

Using the EQS statistical software program,²⁹ latent variable confirmatory factor analysis (CFA) was used to determine the psychometric adequacy of the hypothesized model. This analysis was followed by a test of the longitudinal structural model. The SEM portion of the analysis tests associations among baseline predictors and the hypothesized across-time effects. All within-time associations among baseline measures and separately those among outcome measures were left intact. Across-time associations were replaced with unidirectional regression or "causal" paths. The fit of the model was evaluated using several criteria, including the comparative fit index (CFI), a *P* value, and the ratio of χ^2 to degrees of freedom (*df*).^{30,31}

Descriptive statistics for baseline and outcome variables are given in the Table. The right-hand column presents point-biserial correlations of each variable with gender. There were no significant differences between boys and girls, so they were combined in all analyses.

Attrition

The 88 subjects completing the study represented 45% of 157 subjects who entered. The baseline characteristics of the subjects completing follow-up psychometric testing were compared to those of the entire group. Subjects who failed to complete the follow-up testing were more likely to be on welfare, scored higher on one subscale of the behavior questionnaire, and were less likely to have failed previous anticonvulsant therapy. These limited differences indicate that there was little bias resulting from attrition. In addition, we repeated our CFA using baseline data from all 157 subjects, and found the factor structure and loadings to be virtually identical to those for the subset of subjects completing the study.

RESULTS

The final model included baseline factors for Sociocultural Risk, Seizure Risk, and Behavior Problems and outcome factors for Medical/Seizure Problems, Parent's Negative Attitudes Toward Epilepsy, and Behavior Problems. In addition, two measured variables, IQ and life events, were included as baseline predictors.

In a preliminary model, we included measures of cognitive functioning at both baseline and outcome assessments, with particular interest in detecting subjects whose cognitive function deteriorated. However, given the brief developmental period between assessments and the stability of cognitive functioning, the correlation between IQ at baseline and IQ at outcome was nearly perfect ($r = .96$). No subject experienced clinically significant declines in IQ over the course of the study. Thus, IQ was not included as an outcome measure. We retained IQ at baseline to assess its unique contribution in predicting outcomes and to control for the important interactions of IQ with other baseline measures.

Results of the CFA

Figure 1 depicts the results of the CFA model. Confirmatory factor analysis differs from exploratory factor analysis in that the measured variables are constrained to load on a single factor and are not allowed to cross-load on any other factor. The resultant parameter estimates reflect the strength of an item as an indicator of the factor. In the figure, the

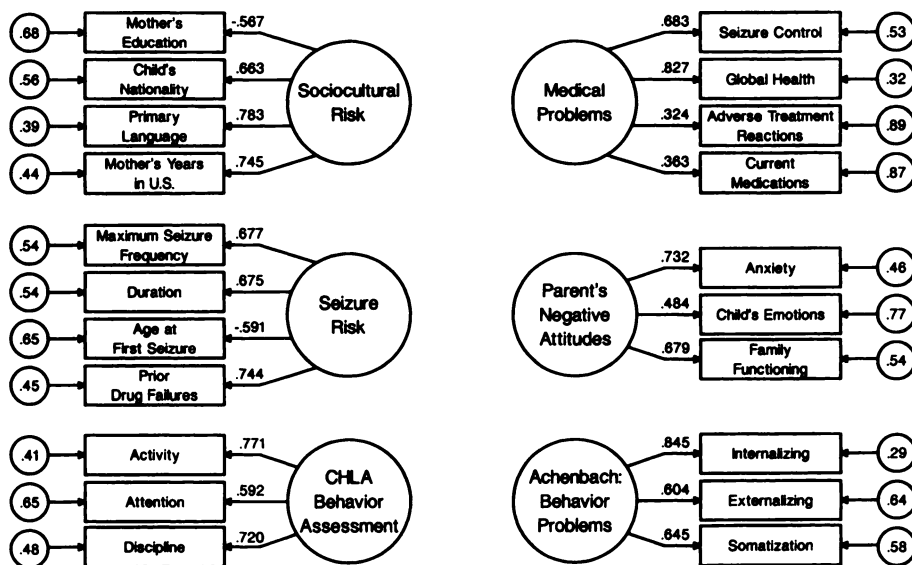
large circles represent hypothesized latent factors and the rectangles are the measured variables. Numbers on the lines going from the latent factors to measured variables are the standardized parameter loadings. Numbers in the small circles represent the residual variances, ie, the proportion of total variance of the measure not explained by the common factor. The fit of the CFA model was adequate according to several criteria. $\chi^2 (204, N = 88) = 309.55$, $P < .001$, $\chi^2/df = 1.52$. The CFI indicated that 81.3% of the covariation in the sample data could be accounted for by the hypothesized model. The significant P value indicated that alternative models could not be ruled out. As depicted, factor loadings for the latent constructs were all significant and moderately large, indicating that the latent constructs were psychometrically sound and statistically reliable.

SEM Analyses

Next we conducted the SEM portion of our analyses. Across-time covariances between latent factors and the two measured variables (IQ and LES) were replaced by unidirectional paths indicating regression over time. Figure 2 depicts the final structural model and includes only significant paths and associations. The SEM includes only hypothesized construct-construct paths from baseline to outcome, although several other nonstandard paths (effects other than those hypothesized) could be included in the model and might improve the overall model fit. As with any model, numerous effects could be added to achieve a final well-fitting model. However, the small sample size and the potential of chance findings preclude extensive model modification.³² Thus, we added only a few theoretically meaningful nonstandard effects. The fit of the final SEM was adequate: $\chi^2 (202, N = 88) = 261.9$, CFI = 0.894, $P = .003$. The χ^2/df ratio of 1.3 indicates an almost perfect fit, and the CFI indicates that nearly 90% of the sample variability was accounted for by the hypothetical model.

Among the main research hypotheses, Seizure Risk increased the outcome Medical Problems. In-

Fig. 1. Confirmatory factor analysis model. Large circles are factors; rectangles are measured variables. Numbers on arrows represent standardized loadings indicating the contribution that the measured variable makes to the factor. The potential range of loadings is from -1 to 1, with 0 indicating no relation. Numbers in the small circles represent residual variances and reflect assessment-specific variability not explained by the factor. All loadings are significant at $P < .01$ except for adverse treatment responses and current medications, which both loaded on Medical Problems at $P < .05$. CHLA, Childrens Hospital Los Angeles.



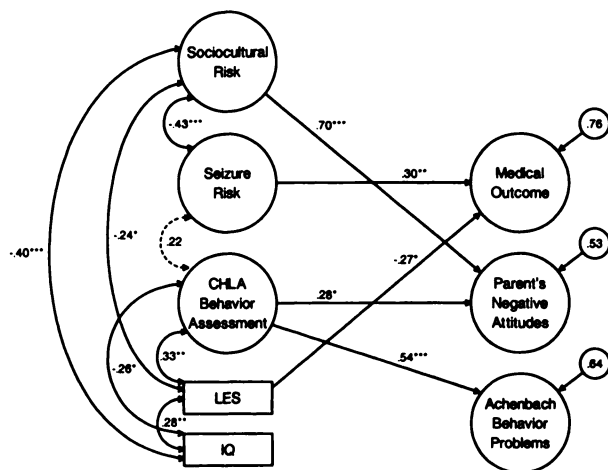


Fig. 2. Path diagram from structural equation model, showing intake factors and freestanding variables on the left and outcome factors on the right. Statistically significant paths are included in the figure as solid lines. Numbers on lines represent partial standardized regression coefficients, representing the unique contribution of the predictor to the outcome. The possible range of standardized regression coefficients is -1 to 1 . The dotted line between Childrens Hospital Los Angeles (CHLA) Behavior Assessment and Seizure Risk represents a path that approaches statistical significance ($P = .06$). Numbers in small circles are residual variances, which capture variability in outcome not explained by the model. * $P < .05$; ** $P < .01$; *** $P < .001$. LES, Life Events Scale.

creased LES decreased Medical Problems. Both Sociocultural Risk and Behavior Problems at baseline increased Parent's Negative Attitudes. The influence of Sociocultural Risk on Parent's Negative Attitudes was substantially greater than that of Behavior Problems. Behavior Problems were moderately stable over the duration of the study (standardized regression coefficient (β) = .54, $P < .001$).

Several significant within-time associations at baseline are worth noting. Although these associations were cross-sectional, their statistical interaction and conceptual overlap may reduce some of the longitudinal effects obtained in the path model. Significant associations were obtained between the following: Life Events and Sociocultural Risk ($r = -.24$, $P < .05$), Life Events and CHLA Behavior Problems ($r = .33$, $P < .01$), Life Events and IQ ($r = .28$, $P < .05$), IQ and Sociocultural Risk ($r = -.40$, $P < .001$), and IQ and CHLA Behavior Problems ($r = -.26$, $P < .05$). Sociocultural Risk was moderately and significantly negatively associated with Seizure Risk ($r = -.43$, $P < .001$). A marginal association was obtained between Seizure Risk and CHLA Behavior Problems ($r = .22$, $P < .06$). None of the residual disturbances (reflecting variances after prediction) among the outcome factors were significantly associated.

DISCUSSION

We began this study with the assumption that by collecting medical, demographic, and behavioral data, we would be able to identify those children with epilepsy who are at a higher risk of poor medical outcome and psychosocial function. The intent was to use this information for interventions aimed at reducing psychosocial morbidity in the highest-

risk individuals and families. We hypothesized that whereas medical factors such as seizure history would be strong predictors of medical outcome, sociocultural factors and preexisting behavioral problems would provide additional information to predict adverse behavioral and attitudinal outcomes. We also hypothesized that cognitive functioning would influence medical and behavioral outcomes.

Overall, most of the research hypotheses were supported by the data, with a few significant exceptions. Seizure history, particularly age at onset, past treatment failures, and duration of epilepsy before the first visit were strong predictors of ongoing difficulties with both seizure control and general health status. Thus, the severity (and controllability) of the seizure disorder remained fairly stable over the observation period. However, other factors influenced medical and psychosocial outcomes when controlling for seizure risk, and it is to these effects that we turn our attention.

Sociocultural Risk, a measure incorporating several individual aspects of family acculturation (or lack thereof), was associated with ongoing parental fears and negative attitudes toward the child's epilepsy. Furthermore, parental attitudes were largely independent of both seizure severity at enrollment and seizure control at outcome. Good seizure control with few accompanying medical problems did not appear to reduce parental anxiety. We speculate that when the child's seizures were controlled, and therefore not recently witnessed by the family, the parents remained fearful and uncertain of their ability to cope with a seizure, whereas parents who had more experience dealing with ongoing seizures were more confident and had fewer inappropriate fears. It should be noted that throughout the study, there was ongoing effort to educate parents regarding seizure management. Despite this, inappropriate and exaggerated fears of the child's seizures and excessively protective attitudes were relatively common, particularly among less acculturated, poorly educated parents. These very strong cultural influences must be taken into account in future investigations of the effects of epilepsy upon family functioning and quality of life and are essential to designing effective intervention programs.

Behavioral problems were relatively stable over the course of the study: children perceived to have problems with activity, conduct, or attention span at the beginning of the study were likely to have behavioral problems at outcome. However, children with more severe seizures, or worse seizure control at outcome, did not have more behavioral difficulties. Contrary to our expectations, IQ did not directly influence behavior problems at outcome, although the moderate and significant relation between IQ and behavior problems at the initial evaluation may obscure any across-time effects.

Stressful life events were hypothesized to have a negative influence on seizure control, parental attitudes, and child behavior. However, although a higher life events score was associated with more behavior problems at baseline, it did not influence negative parental attitudes. Higher life events scores

were a significant factor in better medical outcome. This may partially reflect differences in recall of life events, as there was substantially greater reporting of life events by more acculturated participants.

Comparison of This Study With Other Investigations

Other investigators have examined risk factors predicting psychiatric or psychosocial dysfunction in subjects with epilepsy or their families. The majority of studies were cross-sectional, correlating various medical and social variables with maladjustment.

Hoare and Kerley³³ studied a group of epileptic children and their families in an attempt to identify factors associated with psychological disturbance in the child and maternal fears about epilepsy, as a first step in developing a program to treat the psychosocial problems of children with epilepsy and their families. Their study and the present study share several goals, but the study designs and measures used differ substantially, thus limiting direct comparison of the results. Hoare and Kerley's study was cross-sectional, whereas ours is longitudinal. They included severely retarded and multiply handicapped children, whom we excluded. Thus, our sample was more homogeneous medically, but more heterogeneous with respect to sociocultural factors. Assessments varied between the studies, although there was substantial conceptual overlap. Hoare and Kerley found a correlation between psychologic disturbances in the children and early onset and high seizure frequency, but no association with seizure type. Children from families of lower socioeconomic status had higher rates of psychologic disturbances, and the mothers had more negative attitudes. We also found that sociocultural factors were the major determinants of negative parental attitudes toward epilepsy. Consistent with our findings, Hoare and Kerley did not observe an association between psychosocial morbidity and lower cognitive function.

Austin et al³⁴ used a cross-sectional design to examine 127 children with epilepsy to determine predictors of behavior problems. Potential predictors in their regression model included demographic, seizure, and family variables. Overall, family variables were found to be significant predictors of behavior problems, with additional predictive variance shared with seizure frequency, but not with type or etiology of seizures.

Many studies have focused on the psychosocial difficulties of epileptic adults. In a cross-sectional study of psychosocial correlates of psychopathology in 102 adult epileptics admitted to an epilepsy center for seizure monitoring, Hermann et al³⁵ found that current stressful life events were an important predictor of psychopathology. This differs from our finding that life events were not a predictor of either behavior problems or adverse parental attitudes.

Camfield et al³⁶ studied the social outcomes of children and adolescents with epilepsy in Nova Scotia, Canada. Subjects were contacted 30 to 184 months (mean of 7 years) after the initial diagnosis of epilepsy. Medical factors related to seizures and seizure control did not adequately explain the adverse social outcomes. Measures of sociocultural status and family functioning were not included, and the

authors noted that further explanation of social outcome may rest upon these factors. Our data support this line of inquiry.

Possible Biases: The Effect of Referral Patterns

One important point about referral patterns must be made, as it may affect our understanding of the influence of sociocultural and economic factors upon outcome: there appear to be differences in referral patterns (and thus in enrollment) of subjects of various sociocultural and economic backgrounds. More acculturated, higher-income families were generally referred by pediatricians or other neurologists after a period of treatment of seizures. Prior treatments were often unsuccessful or had produced unacceptable side effects. Some of these secondary referrals probably were made because the primary physician perceived the family to be "difficult" or to have ongoing questions and doubts about the prescribed treatment. Less acculturated, lower-income families more often presented to the emergency room at CHLA after a first or second seizure and were referred directly to our Seizure Clinic without prior treatment. Thus, the effects of severity of the seizure disorder upon family attitudes may be confounded by the more powerful effects of acculturation and differences in referral patterns.

Limitations

Several limitations are associated with this study. Because of the small sample and large numbers of estimated parameters, the results must be interpreted with caution. A necessary step is to cross-validate these findings with comparable clinical samples. The power to detect significant effects is considerably diminished with small samples, and in our case, statistical relations of a large magnitude were required to achieve significance. The latter concern underscores the importance of distinguishing statistical from practical significance when evaluating these results. Second, our analyses were restricted to a specific set of psychosocial, behavioral, attitudinal, and medical measures, and other unexplored variables may enhance the overall predictive capability of our model. Some important factors that may influence medical and psychosocial outcomes among epileptic children include: medical complications unrelated to seizures (eg, birth problems, neurologic abnormalities, other chronic illnesses), a wider definition of family functioning, and greater elucidation of social functioning such as school achievement, interpersonal skills, and emotional development.

An additional limitation is that over half of the subjects originally enrolled in the project dropped out. Although there were few, if any, significant demographic, medical, or behavioral differences on baseline measures between subjects who completed the study and dropouts, we cannot eliminate the possibility that their outcomes were substantially different. Patients change their source of care for a variety of reasons. Geographic mobility is high in southern California. However, dropouts may have left our clinic because they were doing poorly clinically, were unsatisfied

with our care, or were very anxious and continued to seek other treatment or opinions.

Speculation and Future Directions

Overall, this study supported the hypothesized importance of sociocultural and behavioral factors in the functional outcome of childhood epilepsy. We speculate that a similar pattern of effects may apply to other chronic childhood illnesses. We encourage further longitudinal studies that assess the impact of psychosocial and behavioral risks on medical and behavioral outcomes in epileptic children. As negative parental attitudes toward epilepsy were much more dependent upon sociocultural factors than upon seizure history, ongoing medical problems, or family stress, interventions to alter these attitudes must be culturally appropriate. If the effect of epilepsy on the family is to be understood adequately, studies of the quality of life of the child and family must include appropriate measures of the sociocultural background and beliefs.

ACKNOWLEDGMENTS

Supported by a grant from The Robert Wood Johnson Foundation. The authors thank John Chavez, PhD; Betty Mendoza; and Bianca Guzman, MA; for their participation in early phases of this project. We are grateful for the encouragement and assistance of S. Robert Snodgrass, MD.

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Pediatrics 1994;94:471

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