Psychopathology and psychological adjustment in children and adolescents with epilepsy

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Background: **Epilepsy is the most common chronic neurological illness in childhood and adolescence, and this condition may increase the risk of psychopathology at these ages.**

Data sources: **A literature review, including MEDLINE and PsychLIT database, was made covering the period of 1966-2007. Research studies were included if they were concerned with children suffering from epilepsy and measures of psychopathology.**

Results: **Studies found a more elevated rate of psychological and psychiatric disorders, both behavioral and emotional, in these samples compared to general population or children with other chronic conditions. The problems presented in children and adolescents with epilepsy are quite similar to those in general population with a slight increase of hyperkinetic and attention problems likely related to both direct brain damage and anticonvulsant treatment. There is no evidence of psychotic disorders and/or specific personality traits associated with epilepsy at these ages.**

Conclusions: **Family factors, specially those related to psychopathology in other family members and parent-child relationships, appear to have stronger influence on children psychopathology than illness factors themselves. Some guidelines are provided in order to improve future research.**

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Introduction

Childhood epilepsy is a biologically based risk factor for child and adolescent psychopathology and family adjustment problems. Epilepsy is the most common chronic neurological illness in childhood. The prevalence of epilepsy at school age is between 4 and 7 per 1000.[1,2]

The association between psychopathology and epilepsy is so old as the scientific characterization of illness. In the last decades, we assisted to an increased interest in research in this field mainly due to recent development of specific measurement instruments in child psychiatry and the improving knowledge about neuro-development illness factors. At the same time, family and social aspects have been recognized as influential factors in adaptation to illness.

There are a large number of studies on the psychological consequences of epilepsy in children and adolescents, with diverse methodologies and samples, which make it difficult to find out clear clinical and therapeutic implications. Some of them are dispersed and not easily available. Confounding factors associated with epilepsy include neuro-developmental issues, intellectual deficits, different types of seizures and classifications, and medication effects on behavior. This review aims to clarify findings on this subject and suggest future research directions.

Methods

A MEDLINE and PsychLIT literature review was made covering the period of 1966-2007. Studies were included if they were concerned with children and adolescents with epilepsy (psychopathology, epilepsy, and all children up to 18 years). Those papers on the topic published from 2000 were reviewed

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more closely in order to assess current trends in the research on epilepsy and psychopathology. The results are organized into two main topics having in mind the interdependence between both aspects: firstly, methodological issues of published research studies, and secondly, the analysis of findings. Finally some suggestions and conclusions are offered.

Results

Methodological issues

Study design

Most of the studies are cross-sectional and retrospective, some of them with control group, either healthy controls, or more often, siblings[3] and/or children with other chronic illness such as asthma or diabetes.[4-9] The cross-sectional design only allow for analysis of correlation. Longitudinal prospective studies are rare, but this type of design[10,11] permits to assess the natural course of factors implicated and to suggest some of causal relationships between them.

Sample selection

Investigators have tried to achieve homogeneity aiming to control for confounding factors and to be able to test specific hypotheses. However, this has limited the generalization of the results. Most of studies use outpatients from second and/or third level (general pediatrics or specialist epilepsy clinics),[5,6,12-16] few studies have samples from primary care[17] or from community institutions.[2] Children with febrile seizures or those with good control of illness are managed in primary care and probably will have less psychopathology and family stress than those children attending specialist epilepsy clinics. Inpatients and those with concomitant illnesses, additional disabilities, intractable seizures or cerebral palsy[18-20] are also underrepresented and presumably this group has more psychological and family difficulties. Many of these studies have a small number of subjects, limiting the value of their conclusions.

Psychopathological measurement

Different types of instruments are used to measure psychological variables in children and adolescents. Scales and questionnaires, self-reports of attitudes and behavior are the most simple and frequently used in research in this field. Most of them are screening instruments and the information is gathered mainly from parents and teachers. Rutter scales[5,6,9,13] or Child Behavior Check List[7,9,12,21,22] are the most common methods. Psychiatric interviews[11,23,24] and direct observation with appropriate scoring systems are more interesting but less used.

Other aspects of psychological adjustment in children have been measured with specific questionnaires. Children's dependence has been assessed with the self-administered dependency questionnaire (SADQ),[19,25,26] self-esteem with the Harter Questionnaire[8] and self-concept with the Pierre-Harris self-concept Questionnaire.[19,22,23]

Other central aspect is the assessment of epilepsy. It is important to recognize the heterogeneous nature of epilepsy. Comparisons are often difficult because investigators have adopted different classifications or definitions of epilepsy. Furthermore, classifications have changed over time. Apart from possible differences in underlying pathology, patients differ in their clinical and electroencephalographic types of seizure, frequency of the seizures and their control. All these variables may have some effect on child psychopathology and family adjustment.

Analysis of findings

Epilepsy not only can increase the direct risk of disturbance in the child but also seems to have an adverse effect on the health of the rest of the family members. Factors which may be involved with this increased vulnerability include the type and severity of epilepsy, therapeutic control, adverse effects of anticonvulsants, individual characteristics of children and their families, and presence of psychopathology in the child and/or other family members.

Psychological effects on the children

A large number of studies on the association of psychopathology and epilepsy have found that the rate of psychiatric disorders increased more significantly in these samples than in the general population of children. The classic community study of neuro-psychiatric disorders of Rutter et al[2] found that one-third of children with epilepsy have psychiatric disorders in comparison to a rate of 6.6% in the general population of children and 11.6% in children with chronic physical disorders. A Finland study[27] showed a different profile with a rate of 29.7% for neurotic disturbance, a rate of 11% for autistic features or psychosis, and a rate of 33.5% for hyperkinetic disorder. These findings indicate that there are differences in diagnosis, classifications and sample selection than in real prevalence of psychopathology. Until recently, children with epilepsy were described with a typical syndrome characterised by over-activity, impulsivity, aggression, and distractibility. But subsequent research has found that the most disturbed children with epilepsy have the same range and type of psychopathology as other disturbed children.[5,8,9]

Furthermore, the concept of "epileptic personality" has been abandoned. These children demonstrate more but not different psychopathology than children with other chronic illnesses like diabetes or asthma. Several authors reported that neurotic or emotional disturbance is the most common diagnostic category.[19,28] Moreover, some of these "hyperkinetic" features may be related to medication mainly phenobarbitone and benzodiazepines. A meta-analysis recently published[29] resumes this question and underlines some of the results mentioned above. Emotional disturbances are slightly more frequent, mainly depressive symptoms and somatizations, than behavioral symptoms. Attention deficits are also more prevalent in children and adolescents with epilepsy than in those affected with other chronic illness, and are likely related to brain damage. Behavioral and emotional effects of anticonvulsant medication should be studied to clarify its influence on child psychopathology. A recently published study,[30] with a sample of 2.27 millions of adult patients, underlines the increased risk, 2.5-3 fold of schizophrenia or schizophrenia-like psychosis in patients with epilepsy. In this study patients up to 15 years and those with previous psychiatric history are excluded because the diagnosis of psychosis is rare before 16 years, which may explain the inconsistency of these findings compared to those in child and adolescent samples. Nevertheless the association between psychosis and epilepsy remains a polemic aspect.

Gender variations are not consistent. While some studies found that boys with epilepsy show more problematic psychological adjustment than girls with epilepsy,[8,25] others found that girls have more depressive symptoms, somatic complaints, hyperactivity and withdrawal symptoms than boys.[13,22] Some studies have not shown any gender differences.[2,19]

Other aspects concerning child psychology have been investigated, for instance, children with epilepsy are more dependent than children with other chronic conditions like cystic fibrosis[31] or diabetes.[5] The findings are related to neither illness severity nor parental attitudes. Self-esteem, self-concept and adjustment are related to psychopathology: children with behavioral problems have worse self-esteem.[8] Children with epilepsy have poorer psychosocial adjustment at school, more depressive symptoms, and worse self-concept than children with asthma.[7] Furthermore, patients with epilepsy with the kind of difficulties mentioned above ("worse adjustment at school, more depressive, and so on") are found to have worse seizure control rates than those with good adjustment or without depression, which have been confirmed in a study of a larger sample.[13] The author of the study underlines the continuity of depressive symptoms in adult life of some people suffering from epilepsy and suggests that poor self-esteem, a symptom of depression, could begin from childhood.

Psychological effects on family members

Since most of the studies on psychopathology and epilepsy gather information from parents and teachers, it is of interest to review those studies regarding knowledge, expectations and attitudes of adults towards boys and girls suffering from epilepsy. Expectations may modify scale scores and this must be considered in getting generalization from the results. Parents may show diminished expectations for their children with epilepsy in school outcomes, sports, concentration and choice of occupation, and they are expected to be more prone to emotional problems than their healthy siblings.[32] The parents perceive themselves as stricter and are more dominant in relation to their children with epilepsy. Families perceive their children with epilepsy as having higher frequency of aggressive behavior toward parents, with more immature behavior, more dependency, expressing complaints of personal rejection and having frequent periods of emotional distress.[23] Other studies[33,34] found that parental attitudes towards epilepsy are more equilibrated with both positive and negative expectations. Parents of children with epilepsy[33] are realistic about the problems for children, and have appropriate knowledge about seizures, illness and educational problems. There were no differences between mother's and father's attitudes, but they were more negative towards girls than boys.[4] An interesting finding[33] is that parental perception of seizure control is a better predictor of parental adjustment than the level of seizure control itself. In addition, parental attitude towards improving with the length of illness has been suggested.[34]

Epilepsy is a chronic stressful condition for family life, and could have consequences on mental health of family members. Many studies[35-39] concerning psychopathology in children with epilepsy assessed psychological problems of relatives as well. Quality of family relationship satisfaction and degree of disturbance of epilepsy on family life have been shown as the main predictors of psychopathology in children and adolescents with epilepsy.[29,35]

Psychological problems of siblings have been often analyzed, and frequently healthy siblings are control groups of studies measuring psychopathology and behavioral problems in children with epilepsy. Siblings have less psychological problems than their brothers or sisters with epilepsy but they were more disturbed than children in the general population.[6] Interestingly,

siblings of children with chronic epilepsy are more affected than those of the newly diagnosed children.[19] Parents of children with epilepsy are more affected than those of the general population.[6] Most studies show a concordance between psychological problems in mothers and behavioral problems in children with epilepsy.[2,3,11,19] Some researchers[6] suggested that this association could be modulated by the length of illness, in fact it appeared only in those children with more years of evolution. Another important aspect of the relationship between family and epilepsy is the fictitious seizure induced by a relative.[40] Most of these patients have occasional real seizures and additional multiple fictitious seizures induced by a relative, usually the mother. In these cases an increased risk for other fictitious disorders, and child abuse must be investigated.

Illness factors and psychological adjustment

The association between psychological adjustment and illness variables has been frequently investigated as a central point. While some studies showed that the severity of illness predicted only in part psychosocial functioning and adjustment, more frequency of seizures was associated with less social development but not with differences in academic achievement, and type of seizure was not significantly correlated with neither of them.[31,32] As underlined above, the length of illness has been associated with the more prevalence of psychological problems in children and in their relatives.[5,6] In addition, these investigators found that other illness factors significantly associated with the disturbance in this sample are complex partial seizures, focal abnormalities in EEG, and severe fit frequency. Other studies offered a quite different profile underlining the absence of association between illness variables such as the severity or specific type of epilepsy and psychopathology in children with epilepsy.[1,24] When more severe cases including those of brain damage are considered, the results seem to be modified, showing that the quality of life is adversely affected mainly in the group of early onset intractable epilepsy with additional disabilities, and that poorer control of epilepsy is associated with more negative impact on family life.[16,35]

A recent meta-analysis found a consistent relationship between the length of epilepsy and psychopathology.[29,36] Moreover, children with a poorer control of seizures are more prone to social withdrawal, and have more somatic complaints than those with a better control. In samples of adolescents with epilepsy, the degree of seizure control, poli-medication and stigma aspects are significantly associated with internalizing disorders and adaptation problems in teenagers.[37] The studies[29,36] suggest that in those kids with good seizure control, illness variables, except the length of illness, are not related to psychological and adaptation problems. Whereas in those children with more severe illness and/or poorer seizure control, illness variables have a significant impact on psychopathology. Family variables, illness influence on family life and family ability in coping with stress have been suggested as mediated factors on psychopathology of children. Cognitive aspects of children with epilepsy such as IQ and linguistic competence have been related to illness variables (illness length, seizure frequency) and to antiepileptic drugs.[24,39]

Integrating findings

Studies[22,38,39] regarding illness variables and family factors find out that family factors are more "predictive" of child adjustment than illness variables. In fact some authors underline that not only family variables have stronger influence on child adjustment, but adjustment problems in children with epilepsy can exist independently of illness symptoms. Moreover, child-parent relationships are predictors for behavior problems over and above the influence of disease-related factors, even for the children at considerable risk.[12,17] An additional example of this interaction is the research on adherence to antiepileptic treatment. Lack of adherence to medical regimens is a frequent problem in children with epilepsy since successful treatment is based on the regular intake of anticonvulsant drugs. Interestingly, therapeutic compliance is related to child behavior problems[41] and psychopathology both in the mother and the child[11] are significantly related to a lesser adherence to treatment and worse anticonvulsant therapy compliance. These findings suggest that it is necessary to identify those patients and their families needing psychosocial interventions to improve their treatment compliance.

Conclusions

Epilepsy is the neurological prevalent illness associated with more psychopathology. The incidence of behavioral and emotional disorders in boys and girls with epilepsy is greater than those in both healthy children and those suffering from other chronic illness. The disorders are quite similar to a slight increase of attention deficits and hyperkinetic symptoms, both of which are related in some extent to either neuropsychological damage or anti-epileptic drugs. The association with specific personality traits or psychosis-related disorders has not been found in this age group. Surprisingly in most of children with epilepsy, family

factors such as parents' psychopathology and family coping with illness and stress appear as the most important factors influencing psychological problems in children. Illness has less influence on psychopathology except for those kids with more severe illness, with a longer length of illness and worse adherence to treatment. Having in mind the magnitude and extent of psychological problems in children and adolescents with epilepsy and their families, it is necessary to amplify the focus from a multi-disciplinary perspective further away to a classic biological point of view. Consistent with recent approachs,[42] an integrated model explaining interactions between all implicated factors, i.e., brain damage, medication, child and family psychopathology, and cultural variations is largely needed. For this purpose, more follow-up studies are needed, and samples must be more representative, considering both more seriously ill kids and those with less severe illness.

First, it is necessary to consider the use of psychiatric interviews and direct observation to gather information on psychopathology instead of making assessments exclusively relying on scales and questionnaires.

Second, neuro-developmental perspective is essential to improving our understanding of some differential effects including age of onset, damage of neuro-cognitive functions, and other illness sequela. Neuropsychological assessment and neuro-developmental perspective are indispensable in order to reach a model explaining complexity of relationships between epilepsy, brain, and behavior. According to the literature, this complexity is not well understood. While regarding children and adolescent samples, most of the reporters agree that main influences on children psychopathology are illness stress and child/family coping strategies; adult studies seem to suggest a clearer effect of direct brain damage (illness or drugs related).

Third, more pragmatic research is needed, designing and evaluating preventive and therapeutic approaches, identifying groups at risk for social and psychological problems and those factors predicting lack of adherence to treatment. These groups at risk must be the intervention target of identified efficient interventions.

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