

Psychological Factors in Children and Adolescents with Epilepsy and their Families

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S u m m a r y. Children with epilepsy encounter significant adaptive challenges in relation to their illness and the development of their health. However, little is known of the processes by which the psychological factors of their families, such as the family atmosphere and the family expressed emotion affect the development of the individual illness in children. The present study examined systematically the role of psychological factors in the development of epilepsy in a period of nine to twelve months. Specifically, factors related to psychopathology, coping/adaptation mechanisms, family functioning and family expressed emotion (EE) among epilepsy and healthy control children and adolescents were investigated. The parental expressed emotion instrument (FMSS-Five Minute Speech Sample), the McMaster Family Assessment Device (FAD), the Kidie-Schedule for Affective Disorders and Schizophrenia-Present Episode (K-SADS-P) and the KIDCOPE interview were administered to 34 children with epilepsy and their parents. The same instruments were utilized

with 43 healthy controls and their parents. Findings revealed that parental EE is only indicative of the family atmosphere and is not directly related to the development of epilepsy. There were no significant differences between children with epilepsy and their healthy controls in the levels of psychopathology. However, a trend was observed for epilepsy sufferers: they tend to exhibit more symptoms for separation anxiety, dysthymic disorder and learning difficulties more than their healthy controls did. Furthermore, children with epilepsy reported to utilize social support and social withdrawal as an adaptation mechanism significantly better than their healthy peers. The study concluded that interventions with parents of children/adolescents with epilepsy aiming to modify attitudes and emotions could be important in the adaptation of children to their illness.

INTRODUCTION

In child psychiatry literature on paediatric epilepsy, although the relationship between parental characteristics and child psychopathology is well documented, the particular effect of parental expressed emotion (EE) on the psychological development of children has been studied only in

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the last decade. The parental expressed emotion has only been studied in relation to children's depression, bipolar disorder, anorexia nervosa, obsessive-compulsive disorder, agoraphobia, obesity, and diabetes. However, the effect of family functioning and family EE on the psychological adaptation of children with epilepsy has not been easily determined. Some studies have been revealed that EE is usually indicative for the development of the individual illness in different cultural settings (1,2). However, there has been a controversy among studies about the relationship between EE and the relapse of epilepsy, as well as the extent to which the measured EE has clinical validity and utility.

EE is usually defined as a variable which measures the family atmosphere/climate and consists of the following factors: critical comments, positive comments, hostility, warmth and emotional overinvolvement (3). Critical comments, hostility and emotional overinvolvement have been reported as the factors with the most predictive value (3). Specifically, critical comments, which are mainly used for the evaluation of EE, refer to observations in relation to respondent's behaviour (including tone of voice) and personality (3). Hostility is independent from critical comments but most of the times are interrelated. Emotional overinvolvement is the most complicated factor since it consists of the following two elements: overprotection and excessive emotional reactions (e.g., dramatization). The high level of EE is determined by six or more critical comments, and/or a moderate level of emotional overinvolvement, and/or one sign of hostility. A family is characterized by high EE even if only one of the family members expresses it towards the emotional sufferer (4).

In the psychosocial literature on paediatric epilepsy it is well documented that a number of factors have a significant impact on the psychological adaptation of children to their illness and diminish their treatment compliance and the sufficient prognosis of their health. First, there is a consensus among the empirical studies conducted that the chronic nature of the illness, the duration and frequency of epileptic seizures in relation to the presence of the insufficient brain infrastructures impose considerable stress on sufferers and their families and affect the quality of their life and psychological well-being (5-7). Furthermore, several researchers (5,6,8-10) have emphasized the importance of the relationship

between the psychosocial factors (i.e., family relations) and paediatric epilepsy. Specifically, findings have shown that the factors which are significantly related to EE in families with epilepsy sufferers are the following: family disharmony, overprotective or rejective parental attitudes, level of maternal stress, critical comments and hostility, and maternal parenting. These factors have an impact on the level of children's emotional difficulties, their adjustment to their epilepsy and treatment compliance (11,12). Thus, although it is still unclear if high EE is the result of epileptic seizures or the facilitator to their presence, the reduction of high EE could contribute to the relapse prevention and the emotional well-being of sufferers.

To date, little is known of the processes by which psychological adaptation to the challenges of epilepsy are managed during childhood (13). Of particular importance is the association between the levels of EE and the development of epilepsy in children and adolescents. The main objective of the present study was to systematically examine the impact of family factors, and especially those that refer to parental EE, on childhood epilepsy. These factors affect the development of the individual illness in a period of nine to twelve months. Furthermore, the present study aimed at examining the presence of psychopathology in children/adolescents with epilepsy for the same period of time, as well as the association between EE, the development of the illness and psychopathology in children/adolescents with epilepsy. The specific aim of the study was to investigate the protective factors among children/adolescents with epilepsy and their healthy cohorts and explore any differences between these groups.

METHODOLOGY

Participants

The participants were 34 children and adolescents with epilepsy, 17 males and 17 females aged from 5 to 15 years (experimental group). Twenty seven of those were living in the area of Attica. The participants were assigned in two groups: the first group consisted of 16 participants with typical absence seizures in childhood with or without tonic convulsions and the second group consisted of 18 participants with generalized convulsions (grand mal). The sample was recruited through cases of the Specialized Epilepsy

lepsy Unit, Neurological Department of *Agia Sophia* Children's Hospital in Athens. Epilepsy was diagnosed through participants' medical history, direct observation of epileptic seizures during in video- EEG study. A control group of 43 individuals, 25 males and 18 females, aged from 5 to 15 years, with no existing health problems, was obtained as a random sample. The parents of all individuals were also participated in the present study.

Diagnostic tools

The diagnostic tools that were utilized with parents were the following.

- *Parents' demographic characteristics* (gender, age, number of children in the family, educational level, financial situation etc.) were collected through a questionnaire developed for the purposes of the present study.

- *The Family Assessment Device* (FAD) was chosen to assess family functioning based on 6 six domains: problem solving, communication, roles, emotional responsiveness, emotional involvement, and behavioural control (14). The measure comprises 60 Likert-type items in a 4-point format, ranging from 1 (completely agree) to 4 (completely disagree), with higher scores indicating higher levels of family dys-functioning. The measure has demonstrated high internal consistency with alpha coefficients ranging from 0.72 (for the *behavioural control* subscale) to 0.92 (for the whole measure).

- *The recorded interview, that is the Five Minute Speech Sample* (FMSS), is the method that was utilized to assess parental EE (15). The parent is called to express for five minutes his/her thoughts for his/her mother and father and their communication without interruptions. Any questions are clarified before the speech. The content and the tone of the five minute monologue are analysed according to the following categories: the quality of the initial thought-statement, the quality of the relationship, the critical attitude (assessed through an initial negative statement or through a statement that declares a negative relationship), and the emotional overinvolvement (assessed through excessive details for the past, overused praise, comments on overprotective behaviours/self-sacrifice and emotional display). High EE is assessed through the presence of statements which indicate critical attitude and/or emotional overinvolvement.

The diagnostic tools utilized with children and adolescents were the following.

- *The Medical History* of the Neurology Clinic, *Agia Sophia* Children's Hospital was used to gather information in relation to the individual's health and illness development (e.g., diagnosis, description of epileptic episodes, associate symptoms, frequency of seizures, other episodes, laboratory examinations, medical treatments).

- *The semi-structured psychiatric interview for children, Kiddle-Schedule for Affective Disorders and Schizophrenia-Present Episode* (K-SADS-P) (16-18), was utilized to collect information regarding child's functioning level and symptoms of the most recent episode of psychiatric disorder. The K-SADS-P comprises a parent's interview, a child's interview and a clinical observation. It has two parts. The first part consists of questions regarding the starting time and duration of the episode. The second part consists of item-questions on 200 specific symptoms and behaviours, relevant to the Axis III of the DSM-III-R. Most of the items have a 6-7 point format. Reliability test analyses have been performed for K-SADS-R-Greek Version and the Axis I diagnoses of the DSM-R-III (19). The agreement percentages referring to the diagnosis were ranging from 66.7% to 88.9% ($p < 0.05$). The instrument scales have demonstrated high internal consistency with alpha coefficients ranging from 0.60 (for the somatization scale) to 0.89 (for the depression scale).

- *The KIDCOPE questionnaire* was chosen to assess the coping and adaptation mechanisms that children and adolescents endorse to encounter a difficult situation. It comprises 3 scales designed to measure the way by which children react to their illness. The scales refer to the following: common problems, child's problems due to hospitalization, and child's problems related to the chronic illness. The questionnaire is administered by an interviewer. The administration process starts by asking the child to describe a difficult situation during the last month. Then, the interviewer reports child's coping and adaptation mechanisms on this situation through 3 questions referring to the child's emotional state and 15 questions referring on the ways that the child described to overcome the difficult situation. The coping/adaptation mechanisms derived from these 15 questions are the following: distraction, social withdrawal, cognitive restructuring, self-criticism, guilt of others, problem solving at-

tempts, emotional regulation, optimistic relationship-desires, social support, and withdrawal.

Procedures

The study was conducted at the *Agia Sophia* Children's Hospital, Athens. The researcher was initially trained in the Outpatient Clinic of the Neurology Department for a period of six months. Neurologists working in the Clinic were also sensitized for crisis intervention and psychological support of families. An initial informative letter was sent to families of children with epilepsy. Children's parents who gave their written consent for themselves and their child participated in the study. The control group consisted of families who were recruited from the community through a phone contact informing them about the scope of the study and their potential involvement. Upon family's agreement to participate in the study, an interview appointment was scheduled for the child and the parents at their home. A follow-up appointment for participants with epilepsy was scheduled after a period of 9 to 12 months. The participants' follow-up appointment coincided with the examination of their medical treatment at the Neurology Clinic.

Statistical analyses

Hypotheses were tested by use of the following statistical methods: T-test analyses for independent samples and Chi-Square analysis. Statistical significance was declared for $p < 0.05$ and $p < 0.01$. The analyses were performed by the use of the Statistical Package for Social Sciences-SPSS, Edition 10.1 for Windows.

RESULTS

Whole Sample

Since the main aim of the present study was to examine the parental EE among children and adolescents with epilepsy and their healthy cohorts, independent t-test analyses and chi-square analysis were conducted to determine how the variables FAD and KIDCOPE relate with the variable EE for the whole sample.

In relation to the variable FAD the analysis showed that parents with high EE reported significantly lower levels of emotional responsiveness to their children than the parents with low EE, $t(55, 29, 9) = -2.007$, $p < 0.05$. In relation to the variable KIDCOPE, there were no statistically

significant differences among the families with high and low EE. However, a trend was observed: children from families with high EE reported to utilize the social support mechanism more often (31.3%) but with less effectiveness than those children from families with low EE (8.1%), $\chi^2(2, 53) = 5.649$, $p = 0.059$.

Analysis was also conducted to determine the relationship between the variables K-SADS-P (child's psychopathology) and FAD (family functioning) or between the variables KIDCOPE (adaptation mechanisms) and FAD (family functioning). Specifically, independent t-test analyses conducted on children with and without psychopathology group means for each of the subscales of the family functioning (FAD) variable. There were no statistically differences between the two groups (children with psychopathology and children without psychopathology) on the group means of the following subscales of the FAD variable: problem solving, communication, roles, emotional responsiveness, family control, total family functioning ($p > 0.05$). Furthermore, chi-square analysis was conducted to determine the percentages of participants with and without psychopathology who make a lot, little or no use of the ten adaptation mechanisms that the variable KIDCOPE captures. There were no significant relationships between each of the 10 adaptation mechanisms (distraction, social withdrawal, cognitive restructuring, self-criticism, guilt of others, problem solving attempts, emotional regulation, optimal relationship-desires, social support, and withdrawal) and child's psychopathology. The examined variables were not interrelated ($p > 0.05$).

Comparisons between experimental and control group of participants

Independent t-test and chi-square analyses were conducted to determine if there were any differences between the group of participants with epilepsy (experimental group) and those without (control group-non disease participants) for each of the measures in the study (Child's Psychopathology-KSADS-P; Family Functioning-FAD; Adaptation Mechanisms-KIDCOPE). Specifically, no significant differences were revealed on the child's psychopathology variable (second part of the KSADS-P measure) between participants with epilepsy and those without, $\chi^2(1, 75) = 2.172$, $p = 0.141$.

Table 1

Results based on the first part of the Semi-Structured Psychiatric Interview K-SADS-P for the Group of Children/Adolescents with Epilepsy ($n=34$) and the Group of Non-Disease Participants ($n=43$) in relation to Normative Data

DSM-IV Diagnosis	Participants with Epilepsy 1 st Assessment n (%)	2 nd Assessment n (%)	Non-Disease Participants n (%)	Normative Data* %
Separation Anxiety Disorder	3 (8.8)	3 (8.8)	3 (6.97)	3-4
Dysthymic Disorder	3 (8.8)	3 (8.8)	1 (2.93)	2 (in pre-adolescence)-5-adolescence)
Special Phobia	2 (5.9)	2 (5.9)	0 (0)	10 (in children), 2-3 (in adolescents)
Conduct Disorder	0 (0)	2 (5.9)	2 (4.65)	3-10
Encopresis	2 (5.7)	1 (2.9)	0 (0)	3 (up to 4 years), 2 (up to 6 years), 1.6 (up to 11 years)
Adjustment Disorder	1 (2.9)	1 (2.9)	0 (0)	57% recovers after distancing from the stressful situation/event
Communication Disorder	1 (2.9)	1 (2.9)	0 (0)	Data not available
Eating Disorder	1 (2.9)	1 (2.9)	2 (4.65)	1-5
Learning Difficulties	0 (0)	4 (11.8)	0 (0)	2-10

*Data from the general population presented in percentages are derived from the study of Dulcan M., & Richard Martini D. (2005)

However, participants' possible psychopathology levels were also assessed through individual interviews (administration of the first part of the KSADS-P), first from the parents and second from the children and adolescents. Diagnosis was based on the definitions of the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders Fourth Edition-DSM-IV: American Psychiatric Association, 1994). Table 1 presents the assessment findings for the two groups of the present study, as well as percentages of children and adolescents with psychopathology from the general population (20). The normative data for children and adolescents' psychopathology used for comparisons in the present study were based mainly on USA populations, since Greek norms were not available for such diagnosis. Consequently, any comparisons between normative data and data obtained from the present study should be considered in relation to the fact that these data might represent populations with different social, cultural and psychological characteristics. Results on Table 1 indicate that children and adolescents with epilepsy were more prone to separation anxiety disorder and dysthymic disorder than those in the general population. Furthermore, it appears that participants with epilepsy exhibited a higher percentage of learning difficulties than that in the general population.

Furthermore, data presented on Table 2 indicate that family roles were significantly better

structured in families with children without epilepsy than in families with children with epilepsy. In relation to Adaptation Mechanisms (KIDCOPE), summary of findings on Table 3 shows that less children/adolescents with epilepsy (3.7%) than those without (18.4%) utilized the adaptation mechanism *guilt of others* as a way to solve their problems, while more children/adolescents with epilepsy (77.8%) than those without (48.6%) utilized more effectively the adaptation mechanism of social support as a way to solve their problems.

Table 2

T-test results for the group of participants with epilepsy and the non-disease participants for the measure of Family Functioning-FAD and its Subscales ($N = 77$)

Measure and Subscales	t value	$d.f$	p (2 Tailed Prob.)
Family Functioning-FAD	1.101	68	0.275
1. Problem Solving	1.058	68	0.294
2. Communication	0.564	71	0.574
3. Roles	3.056	69	0.003**
4. Emotional Responsiveness	0.636	70	0.527
5. Involvement	-0.036	66	0.971
6. Control	1.179	69	0.242

** $p < 0.01$

Table 3

Chi-Square results for the group of participants with epilepsy and the non-disease participants for the subscales of the measure Adaptation Mechanisms-KIDCOPE (N = 77)

Subscales	χ^2 value	d.f	p (2 Side Prob.)
KIDCOPE			
Cognitive Restructuring	1.008	3, 65	0.779
Self-Criticism	0.852	3, 65	0.837
Guilt	8.138	3, 65	0.043*
Social Support	5.673	2, 64	0.059
Withdrawal	1.983	3, 64	0.576
Problem Solving	0.571	3, 64	0.903
Emotional Regulation	0.585	3, 65	0.900
Distraction	1.679	3, 67	0.642
Optimal Desires	3.774	3, 65	0.287
Social Withdrawal	11.025	3, 65	0.012*

*p<0.05

DISCUSSION

One of the major aims of this study was to investigate the quality and the level of EE among families with children who suffer from epilepsy and families with non-disease children. It is noteworthy that, based on the analysis of the Five Minute Speech Sample, no difference existed for EE between families whose children presented with epileptic episodes and especially *tonikoklonikus spasmodus* and families with non-disease children. This finding is consistent with research supporting that there is no clear relation between epilepsy, EE and/or psychiatric co morbidity (21). However, this is partly due to methodological issues. Sample sizes for groups of participants with epilepsy used in research studies are usually small and consequently non-representative of the general population. Furthermore, only a few studies have utilized diagnostic instruments based on specific DSM-IV criteria. Even under these circumstances, there is usually no distinction between clinical disorders of Axis I and personality disorders of Axis II. In relation to the present study, the EE of only one parent was investigated, since in the majority of the cases participated, the child or the adolescent was mainly accompanied by his/her mother (90%). Only in the 10% of the cases both parents were present. However, co-operation with both parents was particularly difficult since father was present in the hospital only for a few hours, and conse-

quently, very difficult to contact him/her and establish a relationship to facilitate his participation in the study. Furthermore, in those cases coming from the rural areas of Greece, which comprised a significant sample for the study (21%), only the mother accompanied the child. Nevertheless, consistent to previous research studies (5,22-25), a number of ideologies, social attitudes and racial or biological reasons have determined that child's care basically belongs to mother even in cases where the child have a chronic illness. Furthermore, in the psychosocial literature of EE, a family is characterized by high EE even if only one of the family members expresses it towards the emotional sufferer (4). The process of the Five Minute Speech Sample used to assess family EE caused difficulties to parents and made them feeling embarrassed and paranoid in relation to the future use of the recorded speech. This possibly affected the way parents gave their speech. Consequently, it is doubtful if participants' Five Minute Speech Sample is indicative enough of the way they handle their EE in their daily life.

This study also aimed to examine the relationship among family functioning, adaptation mechanisms and EE. Specifically, no significant differences existed in participants' family functioning according to the level of EE. The only significant difference existed was between parents' emotional responsiveness and EE. Specifically, parents with high EE showed significantly lower levels of emotional responsiveness to their children than parents with low EE. In a similar way, a trend was observed for the relationship between adaptation mechanisms and EE: children and adolescents who were members of families with high EE utilized more often but less effectively the social support mechanism than those members of families with low EE did. Other researchers (26,27) have reported that withdrawal and non-flexible problem solving strategies are the most common ways that children with a chronic illness endorse more than non-disease children.

Another aim of the study was to investigate whether levels of psychopathology in the child are related to family functioning. Findings showed that no significant relationship was existed between low family functioning levels and child's psychopathology. It might be the case that children utilize effectively adaptation mechanisms and as a result they become resilient and suffi-

cient in their psychological well-being despite their chronic illness (28,29).

This study also aimed to examine differences in the level of psychopathology, family functioning and adaptation mechanisms between children/adolescents with epilepsy and the non-disease ones. Specifically, no significant differences existed in the experience of psychopathology levels between the two groups. However, consistently with previous studies, the present findings confirmed the frequency of a psychiatric disorder in children and adolescents with a chronic illness. The present findings indicated that separation anxiety disorder, dysthymic disorder and learning difficulties were the most prevalent in the group of children and adolescents with epilepsy. Previous studies (21,30) have found that epilepsy has a negative effect on children's learning process, while the psychological symptoms reported for children/adolescents with epilepsy are sadness, anger, guilt, obsessiveness, emotionality. The findings of the present study also indicated that the roles in families with non-disease participants were better structured than in families with children/adolescents with epilepsy. Furthermore, the present findings propose that children and adolescents with resilience, sufficient psychological functioning, and constructive coping/adaptation mechanisms will not develop psychopathology even in case they have a chronic illness such as epilepsy. Specifically, children and adolescents with epilepsy in the present study were found to develop effectively adaptation mechanisms towards their illness. For example, support from others, or, sometimes, social withdrawal were the significant mechanisms that children and adolescents with epilepsy endorsed to solve their problems more than their healthy peers. This difference in utilization of adaptation mechanisms might reflect the possibility that non-disease children do not realize the presence of problem or they generally do not have such a level of insecurity which would direct them to utilize this type of adaptation mechanisms.

Conclusively, the results of the present study propose that EE can only be an indicative measure of family atmosphere especially for children and adolescents with epilepsy. This measure might also reflect other dynamic interactions between parents and children. Thus, families with high EE are not in the position to respond effectively to the emotional needs of their children and especially to those needs which stem from a

chronic illness such as epilepsy. Consistently with international studies (20), children with epilepsy are presented with a significant level of psychopathology. However, these children show a level of resilience which helps them to adapt to the challenges and demands of their chronic illness through the utilization of adaptive coping mechanisms (such as social support), or even less adaptive (such as withdrawal). It generally seems that a positive family framework with emotional responsiveness, communication, structured roles and control of behaviour helps a child to utilize effectively coping mechanisms towards his/her chronic illness.

The data obtained in this study could enhance the better understanding of needs and desires for children and adolescents with epilepsy. Consequently, they could contribute to the development of suitable and valuable psychotherapeutic interventions for the most optimal psychosocial adaptation of children and adolescents with epilepsy. A potentially valuable intervention may refer to parents. Specifically, it could be targeted at the expression of their feelings and the modification of their attitudes and behaviours towards their children. This might help them to become more effective in their attempts to understand and contain their children's feelings for their chronic illness and, consequently, to direct them to develop positive coping skills.

The present study used cross-sectional data. Longitudinal research designs could further explore the present findings. Future research could use experimental designs with larger samples and secured participation from both parents to investigate the role of EE and adaptation mechanisms on the psychological and emotional functioning of children and adolescents with epilepsy.

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