

IDENTIFICATION OF FAMILY VARIABLES IN PARENTS' GROUPS OF CHILDREN WITH EPILEPSY

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ABSTRACT - Objective: To verify the effectiveness of the support group in the identification of family variables linked to epilepsy. **Method:** Pre-test were applied to parents of 21 children with benign epilepsy of childhood recently diagnosed, from 5 to 15 years, who participated in the groups at HC/Unicamp. There was a presentation of an educational video, discussion and application of the post-test 1. After six months, the post-test 2 was applied. **Results:** The beliefs were: fear of swallowing the tongue during the seizures (76.19%) and of a future mental disease (66.67%). Facing the epilepsy, fear and sadness appeared. 76.19% of the parents presented overprotection and 90.48%, expected a new seizure. In the post-test 1, the parents affirmed that the information offered had modified the beliefs. In the post-test 2, 80.95% didn't report great doubts about epilepsy and 90.48% considered their relationship with their children better. **Conclusions:** The demystification of beliefs supplied from the groups influenced the family positively, prevented behavior alterations and guaranteed effective care in the attendance to the child with epilepsy.

KEY WORDS: childhood epilepsy, family variables.

Identificação de variáveis familiares em grupos de pais de crianças com epilepsia

RESUMO - Objetivo: Verificar a eficácia do grupo na identificação de variáveis familiares ligadas a epilepsia. **Método:** Aplicou-se o pré-teste em pais de 21 crianças, de 5 a 15 anos, com epilepsia benigna da infância de diagnóstico recente, que participaram dos grupos no HC/Unicamp. Seguiu-se apresentação do vídeo educativo, discussão e aplicação do pós-teste 1. Após seis meses, foi aplicado o pós-teste 2. **Resultados:** Apareceram crenças como: medo de engolir a língua durante a crise (76.19%) e de apresentar doença mental no futuro (66.67%). Frente à epilepsia, apareceram sentimentos de medo e tristeza. 76.19% dos pais apresentaram superproteção e 90.48%, expectativa de nova crise. No pós-teste 1, os pais afirmaram que informações oferecidas modificaram as crenças. No pós-teste 2, 80.95% não relataram grandes dúvidas sobre epilepsia e 90.48% melhoraram a relação com seus filhos. **Discussão:** A desmistificação de crenças e preconceitos nos grupos de pais, influenciou positivamente a família, prevenindo alterações de comportamentos e garantiu cuidados efetivos no atendimento à criança com epilepsia.

PALAVRAS-CHAVE: epilepsia infantil, variáveis familiares.

Epilepsy is a common chronic neurological disease in childhood with high incidence of psycho-social difficulties that affect the social adjustment and the quality of child's life and his family¹. The diagnosis of a chronic disease like epilepsy, generates a series of feelings in the parents, that almost always include: fear, anger, guilt, sadness, anxiety, confusion, denial, concern, fear of the epilepsy coming on accompanied by personality disorders and fear of the effects of medications². These feelings usually provoke inappropriate behavior in the parents, such as: overprotection, permissiveness, rejection and low expectation in relation to their children. The parents treat them as sick, believing that any activity can precipi-

tate a seizure³. Many times, the excess of care leads the parents to end up forgetting about the other members of the family. From these reactions, the children learn quickly that there is something wrong with them and consequently they begin to present inadequate behavior of dependence, insecurity, irritability, immaturity. The parents, in this way, perpetuate the stigma, influencing their children to feel apprehensive and full of prejudice in relation to epilepsy. In this context, the family begins to have less proximity and more restrictions of behavior, activities and communication³.

As the seizures are unexpected and they happen in an unexpected frequency, the parents use inap-

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propriate behavior to compensate for the lack of control they feel towards them, which contributes to the problems of the children's adjustment, besides generating family stress, related to tension in the relationships among parents and children, spouses and siblings, interfering negatively in the quality of life. Several studies confirm that the family situation is one of the most important predictive factors of the psycho-social problems in children with chronic diseases^{4,5}. The behavior of parents of children with epilepsy depending on the type of seizures, severity of epilepsy, presence of other disorders, medication effects and also on the psycho-social-cultural factors as beliefs, aspects related to the family and social dynamics and the child's individual characteristics^{6,7}.

There are many myths and prejudices in relation to epilepsy which brings about serious damages to the behavioral and psycho-social adjustment of people⁸. The most common beliefs are: epilepsy causes mental disease; people with epilepsy will swallow the tongue during the seizure; the seizure appears when somebody reprimands (says "no") the patient. Most of the feelings and the parents' reactions are based above all on the ignorance of the disease and the misunderstandings and fears of the seizures, medications, what they can and what they cannot do, stigma and discrimination⁹.

In this context, psychology appears with a wider approach, considering the individual as a whole. It evaluates the impact of the disease in the person's life and his/her family, the quality of life, the social, psychological and emotional aspects (behavior in different situations, interpersonal relationships, academic abilities, perceptions and feelings) and it prevents or reduces the risks of psychological complications inherent to the diagnosis of epilepsy^{4,6,7}.

Austin and collaborators¹⁰ used an intervention program with parent groups that discusses the child's psycho-social difficulties and his family. The group work provides an opportunity for exchanging experiences and family existences, besides facilitating the interaction between parents and health professionals. It is the aim of this groups to assist in the knowledge of information, of children's reactions in the seizures; in the fears, anxiety and the parents' confusions regarding the infantile epilepsy. The group is an opportunity to share ideas, to express the fears and to exchange experiences with other people living in similar situations. This group intervention possesses a strong potential to provide well-being, reducing the parents' anxiety, helping them see their children in a more positive way and help with the child's adjustment and his family^{2,4}.

The objective of this research is to verify the effectiveness of the parent groups, in identifying and clearing the family variables linked to the parents' dynamics and children with epilepsy.

METHOD

Subjects

The members who participated in this research were 16 mothers and 10 fathers of 21 children (12 boys and 9 girls) with benign epilepsy of childhood which have been recently diagnosed (less than one and a half year), with ages between 5 and 15 years. Out of these children, 57.14% had partial seizures and 42.86%, generalized seizures. The parents participated voluntarily in the support groups at outpatients clinic of Neurology at HC/Unicamp.

Instruments

Investigation protocols (questionnaires) were used in this research with the objective of evaluating the different aspects which affect the life of children with epilepsy, as well as the impact of the disease on the family dynamics, that is to say, the involved family variables. These protocols were divided into pre-test and post-test (Appendix).

Pre-Test:

- *Child's identification*: child's personal data and his disease.
- *Protocol of identification of irrational beliefs*: it seeks the identification of ideas and prejudices linked to epilepsy and the child's behavior.
- *Protocol of the impact of the disease in the family*: it tries to identify feelings and reactions of the epilepsy in the family, the most stressing factors and the most affected areas (social, family, school, health, self-concept).
- *Protocol on the relationship of the child and family*: it seeks the identification of the children's and parents' behavior and the child's social relationship.

Post-tests 1 and 2:

- *Protocols of identification of the psychological and behavioral changes*: it seeks the identification of alterations in the parents regarding behavior, interactive attitudes and beliefs, in relation to previous information regarding epilepsy.

Procedure

The parent groups were supervised by the psychologist responsible and the sessions lasted for approximately one hour. Firstly, the pre-test tried to evaluate the beliefs, the impact of the disease in the family, the parents-children relationship and the social and psychological aspects.

Later, there was the presentation of an educational video "Guiding the parents"¹¹, which brings information on: epilepsy and epileptic seizures, types of seizures, attitudes when facing a seizure, treatment with medication,

APPENDIX

Pre-test:

- Examples of questions of *Protocol of identification of irrational beliefs*:

1. Is epilepsy a contagious disease ?

 yes no _____

4. Do you fear that your child might get any mental disease?

 yes no _____

11. Do you think your child can improve with energization or blessings?

 yes no _____- Examples of questions of *Protocol of the impact of the disease in the family*:

1. Which was the most difficult phase?

 when your child had the first seizure when you got to know that your child had epilepsy during the treatment

Comments _____

2. What did you feel when your child had the first seizure? Why did you feel that ?

 rage confusion fear depression sadness nervous disappointment anxious shame fright denial sorrow rejection blame others: _____

Why? _____

- Some examples of questions of *Protocol on the relationship of the child and family*:

2. Do you think your child's behavior was different before he began having seizures?

 yes no _____

5. What is your child's relationship with his siblings like? _____

11. Do you notice any relationship between your attitude and your child's behavior?

 yes no _____

Post-tests 1 and 2:

- Example of question of *Protocols of identification of the psychological and behavioral changes*:

1. Did this information modify some beliefs you had about epilepsy?

 yes no Which? _____

school, beliefs and support groups. A discussion was followed on epilepsy, treatment, social and psychological aspects involved.

Right after, there was the application of the post-test questionnaire 1 to the parents, that had as objective to verify whether there were changes regarding attitudes, behavior and beliefs in respect to epilepsy and family relationship.

The post-test 2 was applied six months later and aimed at evaluating the persistence of the changes that happened in the family situation.

RESULTS

PRE-TEST

The beliefs that appeared most were: fear of the child swallowing the tongue during the seizure (76.19%); fear of the child presenting a future men-

tal disease (66.67%); greater dependence of the child because of epilepsy (52.38%).

Regarding the impact of the disease in the family: 52.38% of the parents think the first seizure was the most difficult phase. In this situation, the feelings that appeared most were: fear (85.71%), confusion (52.38%) and sadness (19.05%).

The emotional reactions facing the epilepsy diagnosis were sadness (47.62%), confusion (33.33%) and fear / preoccupation (19.05%).

Parents reported the expectation of the seizure as being the most stressing factor in the disease (57.14%). In relation to this aspect, because of their concern (47.62%) they offered exaggerated care (47.62%).

For the parents, the epilepsy of the child affects:

the relationship with the family (52.38%); the social activities (52.38%); the child's behavior (47.62%); the relationship with friends (38.10%).

They believe that the child's disease had changed in the family life: the parents' relationship with the work (66.67%); the relationship among the members (42.86%).

Regarding the child and family relationship: 66.67% of the parents believed that the child's behavior was different before the onset of seizures, being: 38.10% thought that this change may have occurred due to the disease (seizures) and 19.05% thought that it happened due to the anti-epileptic medication.

In their relationship with the child, 76.19% constantly protect him; 38.10% was afraid of reprimanding their child; 80.95% didn't tell other people about the epilepsy and 90.48% lived in the expectation of a new seizure. 95.24% of the parents had changed the way of dealing with the child after the occurrence of the first seizure and they began to offer greater care (66.67%) and to have greater concern (80.95%). 38.10% of the children had their seizures controlled, which tranquilized the parents.

POST-TEST 1

All the parents believed that the offered information modified some beliefs that they had about epilepsy, especially related to the fear of the child swallowing the tongue and presenting some type of mental disease.

Having cleared the doubts, there was a decrease in fear and stress related to epilepsy. All of them got to notice the relationship between their behavior and the child's behavior, believing that it was possible to change the way of looking at and behaving in relation to him.

As proposals of change for the following six months, appeared: to decrease the overprotection (28.57%); to talk more (14.29%); to be calmer (14.29%).

POST-TEST 2

80.95% of the parents didn't have great doubts about epilepsy, their beliefs and treatment. It still appeared the beliefs that the child could swallow the tongue during the seizure (28.58%) and could present any future type of mental disease (21.44%).

The discussion done six months before had helped 90.48% of the parents to decrease anxiety and stress in relation to the disease. That improved the relationship with their children, and after the intervention, 85.71% of the parents changed their behavior

in relation to their child: there were more chats and fewer screams (23.81%), more patience (19.05%), more limits and less overprotection (14.29%).

DISCUSSION

It is known today that epilepsy can be associated to a great variety of social and psychological difficulties, and these can be more harmful than the seizures¹². The cultural perceptions of epilepsy are negative and because of that, there is still a lot of stigma related to this condition. The results of this research showed that there was a high frequency of altered behavior regarding the relationship in families that had children with epilepsy. The presence of beliefs and the ignorance of the disease and its treatment seem to contribute for these results. Souza & Guerreiro⁶ and Lothman & Pianta¹³ related the doubts as usually translated in insecurity, fear and consequent overprotection behavior and the parents' permissiveness in their relationship with the children.

The presence of beliefs in this study (90.48% of the parents) seems to be related to the ignorance about epilepsy and its treatment, that had also generated superstitious behavior, overprotection and concerned feelings, fear and insecurity in the parents, hindering the relationship of them with their children with epilepsy. One of the beliefs that appeared most talked about the fear that the parents possessed of the child swallowing the tongue (76.19%). In agreement with Ford and collaborators⁸ that idea is quite common and the parents usually place fingers, pens, rulers inside the child's mouth. Another belief reveals the concern of epilepsy being accompanied by disease or mental retardation (66.67%), coinciding with data by Thompson and Upton³. When the parents believe that the children, because of the epilepsy, are more dependent (52.38%), that seems to be a consequence of the previously reported beliefs.

The first seizure was considered the most difficult stage by most of the parents. That happened because this was something new and, most of the times, unknown, bringing conflicts into the family relationships and feelings of fear, confusion and sadness. These reactions are inevitable, taking into account degree of anxiety generated by this experience⁴. Consequently, a series of irrational fears appear to limiting the child's life which are harmful to the good family relationships.

The diagnosis of epilepsy generated in the parents feelings of sadness, confusion, fear and concern, which coincides with the data of Lewis and

colaborators² and Fejerman & Caraballo⁴. These reactions prevented them from helping their children appropriately and from communicating. Epilepsy can affect the patient's life and of his/her family in almost all the aspects: school, social activities, behavior and relationship. All these have strong influence on the child's adjustment and his family¹⁰. Most of the parents thought the children were different before the seizures began: most of them were calmer while others were more excited. They had also changed the way of behaving in relation to their children and they placed restrictions which, according to Carpay and colaboradores¹⁴, could influence the development of children with epilepsy unfavorably.

The overprotection appeared in 76.19% of the parents and according to Fejerman & Caraballo⁴, this is one of the parents' most habitual conducts with their children with epilepsy. They believe that their child is more vulnerable and they take a series of measures to protect him from frustrations, accidents and other things that can result in risk. Therefore, they avoid threatening the child with fear of the seizure (38.10%). Unhappily, this care immobilize the child, making them more passive in his environment and interfere in his psycho-social development.

Most of the parents (90.48%) frequently expect new seizure, but 57.14% considered this aspect as a stress factor. There was a significant relationship between the parents' peacefulness and control of seizures. Fejerman & Caraballo⁴ demonstrated that this control led to a good psycho-social, physical and conduct a good prognostic of children with epilepsy.

When the parents expose their doubts and anxieties to the professionals involved in the treatment, they can be well instructed in how to act in seizure situations. This can avoid stress and family tension and promote better adjustment of the child. It is as if they needed permissions and encouragement to impose limits and to treat the children normally⁸. In the group, the parents had the possibility to place their doubts, fears and consequently reduce the stress and prevention of behavior alterations.

As we get to control the parents' anxiety about the child's condition, we observed a decrease in excessive dependence, social inability and family disturbances. When one works with the perceptions and the parents' behavior, a positive influence is gotten in the child's psycho-social development. Though

there is smaller restriction of the children's activities and larger expectation in relation to these children¹⁵.

The investigation of the degree of control of behavior and adjustment to the disease in the family is very important, because it allows the prevention of inadequate behavior and, consequently, promotes an improvement in the quality of life of children and their families. The demystification of beliefs and prejudices, through a social support with correct and appropriate information about the disease and its treatment, supplied in the parents' groups, influenced the family positively and also guaranteed more effective care in the attendance to the child with epilepsy promoting better adjustment^{3,16-18}.

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REFERENCES

- Jacoby A. Epilepsy and the quality of everyday life: findings from a study of people with well-controlled epilepsy. *Soc Sci Med* 1992;34:657-666.
- Lewis MA, Hatton CL, Salas I, Lecite B, Chiofalo N. Impact of the children's epilepsy program on parents. *Epilepsia* 1991;32:365-374.
- Thompson PJ, Upton D. Quality of life in family members of persons with epilepsy. In Trimble R, Dodson WE (eds). *Epilepsy and quality of life*. New York: Raven Press, 1994;2:19-31.
- Fejerman N, Caraballo R. Impacto de la epilepsia en el niño y su familia. In Devilat M (ed). *La epilepsia en Latinoamérica*. Santiago de Chile: Iku Editorial, 2000;245-254.
- Trimble R, Dodson WE. *Epilepsy and quality of life*. New York: Raven Press, 1994.
- Souza EAP, Guerreiro MM, Guerreiro MM. Qualidade de vida e epilepsia. In Guerreiro CAM (ed). *Epilepsia São Paulo: Lemos Editorial*, 2000;223-229.
- Hoare P, Kerley S. Psychosocial adjustment of children with chronic epilepsy and their families. *Dev Med Child Neurol* 1991;33:201-215.
- Ford CA, Gibson P, Dreifuss FE. Psychosocial considerations in childhood epilepsy. In Dreifuss FE (ed). *Pediatric epileptology classification and management of seizures in the child Massachusetts: John Wright & Sons*, 1984;18:277-295.
- Devinsky O, Penry JK. Quality of life in epilepsy: the clinician's view. *Epilepsia* 1993;34(Suppl 4):S4-S7.
- Austin JK, Smith MS, Risinger MW, McNelis AM. Childhood epilepsy and asthma: comparison of quality of life. *Epilepsia*. 1994;35:608-614.
- Souza EAP. Avaliação de vídeo educativo sobre epilepsia na infância. *JLBE* 1994;7:103.
- Collings JA. Psychosocial well-being and epilepsy: an empirical study. *Epilepsia* 1990;31:418-426.
- Lothman DJ, Pianta RC. Role of child-mother interaction in predicting competence of children with epilepsy. *Epilepsia* 1993; 34:658-669.
- Carpay HA, Vermeulen J, Stroink H - Disability due to restrictions in childhood epilepsy. *Dev Med Child Neurol* 1997;39:521-526.
- Mitchell WG, Scheier LM, Baker SA. Psychosocial, behavioral and medical outcome in children with epilepsy: a developmental risk factor model using longitudinal data. *Pediatrics* 1994;94:471-477.
- Fernandes PT, Souza EAP. Inventário simplificado de qualidade de vida na epilepsia infantil: primeiros resultados. *Arq Neuropsiquiatr* 1999;57:40-43.
- Amir M, Roziner I, Knoll A, Neufeld MY. Self-efficacy and social support as mediators in the relation between disease severity and quality of life in patients with epilepsy. *Epilepsia* 1999;40:216-224.
- Hanai T. Quality of life in children with epilepsy. *Epilepsia* 1996;37(Suppl 3):28-32.