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RESEARCH

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Epilepsy bearing children: viewpoint and familyhood

Crianças com epilepsia: percepção e vivência de famílias

Niños con epilepsia: percepción y vivencia de familias

Délis Renardin¹; Leticia Gramazio Soares²; Larissa Gramazio Soares³; Ieda Harumi Higarashi⁴; Isabella Schroeder Abreu⁵

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ABSTRACT

Objective: The study's main purpose was to describe the perception and the living of families of children with epilepsy. **Methods:** It was performed a descriptive study with a qualitative approach, carried out in Guarapuava city, Paraná State. The data collection was performed in January and February 2016, through semi-structured interviews with seven relatives of the children with epilepsy. The reports were transcribed and submitted to the Analysis of thematic content modality. **Results:** The results highlight the social impact of the disease in the family, from the diagnosis time, with implications for the development of attitudes of overprotection, to changes in family dynamics, and the stigma of epilepsy. **Conclusion:** The unveiling of the perception and experience of families, reveals that this may influence the care of the child with epilepsy. Furthermore, it emphasizes the importance of supporting those families in care, by means of a humanized and qualified assistance, based on the real needs of each family unit.

Descriptors: Family nursing, family, child, chronic disease.

RESUMO:

Objetivo: descrever a percepção e a vivência de famílias de crianças com epilepsia. **Método:** Estudo descritivo de caráter qualitativo, realizado no município de Guarapuava/PR. Os dados foram coletados nos meses de janeiro e fevereiro de 2016, por meio de entrevistas semiestruturadas realizadas junto a sete familiares de crianças com epilepsia. Os relatos foram transcritos e submetidos à análise categorial temática. **Resultados:** Os resultados ressaltam o impacto social da doença na família, desde o momento do diagnóstico, com implicações para desenvolvimento de atitudes de superproteção, até mudanças na dinâmica familiar, além do enfrentamento do estigma da doença. **Conclusão:** O desvelamento da percepção e da vivência de famílias de crianças com epilepsia permitiu verificar em que medida estas influenciam o cuidado dispensado a elas, ao mesmo tempo em que ressalta a importância do apoio a estas famílias no cuidado, por

- 1 Nursing Graduate by the Universidade Estadual do Centro Oeste (UNICENTRO).
- 2 Nursing Graduate by the UNICENTRO, PhD student enrolled in the Nursing Postgraduate Program by the Universidade Estadual de Maringá (UEM), Professor of the Nursing Department at UNICENTRO.
- 3 Nursing Graduate by the UNICENTRO, PhD student enrolled in the Nursing Postgraduate Program by the Universidade Federal do Paraná (UFPR), Professor of the Nursing Department at UNICENTRO.
- 4 Nursing Graduate by the UEM, PhD in Nursing by the Universidade de São Carlos (UFSCar), Professor of the Nursing Department and the Nursing Postgraduate Program at UEM.
- 5 Nursing Graduate by the Universidade Federal do Paraná (UFPR), PhD in Nursing by the Universidade São Paulo (USP), Professor of the Nursing Department at UNICENTRO.

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meio de uma assistência humanizada e qualificada, pautada nas reais necessidades de cada unidade familiar.

Descritores: Enfermagem familiar; Família; Criança; Doença Crônica.

RESUMEN:

Objetivo: describir la percepción y la vivencia de familias compuestas por niños con epilepsia. **Método:** Estudio descriptivo de carácter cualitativo, realizado em El municipio de Guarapuava-PR. Los datos fueron recolectados em El mes de enero y febrero de 2016, por medio de instrumento semi estructurado, se obtuvo La participación de 7 familiares de niños con epilepsia. Los relatos fueron transcritos y sometidos al análisis de Contenido modalidad temática. **Resultados:** llaman La atención sobre el impacto social de La enfermedad em La familia, desde el momento del diagnóstico, com implicaciones para el desarrollo de actitudes de sobre protección, hasta los cambios ocurridos em La dinámica familiar, además del estigma de la epilepsia. **Conclusión:** La comprensión de La percepción y la vivencia de las familias, revela que ésta puede influir em el cuidado del niño con epilepsia. Además denota La importancia de apoyar a La familia em el cuidado, con una asistencia pautada em las reales necesidades de La familia y por lo tanto, más humanizada y calificada.

Descritores: Enfermería familiar; Família; Niños; Enfermedad crónica.

INTRODUCTION

Reports on epilepsy date back to remote times, with records dating back to 2,500 B.C. Over the last 4,500 years, the vision about epilepsy has evolved from a primordial idea, which attributed the disease to a kind of divine punishment, to a scientific conception involving the pathways of impulse driving in the brain. Now, it is known that epilepsy is the result of an abnormality in brain functions, and that its cause may be linked to pathological processes and syndromes, resulting in repeated epileptic seizures.¹

It is a neurological condition that arises most commonly during early infancy, impacting throughout the development of the individual, because of the manifestation/experience of this condition and specific needs of support, besides the respective influence on the family dynamics.^{2,3}

This disease can unleash several effects in people affected, at the neurological, school, family and social level, and can cause serious illnesses if there is no adequate intervention in this area.⁴

At the same time, family members tend to adopt positions that limit the child's social life, due to the concerns about the risk of injury, imposing stricter restrictions on daily activities. Those attitudes, often reinforced by social beliefs and lack of information, resulting in a situation in which children with epilepsy experience greater social isolation and difficulty in social and school relationships.⁵ In addition, difficulties may occur in the process of developing independence and self-esteem, as well as the ability to enjoy the general health benefits.³

In the context of research in Pediatrics, it is noticed the need to emphasize the accomplishment of studies focused on the children's families with a chronic condition. In particular, regarding the approach to epilepsy, currently, there are scarce scientific evidence available that address the issue from the perspective of the specific biopsychosocial context of these families. Hence, recognizing the important role of the family

member, as a member and protagonist of the care process, taking into account the centrality of the family as the child's first social space and as a promoter of the care and well-being of its members, is an essential condition for research in this area of knowledge.^{6,7}

Considering the abovementioned considerations, it is possible to highlight epilepsy as a chronic and complex disease that brings important repercussions in several spheres of the child's life and in his family. The relevance of family involvement in this type of problem is explicit, and the role of parents turns out to be one of the crucial aspects of the children's integration since parents are the main caregivers.

This article is justified by the need to better understand the perceptions and family living of children with epilepsy, as a strategy for the improvement of professional knowledge with a view to increasing qualification of the assistance provided to this population.

Therefore, the present study sought to address epilepsy that, despite being a common chronic illness in childhood, it has been little explored in nursing area research, especially regarding its repercussions in the family universe. Thus, the objective of the study was to describe the perception and families living with childhood epilepsy.

METHODS

It is a descriptive study with a qualitative approach, carried out in *Guarapuava* city, *Paraná* State.

The research subjects were 07 relatives of children diagnosed with epilepsy, being six mothers and one father. The participants were selected from a doctor's office specialized in Neuropediatrics, in which the children performed monitoring. Firstly, family members were contacted by telephone in order to schedule the home visit for the interviews.

Inclusion criteria were: be a family member of children between 5 and 12 years old, diagnosed with epilepsy for at least six months; have an age equal to or greater than 18 years old and reside in the municipality of *Guarapuava-PR*. Exclusion criteria: relatives of children under 5 years old, with the presence of other comorbidities and the impossibility of a telephone contact.

Data collection was performed in the months of January and February 2016, through a home visit to families. Interviews were conducted from a semi-structured script, composed of questions related to the sociodemographic data and a guiding question: "Tell me about living with a child with epilepsy." The interviews had an average duration of 40 minutes and were recorded for later full transcription.

Data were analyzed according to the thematic content analysis technique, proposed by Bardin,⁸ which consists of three stages: pre-analysis, which corresponds to the organization phase, aiming to operationalize and systematize the initial ideas; exploitation of the material, which consists of the codification of data, with its systematic transformation to be aggregated into units; and treatment of the results, phase in which the inference and interpretation is realized.

The study complied with the formal requirements contained in the national and international regulatory

standards for research involving human beings, and it received approval by the Human Research Ethics Committee from the *Universidade Estadual do Centro Oeste (UNICENTRO)*, under the No. 1.288.123.

RESULTS AND DISCUSSION

As results, data were described regarding the characterization of the interviewees with the goal of contextualizing the subjective reality of the participants, in order to guide the individualized analysis of the study's reports. Subsequently, the data on the central theme of the study are presented, the perception and the families' experience of children with epilepsy.

The universe of this research was composed of 07 (seven) relatives of children diagnosed with epilepsy, six mothers and one father. The children whose family members participated in the study resided in *Guarapuava-PR*, with ages ranging from 6 to 11 years and 9 months old. At the time of the study, everyone attended school and none attended the *Associação de Pais e Amigos dos Excepcionais (APAE)* [Parents and Friends Association of the Exceptional People]. The relatives, respondents of the research, had age ranging from 25 to 42 years old, with an average age of 35.8 years old; five were married and two were divorced. In relation to religion, four were Catholics, two evangelicals and one Adventist. As far as the profession was concerned, four referred to being housewives, two were small entrepreneurs and one was a pedagogue. Schooling ranged from complete high school to full tertiary education.

Consistent with the literature, most of the caregivers of children were their mothers.^{2,9} The mother figure is usually the one who assumes the family responsibilities related to the disease condition of the family members, which means that, in most cases, the male figure becomes the only provider of the family, and therefore, composing a new family configuration, with the reorganization of the members to meet the demands imposed by the pathology.

A congenital study confirms the finding, as it pointed out that the diagnosis of epilepsy has a great impact on the family dynamics, with 81.8% of the mothers being fully dedicated to the care of the family, and most of the times the husband/father becomes the only family economic support.¹⁰

Concerning the central theme of this research, based on the analysis of the interviewees' reports, four thematic categories emerged: the impact of the diagnosis; overprotection; changes in family dynamics and stigma, thus composing the corpus of the analytical process, as presented and discussed below:

The diagnosis' impact

One of the most striking factors related to the theme of childhood epilepsy is the repercussion of the diagnosis in the family context. This event was remarkable in the lives of the families that were part of this study.

It is known that epilepsy, as a chronic disease, causes a series of doubts about the future to emerge in the family, and in relation to possible repercussions and consequences

in the family and social life of the child. In this perspective, the literature warns that it is essential to monitoring family members by a multi-professional team, from the diagnosis, aiming at the integrality of health care.⁶

The family members' speech M5 and M2 reveals the impact that the diagnosis of epilepsy brought to the family:

This diagnosis is terrible, because a person with epilepsy has several crises, several times, and so, it's terrible because you have no security at all, because this person is well, and suddenly can already have a crisis. (M5)

It was not easy, because we never want children to have anything, I was very sad, I cried a lot [...] at first it was very complicated, I was very sad, everything happens to a child, it hurts us. (M2)

Given these reports, it is possible to verify that, along with the diagnosis, the family experiences the insecurity about the confrontation of this situation over the years, the concern is usually related to the quality of life, learning, autonomy, and future of the child.

Therefore, the discovery of the diagnosis of a chronic disease in the family, usually unleashes a series of emotional reactions, reports of fear, insecurity, depression, suffering, anguish, and feelings of guilt are common.^{4,11,12}

The literature also refers to the way in which the diagnosis usually generates a shock in the relatives. In general, they seek to know why the child is not well, and a priori, do not expect to be a serious, incurable and chronic disease.¹³ These aspects are evident in the following speeches:

When the doctor noticed that she had a "seizure", because we were layperson, we do not understand, why she needs to take a medicine for life, I worried a lot, because I did not know what it was, I did not understand why she has to take a black stripe drug and make such a long treatment. I was very nervous. (M4)

At the time it was desperation, I thought I was losing my son. (M3)

It is possible to perceive in this unit of context that the feelings experienced by the relatives reveal the confrontation with an unimaginable and unexpected situation, in which they often end up not knowing what to do. Because they do not know, among other things, what caused the pathology, feelings of guilt for not being able to realize the dream of the perfect child are common.

In this perspective, parents realize the need to understand the diagnosis, adapt to the requirements imposed by the symptoms and treatments, have to deal with diverse information and, at the same time, provide conditions for a life as normal as possible, not focusing excessively on the differences imposed by the disease.²

Diagnosis represents one of the most important occasions, reinforcing the need for a multi-professional team with the goal of minimizing the suffering arising from having to

deal with something that is not fully known.⁶ The better the preparation of the parents to receive the diagnosis, and the more qualified the process of training them to care for the child with epilepsy, the better the adaptation, considering the children's dependence on their families, for any taken decision-making and for more effective communication with health services.²

Bearing in mind this analysis, it is important to get help from health professionals in the fight against the excessive anxiety of the parents, clarifying their doubts, since their in-depth knowledge about the disease is a good strategy to ward off some "ghosts". Health care professionals team should be supportive figures to preserve the health of the caregiver and the process of taking care of the child.⁹

Therefore, the promotion of management of family stress, fears and concerns, after the diagnosis of the child with epilepsy, can lead to better results in the quality of life of the children and their family.¹⁴

Overprotection

In this category, we discuss the overprotection exerted by parents considering the impact of the diagnosis. Such a response is probably related to the feeling of uncertainty and the lack of information about epilepsy, which ends up contributing to the family members assuming defensive behavior towards the raising of their children. Rigorous supervision and restriction of activities are examples of overprotective behaviors aiming to avoid crises.

The national and international scientific literature presents results that corroborate these findings, and which refer to the behavior of the parents. Thus, several authors mention that when the children present this condition, the parents end up adopting an attitude marked by the excess of protection.^{2-4,14-6}

The following reports illustrate the conclusions drawn by the literature:

The fact is that, actually, we get a little insecure, afraid that the child has seizures again. But I try to police myself, control me a lot, so I do not stay on top, I do not let him get into a pool anymore [...] We always have a concern, [...] I'm careful, I do not leave him alone at home (M3).

We protect more, in cases when we see that she will be very nervous, that she cries a lot, we will find a way to change the subject and even not to attract attention. We are already more worried, she never had seizure because she was nervous, but, that we are afraid to reconcile... Because in fact, we do not know what is the triggering factor (M2)

It's a mother overprotection, I guess. (M4)

As shown in the last report, the lack of information regarding this clinical condition may act as a pole generating behaviors of overprotection.⁹

In this scenario, a study developed by CUKIERT¹³ found that this type of overprotective behavior ends up making children with epilepsy dependent because their relatives treat

them as patients. These attitudes often lead children to social isolation, which helps them become fearful, insecure, with adjustment disorders, preventing them from developing social skills, which reduces their quality of life.^{14,16}

According to the Psychosocial Theory of Development, proposed by Erikson, the phase of the 6 to 11 years old, age in which the children of the present study are, is called the phase of Constructivity x Inferiority, which presents importance in the formation of the personality and human identity. During this period the child is being literate and attending school, which extends his social life beyond the family universe, thus requiring greater socialization, joint work, cooperativity, and other skills. When faced with difficulties or limitations in the exercise of such abilities, the child will come to live inferiority, instead of constructivity. In the case of the child with epilepsy, the overprotection of the parents may be a hindrance to the formation of the subject's personality.³

Under this perspective, it is understandable that family members, because they are emotionally involved directly with their children, have a natural reaction of protecting them, which ends up interfering directly in their interaction process, depriving them of much-needed stimulus to the development.

Taking into consideration this discussion, it is essential to implement actions that contemplate health education for families of children with epilepsy, with the intention of establishing a more effective communication channel, and also increase their knowledge of the disease. Families can benefit from discussions with health professionals about medication use, side effects, and their impact on the child's daily functioning.¹⁴ In this respect, the role of the nurse as an active agent in this process is highlighted, which should provide a care plan and direct the treatment so that families feel safe and welcomed in the health services.

Changes in family dynamics

This category describes the changes in family dynamics after the diagnosis. Then, there is a rearrangement in the family dynamics to receive the sick child. The family experiences many changes to provide adequate care for the child. The literature points out that chronic childhood illness affects the members of the family microsystem, who restructure their daily organization to receive and care for the sick child, thus resulting in a structural crisis in the family.⁶ Family functioning plays a central role in the adaptation of the child and the whole family to chronic child health conditions.²

The restructuring of the daily routine according to the demands imposed by the condition, reflected in the family well-being, is evidenced in the following statements:

I did not sleep well since she had crises like this, I cannot anymore. And I could not keep the door shut, you know? Any noise from her, you know, I'd wake up, get up from the bed, I was already awake. I was already running to see, I was very insecure, stayed like this for a year and a half (M6).

We did the first aid training, so I could help her when she was in crisis. In my college, the biggest incentive was her, because the first time she had a crisis, we did not know what to do, we did not know which way to go, we did not know what was happening, we were frightened, scared... (M5).

The above reports demonstrate the great difficulty encountered by family members in maintaining the routine, because the concern is so great that it requires a change in personal and professional life so that they can take a better care, and attend to the needs of their children.

The experience of chronic illness in childhood requires the family caregiver, the retraction of their daily activities, compromising their interpersonal relationships and modifying their way of life.¹²

In this sense, the literature cites the caregiver's overload, perceived as a risk factor for the child's quality of life, since it can lead to physical, psychological, social and financial problems,⁹ which in turn may end up affecting not only the caregiver well-being but also of the child under their care.

A study carried out in the state of *Paraná* showed that 52% of the families had a member that changed their working condition to care for the child or adolescent with chronic neurological disease.¹⁷

The changes in family dynamics are more intense at the moment of the discovery of the disease, when the impact of the diagnosis occurs, as evidenced in the speech below:

At first, I did not even sleep, every time she moved, I was already like that, on top of her, to see how many times she was in crisis, and to see if she was giving more than once in the night (...) (M2)

An international study on the subject strengthens these conclusions by establishing that family stress is more intense in the first year after diagnosis because families are dealing with something new, such as the treatment regimen and recurrent crises. According to the evolution of time, the impact of these aspects on the quality of life of children and youth is reduced, as a result of the adaptation process to the disease and of the familiar emotional control.¹⁴

Stigma

In this category, it was evidenced that the association of epilepsy with negative stereotypes is perceptible, through the stigma that still persists in society, resulting in attitudes of discrimination and prejudice and, in some cases, even exclusion.

The term stigma is used in relation to extremely derogatory attributes in the social context in which the individual is found, and that classify him as someone who has diminished, with weaknesses or disadvantages,¹⁸ and can consolidate himself as a barrier to successful treatment.¹⁹

However, there is not a single cause of stigma, since this usually stems from the lack of information, the behavior, and interpretation of people in different situations. Therefore, one of the ways to reduce stigma is to promote adequate knowledge

about the disease to the population.²⁰ The following reports highlight this aspect of the disease:

When they see a person in crisis or know that this person has epilepsy, everyone is suspicious, with that look of fear, fear that the person sits close, has a crisis, that the person falls and someone has to help because still there is a lot of prejudice (M5).

It is an insecurity, you are in the midst of the people and she has a crisis, because of the prejudice issue, and as a mother, I am apprehensive about it, with the reaction, how it will be because it is a very big uncertainty.

I worry a lot about prejudice because it exists! For example, a situation that you see on the street, a person having epileptic seizures, gives you a bad feeling, you cannot do anything, because you have nothing to do until the crisis passes. I'm afraid because people keep looking, it's complicated (M2).

Through the reports of relatives, it can be verified that there is a great concern with regards to prejudice, which they know exists and that can even lead to the retraction of their child from social interaction. This is a constant stress issue because the unpredictability of crises makes the parents themselves unsafe and fearful that they will happen at any time, exposing their children to discrimination.

Concerning the aforesaid, it is possible to perceive that misconceptions and prejudices vis-à-vis epilepsy, designate children with neurological diseases as being delayed, retarded or crazy, generating all sorts of stereotypes that affect their self-esteem and quality of life.²⁰

The literature makes reference to the consequences of stigma, emphasizing that these tend to worsen when the school environment is considered.¹⁸ With the purpose of demystifying erroneous conceptions about the cognitive capacity of children with epilepsy, in another study on the subject, no learning problems were evidenced as a result of the aggravation, but rather, problems of discrimination that the epileptic child faces, leading to the establishment of obstacles to education.⁴

Another concern present in the parents' reports referred to the onset of seizures. Regarding this aspect, the literature indicates that difficulties are related to the fear of the crisis occurring in public, as well as the impediments that the child or adolescent happens to have as a result of the diagnosis.¹⁸

It is also evident that children and their families experience feelings of stigmatization deriving from restricted social relationships and ineffective support networks.²¹

Another factor that contributes to stigma, according to the literature, is the lack of information. For the purpose of putting an end to discrimination, the dissemination of information about this topic is essential, seeking social insertion and understanding of the condition of the child with epilepsy.^{19,22}

The increase in the process of producing knowledge about epilepsy is undeniable, including the therapeutic approach of this disease. Nevertheless, the information on these scientific advances finds obstacles to reach patients, family, and society

in general, which contributes to the maintenance of the stigmas surrounding the theme. It is necessary that health professionals seek to overcome this situation, with a view of providing a better quality of life for patients.¹⁹

In order to break the stigma, there is a need for guidance and guidance not only for children but also for parents, since they also need clarification.

Hence, it is worth mentioning the importance of the nursing team role in the process of demystification of the disease, helping parents in the process of caring for children, as well as in emphasizing the adherence to drug treatment and also psychological.²¹

FINAL CONSIDERATIONS

Knowledge about the families' experiences with childhood epilepsy shows the importance of family dynamics and how much this influences child care. The results obtained draw attention to the social impact of the disease in the family, outlining a trajectory that begins at the moment of diagnosis discovery, with implications for the development of attitudes of overprotection, going through the changes in family dynamics, and facing the challenges related to the stigma of epilepsy and the search for insertion in society.

The reports have emerged the experiences permeated by varied feelings, such as fear, guilt, uncertainty, and despair, often motivated by the innumerable negative stereotypes that the disease still arouses today.

Considering this perspective, it is believed that this study can contribute to other research initiatives that have as a scope of Family Nursing, focusing on the child who experiences a chronic condition. Hence, dealing with the epilepsy issue, we hope to subsidize and foster a broader discussion about this condition, in order to promote the pursuit of actions aimed at monitoring this child, based on the strengthening of family ties and potentialities for coping with adverse situations that punctuate their trajectories.

Despite the limitations of this research, either because of the small number of family members interviewed, or because the study was carried out in a single local specialty center, it is a qualitative research and without the concern of generating generalizations, it is clear that it is important as an attempt to better understand this specific assistance scenario.

Conclusively, this study reinforces the need to give voice to families in terms of their care demands, while at the same time seeking to contribute to professional practice, highlighting the important role of the nurse as an agent in the process of demystification of beliefs and qualification of health care.

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Corresponding author

Délis Renardin

Address: Rua Júlio de Castilho, nº 1420, 08A, Vila Carli,
Guarapuava, Paraná, Brazil

Zip Code: 85.040-170

Telephone number: +55 (42) 9 9942-0956

E-mail address: drenardin@gmail.com

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