PREVALENCE OF INTRINSIC AND EXTRINSIC FACTORS OF THE LEARNING PROCESS IN CHILDREN WITH EPILEPSY

Prevalência dos fatores instrínsecos e extrínsecos do processo de aprendizagem em crianças com epilepsia

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ABSTRACT

Purpose: to raise the prevalence of intrinsic and extrinsic factors of the learning process in children with epilepsy. Methods: this descriptive study was conducted at the Clinic of Neurology Children's Hospital of Pediatrics Professor Heriberto Bezerra, HOSPED – UFRN. Data collection occurred during the September/2009 to March/2010 through a questionnaire with parents and carers of children with epilepsy. The sample comprised 41 children, according to the following inclusion criteria: a) parents or caregivers of children with an unequivocal diagnosis of epilepsy seen at the outpatient clinic of HOSPED; b) children aged between 3 and 12 years; and c) parents or guardian sign the consent form free and clear. Results: 61% of children were diagnosed with pure epilepsy. 59% had their first crisis before the age of 03. 34% presented generalized crisis type. 51% presented crisis during the survey period. 98% were on medications to control crisis, and from these children, 55% monotherapy and 45% polytherapy. 76% were at school, 50% inserted in public school. 66% never repeated the school year. 49% of children had school attendance affected because of the crisis. 64% have never been excluded from school by teachers because of epilepsy and 85% of parents affirmed to overprotect their children. Conclusion: the study concluded that, in addition epilepsy, children with that pathology are also exposed to other factors, resulting from the disease, which may negatively affect these children learning process.

KEYWORDS: Epilepsia Partialis Continua; Learning; Child

■ INTRODUCTION

Epilepsy is one of the most commonbrain disorders, affecting about 50 million people worldwide. In Brazil, according to estimates from the Ministry of Health, approximately 157.070 new

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cases are diagnosed each year (100/100.000), with a prevalence of 11,9/1000 to 16,5/1000 of active forms of the disease¹. And, inthe pediatric population it stands on 18,5 per 1000 children². Epilepsy is a chronic disorder characterized by recurrent crisis, resulting from an excessive discharge of neurons in certain areas of the brain, usual inchildhood, impacting on cognition, language and education of epileptic children³.

Any chronic disease during childhood brings risks to child's physical, mental and cognitive development,increasing psychosocial morbidity⁴. However, epilepsy, while chronic disease seems to affect children more than other diseases such as asthma or diabetes⁵, presenting repercussions on the behavior and learning of epileptic children and adolescents⁶. This is probably because the epilepsy, as mentioned above, affects directly the nervous

system and consequently can bring conflicts in perception, in movement, inconscience and in other cortical functions, which may compromise thequality of lifeof those living with this disorder7. In addition to physical symptoms, people with epilepsy also suffer psychological and cognitive consequences reflecting higher social and academic impact on their lives8.

There are many factors in childhood epilepsy involved that can compromise a child's development, such as: organic factors (neurological change of basis and their physical and cognitive limitations. the frequency of crisis and the risk of accidents, side effects of medications and surgeries), psychological factors (family and personal concerns, feelings of guilt and rejection, personality development), social issues (limitations in leisure and work, social inclusion) and educational (academic and professional performance)9.

About school education, it is known that there is a high frequency of epilepsy in school ageand adds that, in childhood epilepsy, academic difficulties are linked to organic factors directly related to the disease itselfas the basic neurological disease and their physical and cognitive limitations, beginning age, seizure frequency, type of epilepsy syndrome and etiology, control degree and the frequency of seizures and the risk of accidents, in addition to the side effects of drug therapies and surgeries. However, variables that may be involved in the school learning process as low expectations of parents and teachers about the child's success, the possibility of rejection by teachers and classmates and alterations in child's self-esteem are also important factors that can promote a lower school performance of kids with epilepsy¹⁰.

Believing that epilepsy and its consequences are risk factors to the adequate school development of children with this disease, this research aimed to raise the prevalence of intrinsic and extrinsic factors of the learning process in children with epilepsy.

METHODS

This study was approved by the UFRNResearch Ethics Committee with protocol approval number 124/2009.

This descriptive study is part of a research entitled "Reactions of parents with epileptic children in relation to emotional aspects and language" and was performed at the Clinic of Child Neurology, Hospital of Pediatrics Professor Heriberto Bezerra (HOSPED) from the Federal University of Rio Grande do Norte (UFRN), whose data collection occurred during September 2009 to March 2010.

The sample consisted of 41 children aged between 3 and 12 years old (preschool and school children) and answered the following inclusion criteria: a) parents and/or caregivers of children with unequivocal diagnosis of epilepsy treated in HOSPED; b) children aged between 3 and 12 years. and c) parents and/or quardians signing the consent form.

A structured questionnaire was applied to parents and / or caregivers of children with epilepsy who were on their routine visit in HOSPED, under the mediation of Speech Therapy and Psychology. Initially, the questionnaire was tested in a pilot study during August 2009.

The administered questionnaire (adapted from Aguiar et al. 2007)¹¹ has an objective character, with questions relating to beliefs, feelings and reactions to the epilepsy, as well as stimulation / language development and frequency / school performance. Data collection related to epilepsy was obtained from the patient's chart.

Questions relating to the identification data of the child (age, gender and education) were used in this crop, epilepsy (diagnosis, age at first seizure, seizure type, frequency of crisis and type of treatment) and external factors interfering in the learning process (type of school, school attendance, parents' opinion and behavior regarding the child and the teacher's unawareness about epilepsy).

Those responsible for the participants in this study were informed about its purpose, a written authorization, the free and informed consent form, was requested from them.

A descriptive analysis was performed, obtaining the absolute and relative frequency of all study variables.

RESULTS

The results will be divided into general description, intrinsic factors (epilepsy data) and extrinsic factors (data from the learning process, and family relationships).

General description

70 parents were interviewed and only 41 answered questionnaires (59%) were included for analysis of data research in question, due to the inclusion and exclusion criteria. Of these 41 children of interviewed parents, 28 were male (68%) and 13 are female (32%). The higher prevalence of age (68%) on participating children was between 7 and 12 years old, framed on school level.

Intrinsic factors (epilepsy data):

the diagnosis of pure epilepsy is the most common (61%). The majority (59%) of the surveyed children had their first seizure before 03 years old. A higher prevalence of generalized seizure type (34%) and children who have current seizures (51%) was found. There was a higher rate (98%) of children who currently take medication to control epileptic seizures and are on monotherapy treatment (55%).

Extrinsic factors (information of learning process and family relationship):

the children in this study are, in the majority (76%), inserted in schools and 72% entered the school on ages between 01 and 03 years. 50% of children attend to public and regular schools and that there's prevalence (66%) on absence of school failure in children with epilepsy in this study. The majority (49%) of children in this study had their school attendance compromised because of epileptic seizures. 64% of children with epilepsy in this study never been through the situation of school exclusion suggested by the teacher and 85% of parents with epileptic children have overprotective behavior with their kids.

DISCUSSION

The discussion will follow the same organization displayed in the results.

General description:

of the 41 children from interviewed parents, most are male. Some research5,12 also found a higher prevalence of males in studies of epileptic children. These results were due to the fact that epilepsy reaches more boys than girls¹³. The higher prevalence of age found in this study can be justified because epilepsy is the most common chronic brain disorder in childhood, being more frequent in the first ten years, meaning that children are affected on the beginning of their school life.14

Intrinsic factors (epilepsy data):

the diagnosis of pure epilepsy is the most common, but there are also children who have epilepsy and other comorbidity. This is because the study was aimed on children with epilepsy, but did not exclude those with epilepsy and other disorders. In a study with epileptic children, it was found that 16 children (21%) had no other health problems, while 40 (79%) had other chronic diseases, neurological or behavioral problems and learning disabilities or combinations of various conditions. Importantly, children with epilepsy are particularly vulnerable to

language disorders and, consequently, educational problems and emotional maladjustments¹⁵. These consequences can be worse if, with the diagnosis of epilepsy, comes the diagnosis of other comorbidities such as chronic non-progressive encephalopathy. neuropsychomotor development delay, and others found in this study.

Regarding the age when seizures started, we found that most of the surveyed children had their first seizure before 03 years old. Another study¹² found a higher prevalence of epileptic seizure initiation before 02 years of age. These results can be justified by the immaturity of central nervous system in this phase, therefore, preschool children are more likely to have crises by the lack of inhibitory systems¹⁶. It is estimated that 0.5 to 1% of children will present at some point in childhood a single unprovoked seizure, with a recurrence risk of 23-78% until the 36th month17.

With regard to the types of epileptic seizures, a higher prevalence of generalized crisis type was found.In a study conducted5, it was observed that 28 children (50%) had generalized epilepsy, 26 had localized epilepsy (46.4%) and 2 (3.6%) had left undetermined whether focal or generalized epilepsy. In a long term, children with generalized epilepsy, even with good seizure control and with normal cognitive potential, presented significant risks of developing language and learning difficulties¹⁸.

A higher prevalence of children with epileptic seizures was currently collected. In a study performed⁵, data referring to frequency of seizures. showed that 14 of the 56 children of special and regular schools (25%), had seizure control with medication, followed by 10 children (17.8%) presenting between 1-3 seizures per day and 16 children(28.5%) presented seizure frequency ranging from 4 to 11 seizures per year and 1-3 seizures per month. This divergence of results found with the researched literature in this study is probably due to the fact that many childhood epilepsies are benign and achieve remission or seizure control with proper treatment¹⁹. Researchers²⁰ point the long duration of epilepsy, more frequent seizures and early beginning of seizures as major factors associated with low school performance.

As for the currentperforming of drug treatment for epilepsy, there was a higher rate of children who currently take medications to control seizures. Another study found that only 2 of the 56 participant children (3.5%) were not using medications by the time of data collection. In a study²¹ with 20 children suffering from benign childhood epilepsy with centrotemporal spikes, no interference of antiepileptic medication on the results of the Academic Performance Test was observed. When epilepsy begins in childhood the use of anti-epileptic drugs begins concurrently with the cognitive and psychosocial development of the child and this process may have implications over the remaining life cycles²².

Concerning to the type of treatment we found that most children use only one drug (monotherapy) for seizure control. Studies^{5,12} have also found a higher prevalence of children using one drug. Although the study result has found higher prevalence of monotherapy for seizure control, is noteworthy that polytherapy has relatively severe impact on cognitive function when compared to the use of monotherapy, possibly due to exacerbating the problem of drug tolerability²³. So, it is necessary to pay attention to the use of this type of treatment since it can be a strong cause of learning difficulties on children with epilepsy.

Extrinsic factors (information of learning process and family relationship):

most children in this study are inserted in schools. It was found in a longitudinal24 study, which followed 613 children over five years after receiving the epilepsy diagnosis, that 525 (85%) were in school and that these 315 (60%) had used some kind of service related to special education and special classes in regular or resource rooms or attending special schools. A case study¹⁴ at the time of subjects-participants selection found that 35% of children with epilepsy were not attending to any school environment. However, it's important to mention that these children were included in those with higher degree of impairment (absence of verbal language and delayed motor development).

In this research, there was a higher rate of children who entered school between the ages of 01 and 03 years. No studies were found relating to this factor. It must be highlighted the importance of conducting studies that provides a larger focus on these school issues with epileptic children, including those related to age of school integration, since this aspect has a strong influence in the child's learning process.

A higher prevalence of children attending to public and regular schools was found. This result is possibly due to the fact that most respondents had low income, however, it is known that because of the stigma and prejudice, the diagnosis of epilepsy favors attitudes of exclusion, including restricting participation in regular schools¹⁴. In addition, it is also noticed that schools, in general, do not demonstrate aptitude / interest in dealing with children with epilepsy, although in many cases epilepsy is neither limiting nor disabling, because of the social group stigma, these children are placed inadvertently in special education (special schools or special classes), on the understanding that they have special educational needs14. A study25 investigated the prevalence of using special education services for children with epilepsy and found, as a result, epilepsy frequency 30 times higher in children attending special schools or special classes within regular schools than students in regular schools.

The absence of school failure in children with epilepsy was prevalent in this research. This finding contradicts the literature, since children with epilepsy are formed as a vulnerable educational group with high risk for developing specific learning disabilities and consequently compromises academic performanceas well as poor psychosocial adjustment, which can result in dropping out of school²⁶. Probably, this fact is justified because, since 2011, the Ministry of Education (MEC) approved the recommendation of the National Education Council (CNE) which ends student failure in the first three years of elementary school and creates the Cycle of Alphabetization and Literacy.

As for school absence due to epileptic seizures before or during classes, it was found that most children have had their attendance at school impaired. Children with epilepsy may be subject to attitudes of social rejection, marked by the stigma and ignorance about epilepsy. These attitudes often occur in their own familiar environment and in healthcare, with restrictions on participating in activities for children without epilepsy, such as school attendance itself14.

Most children with epilepsy in this study never been through the situation of school exclusion suggested by the teacher. In a study²⁷ conducted in a public elementary school in the state of São Paulo, with the purpose of applying a questionnaire about epilepsy before and after a classroom lecture on the topic "Epilepsy for Teachers", it was found that, in the pre-class, over 50% of the interviewed teachers hit the questions about this comorbidity. It is assumed that teachers' knowledge about epilepsy justify the results of this study, since the absence of prejudice, caused by lack of knowledge, allows the inclusion of students with epilepsy in classroom.

Regarding overprotection of interviewed parents in this study, most of them have that kind of relationship with their children who have epilepsy. The characteristics of epilepsy affect directly the parent-child relationship, increasing anxiety behaviors and parental overprotection. Consequently, the family dynamic brings a high prevalence of abnormal behaviors, learning difficulties, changing the psychosocial adjustment of children and their quality of life²⁸.

There is a need for clinic and school to conduct a direction and guidance work, not only with children but also with their parents, since they also need clarification. They are emotionally involved in a direct way with their children, there is a natural action of wanting to protect them, denying them muchneeded stimulus to the development of language and learning process, such as leaving home, contacting other children, playing in external places, going at friends' houses. They directly interfere on the process of interaction and on extrinsic aspects to the proper learning development.

Then, it is noticed that is imperative that parents. teachers and health professionals, in particular medical who accompany these children are aware of the consequences generated by epilepsy, trying to achieve these children demands, preventing further damage to the psychosocial, linguistic, emotional and educational development.

■ FINAL COMMENTS

The survey data showed that children with epilepsy are exposed to several factors resulting from illness and the stigmas that come with it, which may negatively affect the learning process of these children. Is possible to conclude that, as all chronic disorders, childhood epilepsy is a complex illness that has important implications in many areas of the child's life and, in particular, children with epilepsy are more vulnerable to develop academic problems.

In this way, it is necessary to develop further studies to investigate and recognize which variables are involved with the difficulties faced by children with epilepsy and that can directly or indirectly influence their psychosocial functioning in their social and educational skills; in addition to implementing awareness programs about epilepsy for the population, especially parents and teachers, and accompany children with this disease in their school development.

RESUMO

Objetivo: levantar a prevalência dos fatores intrínsecos e extrínsecos que podem interferir no processo de aprendizagem em crianças com epilepsia. Métodos: este estudo descritivo foi realizado no Ambulatório de Neurologia Infantil do Hospital de Pediatria Professor Heriberto Bezerra (HOSPED) da UFRN. A obtenção dos dados ocorreu durante setembro/2009 a marco/2010 por meio da aplicação de um questionário com pais e cuidadores de crianças com epilepsia. A amostra foi constituída por 41 crianças, seguindo os seguintes critérios de inclusão: a) pais ou cuidadores de crianças com diagnóstico inequívoco de epilepsia atendidas no ambulatório do HOSPED; b) crianças com idades entre 3 e 12 anos; e c) pais ou responsáveis assinarem o termo de consentimento livre e esclarecido. Resultados: 61% das crianças apresentaram diagnóstico de epilepsia pura. 59% tiveram sua primeira crise antes dos 03 anos de idade. 34% apresentavam crises do tipo generalizada. 51% apresentavam crises no período da pesquisa. 98% estavam em tratamento medicamentoso para controle das crises, sendo 55% monoterapia e 45% politerapia. 76% estavam inseridas na escola, sendo 50% em escolas públicas. 66% nunca repetiram o ano. 49% das crianças tiveram assiduidade escolar prejudicada em virtude das crises. 64% nunca foram excluídas da escola pelos professores devido a epilepsia e 85% dos pais afirmaram superproteger os filhos. Conclusão: o estudo concluiu que, além da epilepsia, as crianças com essa patologia são também expostas a outros fatores, decorrentes da doença, que podem influenciar negativamente no processo de aprendizagem dessas crianças.

DESCRITORES: Epilepsia Parcial Contínua; Aprendizagem; Criança

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