

Influence of the COVID-19 Pandemic on the Quality of Life of Families with Children Suffering from Epilepsy in Ukraine

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ABSTRACT

Statement of the Problem: Childhood epilepsy is one of the most common CNS diseases [1]. From the point of view of optimizing care for children with epilepsy and their families during and after the crisis caused by the COVID-19 pandemic, it is important not only the high frequency and severity of the pathology, but also its social consequences - stigmatization, some isolation of the child in many cases [2,3] and economic aspects [4,5].

METHODOLOGY & THEORETICAL ORIENTATION

Taking into account the above mentioned statements, the aim of the study was to identify the most significant and acute problems of families and patients with epilepsy associated with the COVID-19 pandemic and quarantine, which was introduced in Ukraine on March 11.

An electronic version of a specially designed anonymous questionnaire for parents (guardians) of children with epilepsy was used to gather information. The survey lasted from 18 to 23 May 2020.

During this time, information was collected on 133 families with children suffering from epilepsy aged from 3 months to 18 years. In 55.6% of families, boys are suffering from epilepsy, and in 44.4% - girls. All patients are under the supervision of the staff of the GA "Institute of Neurology, Psychiatry and Narcology, NAMS of Ukraine". In 95.5% of cases, the questionnaire was completed by the patient's mother and only in 4.5% cases by other family members. The age of onset of epilepsy in patients ranged from 1 month to 14 years. At the time of the survey, 46.6% of respondents indicated the absence of seizures for more than 1 year, and the frequency of seizures ranged from 1-12 per year to several dozen per day. In 85% of patients, the frequency and nature of seizures during the COVID-19 pandemic did not change.

All patients receive treatment with antiepileptic drugs, children received: in 34.9% - one, in 26.4% - two, in 26.4% - three, and in other 12.4% of cases - 4 or more AEDs. Parents of 34.6% children note the presence of certain mental and / or psychological disorders, namely - intellectual deficit, inattention, conflict, irritability, periodically depressed mood.

In 1 (0.8%) child with epilepsy, was diagnosed COVID-19, and no more cases of the disease were recorded in other children either in parents or other relatives. 36.1% of families were quarantined at the time of the survey, 15% of them had already returned to normal life, 48.9% of families according to the

survey were not in complete isolation, which is due to the need for one or more family members to leave home for work, due to the need to purchase food, medicine, the urgent need to see a doctor, addressing other urgent needs. During the crisis increased the time that parents spend with their children. Thus, 41.4% of respondents were with children before quarantine around the clock, and during it - 66.2%.

We noted that the impact of the crisis COVID-19 is most noticeable in terms of financial condition of families - 48.1%, psychological climate - 24.1%, household and organizational issues - 24.8%, only for 3% of respondents - the physical condition of any of the relatives. Deterioration of the financial condition of families was noted by 64.7% of respondents. 46.6% of respondents reported that the medical institution where the child was observed provided assistance only in urgent cases during the quarantine period.

Only 18% of patients visited the hospital during quarantine, while 69.2% of children continued to receive a distant care. 88.7% had satisfactory contact with a doctor, which was carried out mainly (63.2%) by phone, and via e-mail - 15.8%. 90.2% of parents managed to solve topical issues regarding the condition of children and their treatment in this regimen. Only 25.6% of patients during quarantine did not need urgent contact with a doctor.

Against the background of such a generally satisfactory level of interaction between parents and doctors, the problem of providing patients with antiepileptic drugs attracts attention, so, 33.1% of families had difficulties in obtaining drugs from the state budget and 31.6% in purchasing drugs in the pharmacy network at their own expense.

An analysis of the emotional state and behavior of children, from the point of view of family members during the COVID-19 crisis shows generally insignificant differences compared to the pre-pandemic period. From the point of view of 78.2% of the surveyed children did not have significant changes in behavior, 66.2% did not note an increase in stress and emotional disorders. However, 21.8% of respondents noted some degree of increase in stress levels in children, 12.0% - an increase in behavioral disorders, 10.5% reported deterioration in sleep, 14.3% - a decrease in appetite. 10.5% of patients noted increase in appetite.

84 children (63.1%) from the surveyed families before the pandemic studied in secondary schools, 4.5% of children studied in special programs, 32.3% - did not study, which was due to the age of the children or the severity of the disease. The majority of children - 76 (90.5%) continued their education in distance mode during quarantine measures, 25 (32.9%) of them had difficulties in studying.

In general, 12.8% of respondents noted "acute" problems that are almost impossible to solve due to COVID-19. Regarding the solution of problems that have arisen or may arise in the future, 25.6% of parents consider the most appropriate to solve them help of doctors, 19.5% - help of government agencies, 13.5% - help of relatives and friends, help of psychologists - 7.5%, and help of social employees -1.5%.

CONCLUSION & SIGNIFICANCE

The results showed that the most important for the families of children with epilepsy during the COVID-19 pandemic are financial problems and issues of ensuring continuous use of antiepileptic drugs. The much smaller number of reports of psychological problems can be explained not by their absence at all, but rather by the fact that for parents of patients with such a severe chronic disease as epilepsy, they become secondary, to some extent offset by the main task - to provide children with full care and assistance.

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