Multidisciplinary approach to hospitalized epileptic children and their families

Abordagem multidisciplinar de crianças epilépticas e familiares em enfermaria

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ABSTRACT

Objective: Epilepsy is the most frequent diagnosis in the ward; due to the high degree of complexity of its investigation and treatment, the objective of this work was to proceed to an analysis of the interventions of the team with hospitalized epileptic children and their families. Methods: The data were obtained from the clinical handbooks and individual registers of the specialties. Results: There were 235 elective admissions, 88 regarding the Epilepsy. The services for specialties were distributed among those 88 epileptic children: physiotherapy (34%), psychology (41%) and occupational therapy (88.6%). Conclusion: Given the severity of the social and biological sequelae associated with the diagnosis of epilepsy and the need for a family intervention, the multidisciplinary work focused on the child, in stimulation interventions and promotion of his/her development, with a view to minimize the sequelae; and providing the family with orientation and support, in order to give them more elaborate strategies for coping with the disease and improve conditions for supplying post-discharge infant treatment.

Keywords: Patient care team; Epilepsy; Patients rooms; Caregivers; Child, hospitalized

INTRODUCTION

Epilepsy is a chronic condition that is frequent worldwide and constitutes a serious public health problem, affecting individuals of all ages, races and socioeconomic classes. Its frequency and characteristics lead to adversity not only for the patient and their family but also for society at large(1). In Brazil, studies have estimated a prevalence from 11.9 to 20.3/1000 inhabitants(2-3).

Epilepsy is a range of epileptic syndromes that may be defined by taking the following factors into consideration:...
control seizures is considered – epilepsy surgery (11). Mediation, at which point the possibility of surgery to treat epilepsy may become refractory to any medication. Difficult-to-control epileptic seizures are those that fail to respond to the condition to be controlled. Difficult-to-control epileptic seizures are those that fail to respond to the normally indicated medication that is used successively in monotherapy, often culminating in the need for more than one drug simultaneously (polytherapy) for the condition to be controlled. Difficult-to-control epileptic seizures may become refractory to any medication, at which point the possibility of surgery to control seizures is considered – epilepsy surgery (11).

The group at highest risk of mortality in epilepsy is children who present mental deficiency, non-evolving chronic encephalopathy and congenital malformation of the central nervous system. Onset of seizures under two years of age correlates with more serious epilepsy (12).

According to Sepúlveda (13), epilepsy-related physical consequences can be described as: delayed development, neurological sequelae, intellectual disorders, behavior changes and side effects of drugs (drowsiness, irritability, psychomotor agitation, lethargy, night terror, increased secretions, etc.).

There are also psychological and social consequences associated above all with the unexpected and deeply shocking manifestation of the disease (14-15). The realization that one’s child is different causes a conflict between the ideal child imagined by the parents and the real child delivered into their care, meaning that all hopes and dreams must be reviewed and reconstructed. It is a very delicate situation since bringing a child that has some kind of handicap into the world is a source of great suffering for the parents (16-22).

After the initial perplexity and shock, according to Murphy (23), some parents experience a strong urge to protect, while others remain uncertain and confused about their emotions, fearing emotional investment in a person who may bring them more sorrow than joy. Some parents show initial reluctance in their contact with their child, either through true incapacity to relate to an abnormal child, or through fear of triggering an epileptic seizure.

Reactions to the diagnosis vary among a range of emotions: revolt, hope, worry, depression, rage or guilt. Some parents find the diagnosis a relief, while others completely deny the news or wonder what they have done to suffer so much (24-25). According to Tiengo (26), parents generally show a great need to understand the cause of the problem, seeking tirelessly to find a justification as a way of apportioning blame, either to themselves, to their partners, or, as is common, to the health care team accompanying the child.

According to Thomas and Bindu (27), the severity of epilepsy is directly associated with the psychological and economic damage to the family, since this demands a large amount of medication, prolonged hospital stays and the exclusive dedication of the caregiver, which becomes very burdensome for the parents. In many families the main caregiver, usually the mother, will eventually give up her professional life.

Given the above, it is clear that a diagnosis of epilepsy involves a complex array of factors that influence its treatment and clinical course. However, as Sepúlveda (13) says, the most important factor is the individual being treated: “the patient is a human being who has a complex biological organization with important psychological characteristics. This can influence the therapeutic response: we must treat the epilepsy, but it is more important to treat the epileptic.”
Interventions geared not only to medical therapy but also aiming at coping strategies, education and rehabilitation, working both with the patient and the family, are therefore fundamental.

**OBJECTIVE**

The objective of the present paper was to analyze the team’s interventions in light of physiotherapeutic and psychological care and occupational therapy with hospitalized children with epilepsy and their respective families.

**METHODS**

A retrospective study carried out by the analysis of clinical records of patients diagnosed with difficult-to-control epilepsy, according to the Clinical Neurophysiology Service of the HCFMRP-USP, admitted between November 2000 and December 2002, and individual specialty files (Physiotherapy, Psychology and Occupational Therapy). Multidisciplinary attendances and interventions for patients and parents were counted in this analysis. Among such events, the focus of the present study is on patients with a diagnosis of difficult-to-control epilepsy.

**Characteristics of the Infant Neurology (IN) Ward.**

The IN Ward of the Hospital das Clínicas, Medical School, Universidade de Sao Paulo – Ribeirão Preto campus (HCFMRP-USP), treats a range of neurological conditions, the most common being epilepsy, accounting for 24.6% of the total number of diagnoses (26). Founded in 1978, it currently has six beds for elective admission of patients up to 12 years of age, with a range of neurological conditions, from all regions of Brazil. It treats highly complex cases in terms of diagnostic investigation, medication routine and surgery.

Since epilepsy is the most common diagnosis in this ward and given the long hospital stays that are required because of the highly complex nature of the diagnostic investigation and treatment (medication adjustments for seizure control and surgical indications), a broader intervention is necessary to aid the patient in the various aspects of hospitalization; in other words, the physical, psychosocial and social aspects, as well as giving the family emotional support and information. This requires a multidisciplinary health team.

The HCFMRP-USP NI ward therefore draws on a team of professionals in its daily care – Social Service, Physiotherapy, Nutrition, Psychology and Occupational Therapy (OT), and through referrals, the Speech Therapy Service. In once-weekly clinical meetings the team discusses hospitalized cases in order to plan diagnostic investigations, guidelines for management and draw up care strategies.

**RESULTS**

There was a total of 235 indications for admission in the IN Ward (figure 1), demonstrating the greater frequency of epilepsy and inborn errors of metabolism (IEM).

![Figure 1. Indication for hospital admission](image)

**Figure 1.** Indication for hospital admission

In quantitative terms admissions for epilepsy came to 88, corresponding to 24.6% of cases attended, and symptomatic focal epilepsy was more common (66%) (figure 2).

**Figure 2.** Epileptic syndromes

Of the 88 cases of epilepsy hospitalized in the IN Ward in the period under study, 88.6% were followed by Occupational Therapy; 41% by Psychology, and 34% by Physiotherapy. Distribution of appointments by specialty came to 48% (419 appointments) for Physiotherapy, 39% (421 appointments) for OT and 31.5% (145 appointments) for Psychology, as shown in figure 3.
The multidisciplinary team worked on two fronts: with the child, in interventions geared toward stimulation and the promotion of development so as to reduce the sequelae from the condition; and with the family, in terms of support and guidance, to provide the family with more sophisticated acceptance and coping strategies and enhance the care they would provide the child with at home.

DISCUSSION

The idea of a complex interaction between psychological factors and medical conditions is widely accepted among health researchers. As Stoudimire(29) says, “the belief that psychological factors influence the expression of physical symptoms and that they can affect the clinical course of diseases has been a basic supposition of medical practice since the time of Hippocrates”. The extent to which a patient adapts to a given disease may affect their ties to the health team and affect, either positively or negatively, the medical prognosis and the management of care. In the words of Vilares(30):

“a análise dos resultados de tratamentos oferecidos leva em conta o vínculo entre profissionais e pacientes, os componentes de dedicação, energia e afeto contidos nessa relação. Esses ingredientes são fundamentais para o desenvolvimento de uma postura terapêutica que acolhe, protege, estimula, reflete e constrói intervenções propiciadoras de mudança.”

The need for assistance with rehabilitation and hospital support has thus been shown to be increasing(31). Elective admissions in tertiary healthcare hospitals have taken on characteristics of semi-intensive care, since diseases that once evolved quickly to a fatal outcome are now treated in such way as to give the patient a greater chance of survival. It is important for the team to analyze the needs of each patient and their family, planning suitable interventions involving attention to physical, psychological and social aspects for each particular case.

It is worth pointing out that the fact that difficult-to-control epilepsy is responsible for longer periods of hospitalization than other diseases requiring admission to the same ward, is the main reason for the greater involvement of the team with patients and their families.

Given that infant development is closely linked to the child’s most significant ties, that is to say, its parents, work with the child necessarily includes the family, helping the family to establish a more positive and healthier relationship with the child, despite the child’s differences and limitations (32). With every admission of a child with difficult-to-medically control epilepsy, family members internalize new hope for improved outcome.

The family’s perception of the problems that led to the child’s hospitalization depends a great deal on their degree of knowledge of the disease. However, most families complain that despite medical efforts to promote awareness, many queries remain unanswered. The team needs to carry out interventions so as to enhance the patient’s and the family’s adaptation to the disease and to the emotional stress that comes with the treatment and with the period of hospitalization(32,33).

In our sample we observed that of the total number of patients seen in the ward, work with children with epilepsy and their families accounted for virtually half of physiotherapeutic and psychological interventions and virtually all of the interventions in occupational therapy.

In regard to other specialties, we detected a higher percentage of weekly physiotherapeutic appointments, despite the smaller number of cases seen, owing to the large demand for an intensive (virtually daily) activity with some patients, either in respiratory assistance in order to improve the functional capacity of the lungs and prevent pneumonia and atelectasis, or in motor therapy in order to improve performance of fundamental functional actions, muscular positioning and stretching, depending on neurological condition.

The nature of epilepsy and the range of individual responses to treatments may require an extended period of time, since different medications, adjustments and combinations are used in order to control seizures. In turn, parents, in their anxiety for seizures to be completely controlled, often demand “magic” solutions of doctors and thus may eventually come to mistrust the doctors’ management (34).
Furthermore, the side effects of the drugs often frustrate expectations of improvement. One of the team's approaches, in this regard, is to inform the family that, as De Manreza e Marques-Dias put it, despite the presence of frequent serious side effects, the benefit of anti-epilepsy medication lies in its ability to suppress seizures, affecting the prognosis of epilepsy and enabling cognitive, emotional, educational, and social gains.

Other contributions to the child’s development have to do with motivation to learn, leisure activities, stimulation, dietary and personal hygiene exercises, which are aspects worked on through the assessment of the patient’s resources and potential, thus helping rebuild the interrupted or non-existent daily life, turning situations into meaningful experiences that can somehow contribute the child's social integration.

Based on observations carried out in the work with this group of patients, it can be reaffirmed that the moment of discharge from hospital is essential for building closer ties between the family and the team, to assure compliance with drug therapy and the rehabilitation program. It is for the team of professionals to motive the family, as the main agent in stimulating the activities carried out at home, since the quality of this interaction will significantly influence the child’s prognosis.

Attention must also be paid to contacts with the doctor who referred the child, since it is usually that doctor who will receive the child in their home town, or outpatient clinic, for follow-up. Any prescribed treatment must be well explained in regard to the manner of administration and the period of use of drugs, and the prescriptions must be made out in sufficient quantities until the patient’s follow-up appointment at the hospital, or until the patient can manage to book an appointment in their home town. Likewise, every professional involved in hospital care must fill out a coherent report on the child's situation during hospitalization, addressed to the professional who will provide ongoing treatment. These procedures, albeit routine and obvious in themselves, are nonetheless extremely important since they are the basis of the continuation of the treatment begun at hospitalization.

**CONCLUSION**

In this multifaceted context, feelings such as gratitude, envy and hostility permeate the work of the medical team and their relations with the patient and family members. Providing emotional support to the patient and family, facilitating the expression of feelings and expectations relating to the clinical condition, promoting the ability to self-care and encouraging compliance with therapy, strengthening self-esteem and team-patient-family communications are therefore some of the challenges facing the multidisciplinary team.

**REFERENCES**