THERAPEUTIC INTERVENTION AND FAMILY ACCEPTANCE IN A CASE OF CHILD WITH CEREBRAL PALSY

Intervenção fonoaudiológica e anuência familiar em caso de criança com encefalopatia crônica não progressiva

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ABSTRACT

Our objective was to describe the case of a 5-year-old child with chronic non-progressive encephalopathy and dysphagia since birth. In videofluoroscopy, aspiration was observed with liquid barium, but not with paste barium. Gastrostomy for feeding and fluid intake was indicated. The family did not follow the guidelines determined by the therapist, as the child drank fluids orally and, therefore, had several episodes of pneumonia. Although the mother was advised to provide liquid only by gastrostomy and not by oral feeding, such guidance was ignored for no apparent reason. We emphasize the importance of family adherence to treatment guidelines to prevent pulmonary complications resulting from the aspiration of food.

KEYWORDS: Cerebral Palsy; Pneumonia, Aspiration; Deglutition Disorders; Speech, Language and Hearing Sciences

INTRODUCTION

Chronic nonprogressive encephalopathy (CNPE) is defined as a developmental disorder of movement and posture, causing limitations in activities, resulting in a non-progressive brain lesion occurring during fetal or infant development and is often accompanied by sensory, cognitive, behavioral, and communication disturbances[1].

Difficulty in swallowing is frequent in these children[2]. Although it manifests early changes in swallowing, it is quite often diagnosed and treated late, that is, upon the appearance of clinical complications such as dehydration, malnutrition and pulmonary changes. In children with cerebral palsy, compromise in growth and development, as well as quality of life, are usually associated with chronic dysphagia[3,4].

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Adherence to treatment is one aspect in the life of the health professional that requires attention. The lack of it is a very common problem in medical practice[5]. Adherence to treatment can be considered when the patients and/or family members accept and follow the instructions, prohibitions and prescriptions of the professional responsible for treatment[6]. However, there are definitions that are broader and more conscious of the dynamics of the process that relate to the concept of active, voluntary and collaborative involvement of the patient in mutually acceptable behavior, with the aim of producing the desired therapeutic or preventive results[7].

Associated with the correct diagnosis and indication of treatment, adherence to therapy is necessary for the betterment of the patient[7], since there is a direct relationship between adherence behavior and improvement of results[6]. Considering this fact, studies on adherence, interventions to enhance this aspect and ways to assist the patient should be performed[8].

Thus, the objective of this study was to describe how nonadherence to speech-language pathology (SLP) treatment in a case of dysphagia in CNPE can lead to recurrent pneumonia.

CASE PRESENTATION

The presentation of the case was approved by the Research Ethics Committee of *Hospital das Clinicas*, Ribeirão Preto School of Medicine, University of São Paulo (HCFMRP - USP) on February 3, 2014, process number 11132/2008.

A male child with the medical diagnosis of tetraparetic cerebral palsy due to neonatal hypoxia during cesarean delivery, grade IV in the Gross Motor Function Classification System (GMFCS), was referred to the SLP service in the outpatient Infant Dysphagia Unit of our institution at nine months of age for clinical and objective assessment of swallowing.

According to information provided by the mother and listed in medical records, the child was born preterm in June 2008 with a gestational age of 29 weeks, Apgar score of 4/9 and weight of 3.46 pounds (1570g). The child presented several complications: kidney and liver failure, pulmonary hypersensitivity and hydrocephalus, remaining at intubation in the neonatal ICU for 3 months and 15 days. Gastrostomy (GTM) was performed while in the maternity ward shortly after birth. The prescribed feeding after hospital discharge was by oral pathway (OP) for a pasty and liquid food consistency provided by GTM.

The mother reported that the child had two episodes of pneumonia, one in January and another in February 2009. Following a swallowing assessment in June 2009, a new episode of pneumonia was reported in April, needing hospitalization. By medical request, the child´s diet became solely by GTM. However, 15 days after discharge the patient's mother started, on her own accord, an OP diet (liquid and pasty) and what the child refused was provided by GTM. On clinical swallowing assessment, the child was offered a pasty (yogurt) and liquid (water) consistency. For both consistencies the child was restless, with food refusal. It was possible to observe the presence of previous oral escape of stasis of food in the oral cavity, requiring multiple swallows for clearing the oral cavity. Neck auscultation was altered during and after the offer of food, with the presence of intense noise, suggesting food stasis. Clinical signs suggested the presence of penetration and/or laryngotracheal aspiration. The mother was reoriented to offer all diet by GTM due to the clinical signs of penetration/aspiration observed.

An examination by swallowing videofluoroscopy (SVF) was conducted in September 2009, demonstrating coordination between the phases of swallowing, laryngeal penetration during swallowing, asystematic for liquid consistency and lack of penetration and laryngotracheal aspiration for thickened liquid and pasty consistency. The parents were alerted to the result of asystematic laryngeal penetration for liquid consistency. According to the mother, the child had been receiving OP diet for six months, contradicting previous orientation, with the exception of milk, that the child refused orally. After being informed as to the possible risks of providing liquids, especially water by OP, the parents agreed to offer a diet of liquid consistency by GTM and pasty and thickened liquid consistency by OP. The mother reported that the child was currently clinically stable and had SLP therapy twice a week at the Association of Parents and Friends of Exceptional Children (APAE) in their hometown. The test results were sent to the speech-language pathologist of this association.

In March 2010, the child presented with a new episode of pneumonia, as the mother maintained offering gelatin and small amounts of water by OP, even after both the SLP from our institution and the professional from the family´s hometown had suspended this type of feeding. On return to our outpatient clinic, clinical evaluation for liquids showed continued incoordination of suction-swallowing-breathing, reduced laryngeal elevation, presence of cough and altered cervical auscultation during swallowing, with the mother again oriented to suspend the provision of liquids by OP and observe the child's clinical status.

A worsening pattern of swallowing was noted after repeated pneumonia, which may have occurred to worsening of pulmonary status of the child, reflecting the incoordination of the swallowing phases.

RESULTS

In the management of swallowing in June 2010 it was reported that the child had experienced a new episode of pneumonia. As a consequence, the pulmonologist suggested feeding exclusively through GTM, however, the mother continued diet by OP for all consistencies and that GTM was used only for food supplementation. On clinical evaluation, the child maintained the alterations previously found in the oral and pharyngeal phase of swallowing, speech, and the same SLP course of treatment was transferred to the mother.

With a new episode of pneumonia in September 2010, and as the mother had not followed the previous guidance from the team of speech-language pathologists and pulmonologists from the hometown, it was decided to revisit the case and give free return to the patient, since the mother does not follow the orientation given and was aware of the risks of giving liquids by OP. Before this course of treatment,

the otolaryngology staff of the local hospital had requested reexamination by SVF because the child had been found to be undergoing feeding by OP without restrictions and was suspected of clinical improvement. SVF was performed in October 2011, showing incoordination between the oral and pharyngeal phases of swallowing, presence of penetration and silent micro-aspiration during swallowing to liquid consistency, ingested in free volume and supplied by bottle, and lack of laryngotracheal penetration and aspiration for thickened liquid and pasty consistency. The mother was again counseled about the risks of providing food by OP for liquid consistency and to maintain diet by OP for thickened liquid and pasty consistency. Report of this examination was sent to the speech-language pathologist of APAE and requested food thickener for the hometown social care service.

In November 2011 the speech-language pathologist from APAE contacted a speech-language pathologist of this institution stating that the mother had, on her own accord, removed the GTM from the child, even though the child had not presented good diet acceptance by OP. The orifice left on withdrawal of the GTM had healed in about two days on its own, according to the mother. The SLP professional and the mother were instructed on the need for nutritional monitoring, observing weight gain and lung symptoms and, in case of complications and weight loss, verify the need for a new alternative feeding route.

In February 2013, the patient returned to the outpatient Infant Dysphagia Unit of our institution on the mother's request because the speech-language pathologist from APAE would not accept the mother to provide liquid consistency by OP until a new examination had been given. According to the mother, feeding of the child was being provided exclusively by OP. She denied frequent colds, fever, recent pneumonia or cough and choking during feeding. The GTM had been removed for 2 years. SVF showed the same results found previously and the mother was advised to restrict liquid consistency by OP. Emphasis was given on orientation of the consistencies of food the child would eat, showing the mother the risks that the child ran if medical and SLP orientation were not followed.

At the time of this description, the child is 5 years old. In later return visits for the management of swallowing, in July and December 2013 and April 2014, the child was well, with no health complications found, especially to the lungs. Thus, it was observed that as the mother joined the child's treatment, it was possible to stabilize the clinical condition of the child with significant weight gain. Furthermore, the mother reported having maintained the weekly SLP therapy in her hometown for stimulation of the oral motor sensory system, swallow training and safe feeding.

DISCUSSION

Nonadherence of the mother to SLP treatment and orientation may be due, among other factors, to the denial of her son´s problem, an unstable bond between mother and child, and the lack of understanding of the child's clinical status, with the association of therapy and educational actions directed to the mother being key.

Another factor could be the lack of empathy of the mother with the speech-language pathologist, with no credibility on the part of the mother to the orientation. As children with cerebral palsy require prolonged SLP care, a good relationship with the speech-language pathologist and the child and family is necessary to achieve the therapeutic goals.

In some cases, the mother fails to establish a stable relationship with the child with special needs, significantly affecting their development. From birth, the child can trigger feelings in mothers of inadequate attitudes[9]. Thus, the child with special needs may experience a lack of sensory, motor, affective and cognitive stimulation[10].

One of the important aspects of the adherence process is the cognitive-educational aspect, which is dependent on the degree of information of family members and patients, many with a low educational level. Highlighted with respect to therapeutic and educational factors related to patients and families are aspects concerning recognition and acceptance of his condition, the active adaptation to these conditions, the identification of risk factors in lifestyle, growing habits and attitudes promoting quality of life and the development of consciousness for self-care. Among that which is communicated by professionals, health actions are centered in the person and not solely on procedures that combine counseling, information, adequacy of therapeutic schemes to the lifestyle of the patient, explanations and social and emotional support[11].

There are other factors such as interactional that may promote or hinder adherence to treatment[11]. This interaction can occur between: A) the therapist and family, which may generate empathy and complicity during treatment, when successful; B) the therapist and the patient, providing, for affection, the safety and care needed to make therapeutic treatment a more pleasant time; C) The family and the child, which is crucial for there to be continuity of therapeutic activities at home.

A study of 11 family members responsible for the daily care of children with special needs

demonstrated the relevance of affective involvement and support, not only for family caregivers, but also other members of the family, the community and health professionals, to have best result in relation to the stimulation of the child[12].

The educational activities geared to caregivers of dysphagic patients described in the literature are usually associated with therapeutic process and should include awareness and training of caregivers, preparing them to deal with the operational issues related to food, in other words, with oral handling, type of diet, utensils, mode of offer, posture, signs of difficulty and compensatory strategies . Also, they are oriented in relation to the daily maintenance of stimulation, optimizing the therapeutic results[13,14].

In a study involving children with CNPE and their caregivers, improvement in knowledge and conduct of caregivers about feeding their children was observed after caregivers underwent an educational action aimed at feeding dysphagic children[15]. The role of speech-language pathology is fundamental in guiding, educating families and caregivers, and therapy of these patients.

It is of immense importance to gradually provide orientation to caregivers and, moreover, it should be integrated into the routine of the patient and his family. One should always consider the family context, i.e., the willingness to follow the orientation and emotional state, avoiding increased conflicts and an overload of activities[16].

CONCLUSION

We reported the case of a child with chronic non-progressive encephalopathy demonstrating that non-adherence to medical and SLP treatment of dysphagia can lead to recurrent pneumonia. To prevent pulmonary complications, adherence of family members and caregivers of these patients to the orientation for therapy is key. When the mother realized the importance of adherence to physician and SLP orientation, the child had a favorable outcome.

RESUMO

O objetivo foi descrever como a não aderência ao tratamento fonoaudiológico em um caso de disfagia na encefalopatia crônica não progressiva pode levar a pneumonias de repetição. É seguida no HCPR uma criança, atualmente com cinco anos de idade, com diagnóstico de encefalopatia crônica não progressiva e disfagia desde o nascimento, com episódios repetidos de pneumonia cuja mãe não seguia as orientações terapêuticas determinadas pela fonoaudióloga. Na videofluoroscopia foi observada aspiração com a consistência liquida e não com a pastosa. Foi indicada gastrostomia para alimentação e hidratação, sendo permitida a ingestão via oral da consistência pastosa. A família não seguiu as orientações indicadas, a criança continuou ingerindo líquidos por via oral e, sendo assim, teve vários episódios de pneumonia. Embora a mãe tenha sido orientada a não fornecer alimentação líquida por via oral e sim pela gastrostomia, tal orientação não foi seguida, sem motivo aparente para que tal fato ocorresse. Fica evidente a importância da aderência familiar às orientações terapêuticas para que sejam evitadas complicações pulmonares decorrentes da aspiração de alimentos.

DESCRITORES: Paralisia Cerebral; Pneumonia Aspirativa; Transtornos da Deglutição; Fonoaudiologia

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