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Malnutrition, rehabilitation, and family or caregiver awareness regarding interaction in a patient with cerebral palsy

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ABSTRACT

Cerebral palsy (CP) is a common motor disorder observed during childhood. Malnutrition and dysphagia are common in children with CP. Overdose of medication and seizures may cause aspiration via its influence on the conscious swallowing movement. Some children may experience aspiration because of gastro esophageal reflux. Management of patients with swallowing problems requires the coordinated efforts of healthcare professionals. Patients with CP require appropriate nutritional education and nutritional support. Focusing on improving the nutrition of children with CP in early life offers families and caregivers an opportunity to provide effective intervention that may improve patient outcomes. Family-centered biopsychosocial interventions, rather than technical and short-term rehabilitation interventions that focus only on the pediatric patient, are important for ensuring the rehabilitation of the patient and improving and maintaining his/her health. In the present case, attention was drawn to the influence of caregiver practices on the nutritional status and health of the patient and the importance of family or caregiver rehabilitation.

Keywords: Cerebral palsy, family education, malnutrition, patient rehabilitation

Introduction

Cerebral palsy (CP) is a motor disorder that occurs in the early stages of life; is characterized by abnormal muscle tone, posture, and movement; and is mostly observed during childhood (1). Sensation, perception, cognition, communication, behavioral disorders, epilepsy, and secondary musculoskeletal problems accompany the motor disorders caused by CP. This condition decreases movement coordination, balance, and walking ability, limiting the activities of the affected individual (2, 3).

Drooling, dysphagia, and feeding problems are common in CP patients. In these patients, dysphagia is often characterized by problems in both, voluntary oral movements and the reflexive pharyngeal phase of swallowing (4). Patient care becomes challenging in undernourished and malnourished patients (5). Moreover, there is an increased risk of dehydration and aspiration pneumonia, compromising the patient's quality of life (6). In addition to all these physiological problems, the psychological and physical health of the caregivers is very important for fulfilling the practical daily needs of the patients and ensuring effective rehabilitation (7). It is important to initiate nutritional rehabilitation at the right time for patients and individuals who care for the patient to improve the nutritional status of patients, improve their life quality, and prevent nutritional complications. In the presented case, aspiration pneumonia developed in the patient owing to the family's refusal to implement the recommended nutritional support treatment. The effect of caregivers' practices on the nutritional status and health of the patient was recognized, and the importance of family or caregiver rehabilitation was emphasized.

Case Presentation

We present the case of an 18-year-old male patient with CP who was admitted to the hospital emergency service with 39°C body temperature, chills, shivering, and fainting episodes that had persisted for 2 d. Dysuria was not questioned in the patient who did not have nausea, vomiting, cough, sputum, diarrhea, or constipation during admission to the emergency department. The general condition

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of the patient was moderate to poor; he was conscious, non-oriented, non-cooperative, had lower extremities without chewing reflex due to undeveloped mastication muscles, had bilateral atrophic and scoliosis, was evaluated with thorax computed tomography and antibiotherapy (Sefaperazone 2x1, Clarithromycin 2x500 mg IV) was started with the diagnosis of aspiration pneumonia by the chest diseases department. The clinical nutrition unit was consulted for evaluation of the nutritional status of the patient who was followed up for aspiration pneumonia; the patient could take oral intake and did not have a chewing reflex; nutritional support therapy was initiated. Detailed medical history of the patient was recorded by the nutrition unit; he had no family history of the disease. Both, the mother and father were healthy and at the age of 40 y. Parents are second-degree relatives. Three of the 4 children in the family were healthy, and 1 had CP. It was noted that the patient who was born with a birth weight of 3000 g via normal, spontaneous vaginal delivery did not cry immediately at birth and developed cyanosis and hypoxia; further, motor and mental development retardation was identified. It was reported that the patient did not have a sucking reflex after birth; the mother expressed her milk to the child and started supplementary food in the sixth month after birth.

One and a half years before the patient's admission to the hospital, the patient was diagnosed with aspiration pneumonia and was treated at Gazi University Hospital after which, he was recommended to be fed by percutaneous endoscopic gastrostomy. However, the family did not consent for the implementation of this feeding method because of their concern about the development of infection. They continued to feed the patient orally with liquid foods after his post-treatment discharge.

In the first evaluation of the patient by our unit, his body temperature was 37°C, and blood pressure was 129/82 mmHg. The gross motor function assessment showed level 5; he had no independent mobility and had to be carried. He had contractures that affected his height measurement. The Nutritional Risk Screening (NRS 2002) tool was used to assess his nutritional status; NRS 2002 score was 5. The following anthropometric measurements of the patient were recorded: height 115 cm, body weight 14 kg, body mass index 10.5 kg/m^2, upper middle arm circumference 13 cm, calf circumference 16 cm, stroke width 58 cm, knee length 31 cm, wrist circumference 10 cm, and head circumference 41 cm. It was determined that the height and body weight of the patient were below the 5th percentile as per his age. Moreover, the patient had a cachexic appearance and was at risk of malnutrition; thus, nutritional support needed to be started immediately.

His mother was interviewed to obtain detailed history with respect to his nutritional status. The patient was reported to be able to consume foods orally, and his mother gave him pudding-like liquid foods orally; however, the patient aspirated the food.

Due to the absence of chewing reflex, aspiration history, and aspiration recurrence risk, the patient was recommended to be fed via percutaneous endoscopic jejunostomy (PEJ); however, the patient's family did not consent to PEJ feeding owing to the risk of infection. The relatives of the patients were informed about the PEJ, and daily routine interviews were conducted to relieve their concerns about the method and give them detailed information about the complications that could arise from oral nutrition and the practices recommended for improving the patient's health. However, the patient's family members strongly refused the use of the PEJ method during the treatment and after discharge.

Energy, protein, and other nutrient requirements were determined at the time of the patient's discharge. The risks of oral feeding of the patient were communicated again to the family, and the use of a thickener powder product was recommended to reduce the aspiration risk. The clinical dietitian was contacted, and the patient's family was provided diet training after discharge.

The active ingredients of the drugs used by the patient during the hospitalization were as follows: valproic acid, clonazepam, clarithromycin, cefoperazone + sulbactam, carbamazepine, enoxaparin sodium, lansoprazole, paracetamol, and baclofen.

Discussion

A clear understanding of the mechanisms that cause CP and their effects play an important role in the development of treatment and prevention methods (3). The oral motor function, nutritional problems, and nutritional status of children with CP should be evaluated comprehensively, and rehabilitation and nutritional interventions should be initiated as early as possible (8). Accurate measurement of anthropometric parameters is crucial for accurate interpretation of the causes of malnutrition and the nutritional status in children with CP to enable the development of appropriate nutritional intervention strategies. Contractures generally develop in the muscles of children with CP, and ankle contractures are common. The range of joint range of motion is limited, and the muscles appear func-

tionally short. Ultrasonography is the most common tool that is used to describe the basic muscle structural changes, such as fiber length and tissue thickness. Therefore, anthropometric measurements recorded by measuring the knee length in patients may be misleading (9).

Children with CP have a compromised ability to absorb, chew, and swallow foods. The severity of swallowing problems may vary, depending on the extent of sensorimotor impairment, motor limitations, and cognitive and communication deficits. Dysphagia is common in CP patients with severe motor impairment and may cause nutrition disorders and malnutrition (10, 11). In a meta-analysis of 42 studies, the prevalence of drooling, swallowing, and feeding problems was 44.0%, 50.4%, and 53.5%, respectively (12).

As in our case, insistently feeding a patient with oral motor impairment and dysphagia who cannot protect the respiratory tract leads to pulmonary aspiration and disrupts the nutrition and hydration status (11). Aspiration could cause respiratory failure or death (13). In a study that followed up 3185 CP patients to evaluate survival and mortality, 436 (75.2%) patients died. The primary cause of death in 349 patients for whom death cause data were available was respiratory problems (56.8%). The main cause of respiratory problems was pneumonia (82%), and 45% of the pneumonias occurred due to aspiration (14).

Post-pylorus nasojejunal, percutaneous gastrojejunostomy, or PEJ feeding is recommended to reduce aspiration and should be placed when long-term home enteral nutrition is required (13). In one study, the height and body weight of CP patients who were fed using gastrostomy tubes were higher than those in the control group; another study showed higher mortality risk and hospital stay in children with CP who were fed via gastrostomy tubes than those who were fed orally (15, 16). Although feeding via gastrostomy or jejunostomy tube can facilitate feeding in children with CP, as in our case, most caregivers have difficulty in accepting this intervention emotionally and thus reject it (10). In our case, the family believes that the patient has no nutritional problem, and the patient who has a history of aspiration and signs of cachexia continue to be fed orally despite several warnings. Gangil et al. (17) reported similar findings and showed that the parents of CP patients had low awareness regarding the nutritional problems experienced by their children; the parents were under the impression that their malnourished children were actually healthy. The study also showed that families were pessimistic about the possibility of overcoming and improving the nutritional problems of the patients. Nutritional rehabilitation was given to the patients and their family members. After rehabilitation, nutritional problems, oral motor dysfunction, and nutritional status reduced (17).

Owing to the influence of caregiver practices on patient health, effective nutrition interventions for management of children with CP as well as rehabilitation of the patient, family, and/or caregivers are required. One study that evaluated the nutritional status and caregiver welfare of children with CP reported that the quality of life of caregivers affected the nutritional problems experienced by the children; further, pediatric CP patients who were cared for by caregivers with low quality of life experienced nutritional problems (18). Another trial showed that the family directly affected the health of the patient and influenced the patient's self-perception, social support, and stress management. Empowering the parents of CP patients with cognitive and behavioral strategies to help them manage their children's behavior has the potential to change the health outcomes of caregivers and patients (7).

Thus, there is no gold standard nutrition protocol for CP patients. The primary goal of nutritional support is to prevent the patient from entering the catabolic process, to improve the current metabolic state, and to protect and maintain the integrity of the gastrointestinal system. Swallowing difficulties, gastroesophageal reflux, and constipation symptoms in individuals with CP are associated with different food consumption habits. Therefore, nutritional intervention should be planned, considering the gastrointestinal symptoms and nutritional status (19). A nutrition team that supports the intervention of dieticians and swallowing therapists to evaluate the nutritional status and efficiency of CP patients to determine the optimal nutrition method, reduce the risk of malnutrition, enable early detection of malnutrition, and implement prevention and recovery strategies to improve the nutritional and functional status of these children, is indispensable in CP management (20).

Informed Consent: Verbal informed consent was obtained from the parents of the patients who participated in this case.

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References

1. Braun KVN, Doernberg N, Schieve L, Christensen D, Goodman A,Yeargin-Allsopp M. Birth Prevalence of Cerebral Palsy: A Population-Based Study. Pediatrics 2016; 137: 1-9. [Crossref]
2. Richards CL, Malouin F. Cerebral palsy: definition, assessment and rehabilitation. Handb Clin Neurol 2013; 111: 183-95. [Crossref]
3. Stavsky M, Mor O, Mastrolia SA, Greenbaum S, Than NG, Erez O. Cerebral Palsy-Trends in Epidemiology and Recent Development in Prenatal Mechanisms of Disease, Treatment, and Prevention Front Pediatr 2017; 5: 21. [Crossref]
4. Corrie E, Hulst K, Rotteveel JJ, Willemsen MAAP. Jongerius PH. Swallowing problems in cerebral palsy. Eur J Pediatr 2012; 171: 409-14. [Crossref]
5. Bell KL, L Samson-Fang L. Nutritional Management of Children With Cerebral Palsy. Eur J Clin Nutr 2013; 67: 13-6. [Crossref]
6. Speyer R, Cordier R, Kim JH , Cocks N, Michou E, Sarah Wilkes-Gillan S. Prevalence of Drooling, Swallowing, and Feeding Problems in Cerebral Palsy Across the Lifespan: A Systematic Review and Meta-Analyses. Dev Med Child Neurol 2019; 61: 1249-58. [Crossref]
7. Cramm JM, Nieboer AP. Psychological Well-Being of Caregivers of Children With Intellectual Disabilities: Using Parental Stress as a Mediating Factor. J Intellect Disabil 2011; 15: 101-13. [Crossref]
8. Sığan SN, Uzunhan TA, Aydınlı N, Eraslan E, Ekici B, Calışkan M. Effects of oral motor therapy in children with cerebral palsy. Ann Indian Acad Neurol 2013; 16: 342-6. [Crossref]
9. Mathewson MA, Lieber R. Pathophysiology of Muscle Contractures in Cerebral Palsy. Phys Med Rehabil Clin N Am 2015; 26: 57-67. [Crossref]
10. Sleigh G, Sullivan PB, Thomas AG. Gastrostomy Feeding Versus Oral Feeding Alone for Children With Cerebral Palsy. Cochrane Database Syst Rev 2004; CD003943. [Crossref]
11. Arvedson JC. Feeding Children With Cerebral Palsy and Swallowing Difficulties. Eur J Clin Nutr 2013; 67: S9-12. [Crossref]
12. Speyer R, Cordier R, Kim JH, Cocks N, Michou E, Wilkes-Gillan S. Prevalence of Drooling, Swallowing, and Feeding Problems in Cerebral Palsy Across the Lifespan: A Systematic Review and Meta-Analyses. Dev Med Child Neurol 2019; 61: 1249-58. [Crossref]
13. Bischoff SC, Austin P, Boeykens K, Chourdakis M, Cuerda C, Jonkers-Schuitema C, et al. ESPEN Guideline on Home Enteral Nutrition. Clin Nutr 2020; 39: 5-22. [Crossref]
14. Blair E, Langdon K, McIntyre S, Lawrence D, Watson L. Survival and Mortality in Cerebral Palsy: Observations to the Sixth Decade From a Data Linkage Study of a Total Population Register and National Death Index. BMC Neurol 2019; 19: 111. [Crossref]
15. Day SM, Strauss DJ, Vachon PJ, Rosenbloom L, Shavelle RM, Wu YW. Growth Patterns in a Population of Children and Adolescents With Cerebral Palsy Dev Med Child Neurol 2007; 49: 167-71. [Crossref]
16. Figueroa MJ, Rojas C, Barja S. Morbimortality Associated to Nutritional Status and Feeding Path in Children With Cerebral Palsy. Rev Chil Pediatr 2017; 88: 478-86. [Crossref]
17. Gangil A, Patwari AK, Aneja S, Ahuja B, Anand VK. Feeding Problems in Children With Cerebral Palsy. Indian Pediatr 2001; 38: 839-46.
18. Polack S, Adams M, O'banion D, Baltussen M, Asante S, Kerac M, et al. Children With Cerebral Palsy in Ghana: Malnutrition, Feeding Challenges and Caregiver Quality of Life. Dev Med Child Neurol 2018; 60: 914-21. [Crossref]
19. Caramico-Favero DCO, Guedes ZCF, Morais MB. Food Intake, Nutrıtıonal Status And Gastroıntestınal Symptoms In Chıldren Wıth Cerebral Palsy. Arq Gastroenterol 2018; 55: 352-7. [Crossref]
20. Adamu AS, Sabo UA, Gwarzo GD, Belonwu RO. Nutritional Status in Cerebral Palsy: A Cross-sectional Comparative Survey of Children in Kano, Nigeria. Niger Postgrad Med J 2018; 25: 156-60. [Crossref]