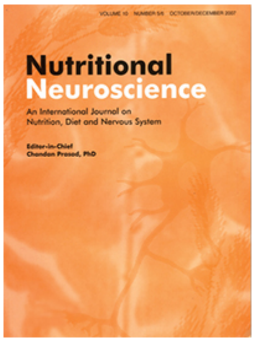

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Nutritional interventions improve quality of life of caregivers of children with neurodevelopmental disorders

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ABSTRACT

Introduction: Children with neurodevelopmental disorders are at high risk for malnutrition. We aimed to investigate the impact of nutritional interventions to children with neurodevelopmental disorders and the quality of life of caregivers.

Materials/Method: This is a prospective interventional study of 91 children with neurodevelopmental disorders. The children were separated into two groups: the intervention group and control group. The intervention group was selected from among children who had not been evaluated for nutrition and feeding problems by a pediatric gastroenterologist or dietician for the past one year. Children in the intervention group were called for follow-up visits and their nutritional intervention and anthropometric measurements were initiated by a pediatric gastroenterologist and dietician, at one month, three months, six months, and one year. The WHOQoL-BREF quality of life scale was completed by the caregivers of the children at baseline and at one year.

Results: The intervention group had increased malnutrition ($p < 0.001$) and gastrointestinal system pathologies such as dysphagia ($p < 0.001$), constipation ($p = 0.02$), gastroesophageal reflux ($p = 0.03$) at baseline. After the nutritional intervention, 77.7% of the intervention group gained weight and 55.5% reached the target weight. The quality of life scale scores at baseline were lower among caregivers of the intervention group; however, they reached those of the control group after the nutritional intervention.

Conclusion: Close multidisciplinary nutrition monitoring enables children with neurodevelopmental disorders to thrive appropriately and improves the quality of life of caregivers.

KEYWORDS
Neurodevelopmental disorders; malnutrition; nutrition; quality of life; feeding disorder; intervention; children; caregiver

Introduction

Neurodevelopmental disorders are a group of heterogeneous conditions characterized by a delay or disturbance in the acquisition of skills in a variety of developmental domains, including motor, social, language, and cognition [1]. Some disorders are static, such as cerebral palsy which is the most common physical disability in children, and some are progressive, such as neurodegenerative diseases like metabolic disorders, epileptic encephalopathies, muscular and genetic disorders.

Nutritional issues play an important part in the care and treatment of children with neurodevelopmental disorders. Many factors should be considered when assessing and devising nutritional and feeding plans for children with neurodevelopmental disorders. The nutritional status, growth rate, and body composition of these children differ from healthy children and their energy needs are often difficult to estimate [2].

Feeding disorders and gastrointestinal system pathologies play a key role in the onset of undernutrition. Nutritional deficiency leads to malnutrition and malnutrition affects respiratory and cardiac function, decreases immunity, brain growth, cognitive development, and social participation [3,4].

The severity of feeding difficulties is related to the cause of developmental delay and the degree of motor function impairment [5,6,7] and feeding difficulties adversely affect the quality of life and the daily care of these children leads to substantial problems for parents and caregivers [8]. This study aimed to investigate the effect of nutritional intervention to children with neurodevelopmental disorders and the quality of life of caregivers.

Materials and method

This non-randomized, controlled interventional study was conducted among children with neurodevelopmental

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disorders who were tracked at the Celal Bayar University School of Medicine, Division of Child Neurology. One hundred children were planned for inclusion in the study at baseline but nine were excluded during the study period because their parents did not attend follow-up clinics. Ninety-one children were separated into 2 groups: the intervention group ($n = 45$) and the control group ($n = 46$). The caregivers in both groups (the responsible adult for the children) gave their informed consents.

Inclusion/exclusion criteria

Ninety-one children aged 2–18 years who were diagnosed as having neurodevelopmental disorders by a pediatric neurologist were included in the study. The intervention group contained 45 children who had been tracked but had not adhered to follow-up visits and had not been evaluated for nutrition and feeding problems by a pediatric gastroenterologist or dietician for the past one year. The control group comprised 46 children with the same diagnoses who had regularly adhered to follow-up visits at the child neurology department and had been evaluated for nutrition and feeding problems by a gastroenterologist or dietician over the past one year. Physical limitations and the severity of motor disability were determined using the Gross Motor Function Classification System (GMFCS). This study included children with GMFCS level 3, 4, and 5. Only oral feeding children were included in the study; those feeding via nasogastric/orogastric tubes (NGT/OGTs) were excluded. Children with tracheostomy and intractable epilepsy were not included in the study. Children with autism spectrum disorders that may have selective eating problems and those on anticholinergic medications, which may cause constipation and dry mouth, were also excluded from the study.

Primary outcomes

The primary characteristics of both groups including age, sex, disease character, muscle tone, GMFCS, and seizure history were recorded. The presence of feeding dysfunction, duration of feeding time, coughing, and cyanosis in feeding was determined through interviews with the mothers, who were the primary caregivers. Weight and height, as well as estimated height in relation to tibial length $(\text{tibial length} \times 3.26) + 30.8$ were recorded as anthropometric measurements. The right side was used in patients who were suitable for tibial length measurement. In the presence of asymmetric deformity, when the right side was more affected than the left side, the measurements were performed on the left side. The same physician (pediatric gastroenterologist) performed all measurements twice and the mean of the measurements was used in the analysis. Both groups were evaluated for dysphagia, constipation, and gastroesophageal reflux by a pediatric gastroenterologist.

Intervention

The intervention group was seen at baseline, and at 1, 3, 6, and 12 months by a pediatric neurologist, pediatric gastroenterologist, and a dietician. The optimal caloric intake was calculated using height-based calorie calculations and the height was estimated in relation to the tibial length [2]. With the support of a dietician, a healthy eating plan with optimal caloric intake (11 kcal/cm energy requirement in children who were non-ambulatory and 14 kcal/cm in children with motor dysfunction who were ambulatory) was designed for the children [9]. The weight range was planned to be kept between the 10th and 25th percentile to avoid obesity. Treatment was initiated for gastrointestinal problems [constipation, gastroesophageal reflux (GER)]. Patients with a history of dysphagia and aspiration were evaluated in terms of nasogastric tube and percutaneous endoscopic gastrostomy (PEG), and the appropriate one was chosen.

Quality of life

The short version of the World Health Organization (WHO) Quality of Life scale (WHOQoL-BREF) was administered to the primary caregivers in both groups at baseline and at 12 months to analyze the quality of life. The WHOQOL-BREF is an assessment tool developed by the WHO for the subjective evaluation of the quality of life [10]. The validity and reliability study of the Turkish version was performed by Eser et al. [11]. The scale covers four domains: the physical health domain evaluates the ability to perform daily tasks, dependence on drugs and treatment, energy and exhaustion, mobility, pain and discomfort, sleep and rest, and the capacity to work; the psychological health domain assesses body image and outer appearance, negative emotions, memory, and ability to concentrate; the social relationship domain evaluates relations with other people, social support systems, and sexual satisfaction; and the environment domain assesses financial resources, physical safety, security, access to healthcare services, home and physical environment satisfaction, resting and leisure activity accessibility, transportation satisfaction, and social pressure (developed in Turkish national version). No total score has been designated. Each domain is rated on a 20-point or 100-point scale; how the scoring is rated is at the discretion of the researcher. However, as in our study, scoring is usually rated on a 20-point scale. No cut-off scores have been designated, and higher scored indicate a higher quality of life.

Data analysis

A *p*-value of less than 0.05 was considered to be statistically significant. Data were analyzed using the SPSS 15.0 statistical package. Categorical variables were compared using the Chi-square test, and continuous variables of the dependent and independent groups were analyzed using Student's *t*-test.

Ethics

Ethics committee approval was obtained at Celal Bayar University, Medical School Ethics Committee of Health Sciences (Reference No. 20.478.486.314, Date: 17.08.16). Informed consent was given by the primary caregivers, who were aged over 18 years at the beginning of the study.

Results

No statistically significant difference was found between the intervention and control groups in terms of age and sex (Table 1). Table 1 shows the characteristics of the disease, its diagnosis, muscle tone, the results of the gross motor function scale, and the presence of seizure of both groups.

Patients in the intervention group had significantly higher rates of dysphagia, constipation and GER and malnutrition. Also, they had significantly more frequent symptoms of coughing, cyanosis, aspiration and prolonged feeding time (> 30 min), stressful meals (Table 2).

Table 1. Evaluation of the intervention and control groups in terms of demographic, disease diagnosis and characteristics.

	Intervention *N* (%)	Control *N* (%)	*P*
Age (mean ± sd)	6.8 ± 3.2	7.7 ± 2.9	0.6
Gender			0.54
Female	20 (44.4%)	20 (43.5%)	
Male	25 (55.6%)	26 (56.5%)	
Disease character			0.54
Static disease	40 (88.8%)	40 (87%)	
Progressive disease	5 (11.2%)	6 (13%)	
Muscle tone			0.46
Hypertonic	34 (75.6%)	37 (80.4%)	
Hypotonic	9 (20%)	6 (13%)	
Axial hipotonic, ekstremity hypertonic	2 (4.4%)	3 (6.6%)	
Gross Motor Function Scale			0.53
5	38 (84.4%)	39 (84.7%)	
4	4 (8.8%)	4 (8.6%)	
3	3 (6.6%)	3 (6.5%)	
Disease diagnosis			0.7
Cerebral palsy	30 (66.6%)	32 (69.5%)	
Genetic / Metabolic	7 (15.5%)	8 (17.3%)	
Muscle Diseases	3 (6.6%)	3 (6.5%)	
Epileptic Encephalopathy	5 (11.1%)	3 (6.5%)	
Seizure+	31 (68.9%)	32 (69.6%)	0.56

Table 2. Evaluation of feeding and feeding-related problems before the intervention in both groups.

	Intervention *N* (%)	Control *N* (%)	*P*
Dysphagia (+)	24 (53.3%)	3 (6.5%)	**0.00**
Constipation (+)	29 (64.4%)	18 (39.1%)	**0.02**
Gastroesophageal Reflux (+)	13 (28.9%)	5 (10.9%)	**0.03**
Duration of Feeding time >30 min (+)	19 (42.2%)	7 (15.2%)	**0.01**
Are the meals stressful? (+)	27 (60%)	9 (20%)	**0.01**
Coughing / Cyanosis in Feeding (+)	22 (48.9%)	5 (11.1%)	**0.00**
Malnutrition (+)	29 (64,4%)	6 (13,3%)	**0.00**

At follow-up, 4 patients (8.9%) started to be fed via NGTs and 6 (13.3%) patients started to be fed via PEG tubes. After nutritional intervention, 77.7% of the intervention group gained weight, 55.5% reached the target weight, and 86.6% avoided from obesity (Table 3).

When the quality of life of the caregivers was evaluated, the parents of the children in the intervention group had lower scores in quality of life subdimensions than those of children in the control group, and there was a significant difference in physical, social, and environmental health between the groups. After the one-year follow-up with intervention, the parents of the intervention group had significantly increased mean scores in all domains of the quality of life scale, reaching or even exceeding those of the control group. There was no significant difference in the mean scores of the control group before and after the follow-up (Table 4).

Discussion

Patients with neurodevelopmental disorders are at increased risk for malnutrition and nutritional deficiencies. The diagnosis of the disease, its characteristics, the level of gross motor function, as well as accompanying gastrointestinal system (GIS) pathologies also play a significant role in those conditions. With a multidisciplinary approach to these patients, we predicted that nutritional and feeding-related problems would decrease and the quality of life of caregivers would improve.

Table 3. After nutritional intervention some parameters of the intervention group.

	Intervention *N* (%)
Weight gain (+)	35 (77.7%)
Reaching target weight (+)	25 (55.5%)
Avoidance from obesity (+)	39 (86.6%)

Studies showed that 29–46% of children with cerebral palsy had nutritional deficiency, 23% had growth

Table 4. Comparison of the mean scores of the WHOQOL-BREF quality of life of caregivers in the intervention and control groups before and after follow-up.

	Intervention average before/after	*P*	Control average before/after	*p*
WHOQOL-BREF The Physical Health	49.2 ± 18.1 / 64.7 ± 19.1	**0.000**	62.4 ± 18.6 / 64.3 ± 17.5	0.301
WHOQOL-BREF The Psychological Health	53.3 ± 18.9 / 67.3 ± 16.1	**0.000**	59.6 ± 15.0 / 60.0 ± 13.4	0.643
WHOQOL-BREF The Social relationships	51.6 ± 24.6 / 64.8 ± 23.2	**0.000**	64.7 ± 17.2 / 63.6 ± 17.8	0.533
WHOQOL-BREF Environment	45.9 ± 16.9 / 61.9 ± 15.4	**0.000**	55.8 ± 16.6 / 57.6 ± 13.7	0.124
WHOQOL-BREF TR The Environment	47.6 ± 16.9 / 63.2 ± 15.1	**0.000**	56.9 ± 16.0 / 58.4 ± 13.4	0.146

retardation, 8–14% were overweight, 89% required help during feeding, and 55% aspirated their food during feeding [12,13]. In neurodevelopmental disorders, it has been reported that swallowing problems, drowning, and vomiting associated with these problems are frequent, leading to malnutrition [14,15].

The most frequently encountered problems in our patients involved dysphagia, aspiration, constipation, and GER. Statistically significant differences between the control and intervention groups were noted with regard to these problems. In the intervention group, an increased rate of constipation in particular, and incompetent GIS passage may result in decreased food consumption and caloric intake. The presence of GER may also lead to cyanosis and aspiration during feeding and treatment of GER minimizes aspiration.

The mothers of children with neurodevelopmental problems spend an average of 3.5–7.5 h per day feeding their children, whereas mothers of healthy children spend only 0.8 h. The prolonged nutritional times of children with neurodevelopmental disorders may cause a decrease in caloric intake compared with their peers. In addition, due to vomiting caused by GER from structural abnormalities such as oral dysfunction, high palate, large tongue, and abnormal tooth structure, this group had low calorie intake [3,15,16]. In a study of 271 children with neurodevelopmental disabilities, 21% had recurrent vomiting, 56% needed help during feeding, and 28% had a feeding time of three hours per day [17]. We observed a longer period of 30 min in the intervention group. The higher percent of dysphagia, GER, and coughing, as well as cyanosis during feeding in the intervention group may lead to the prolonged feeding time, thus resulting in the inadequate caloric intake and higher rate of malnutrition in the group. These data suggest that a prolonged feeding time is associated with malnutrition.

Our study determined that 60% of meals were stressful in the intervention group than in the control group, which could be explained by the higher rates of dysphagia, coughing, cyanosis, and aspiration while feeding. PEG was indicated for six children with a history of dysphagia and aspiration in the intervention group, and NGT was indicated for four children. Thus, the risk for aspiration and stressful meals were prevented and proper weight was gained. Appropriate weight gain could be achieved as a result of interventional modification of food and calorie intake in both groups at regular follow-up visits. Close monitoring of weight gain and nutrition is necessary because patients on nutritional support have a high risk of obesity due to immobility. It is important to take precautions with regard to obesity and to avoid obesity-related complications at follow-up visits. Keeping both the intervention and control group in the appropriate percentile range, the children reached target weight and avoided obesity with close follow-up and evaluation. At one year, 55.5% of the children in the intervention group reached their target weight.

We found that the children in the intervention group had more feeding/nutritional-associated problems and that the quality of life scores of the caregivers were lower in all domains when compared with the control group. Murphy et al. evaluated the health status of the parents of children with disabilities and reported that the physical and mental health statuses of the parents were adversely affected by providing care, thus impairing their daily functioning [18]. Feeding problems in children with chronic diseases cause stress and concern among caregivers [19,20]; therefore, effectively treating feeding problems increases parental physical and psychological health and thus has a positive effect on the child's condition [21]. Avitsland et al. evaluated children who had feeding problems and had undergone gastrostomy, as well as their parents. They found that after the procedure, the parents' anxiety decreased and the children's perception of quality of life increased [22]. In a study by Sullivan et al., the impact of gastrostomy tube feeding on the quality of life of carers of children with cerebral palsy was evaluated. At one year, there was a significant difference in the social functionality domain, the mental health domain, general health perception, and energy/vitality of the parents. The values obtained at one year were found to be similar to the norms of society [23]. Similarly, we found that the quality of life of the caregivers increased significantly after the nutritional intervention. In patients with prolonged or delayed feeding time and with recurrent aspiration pneumonia, switching the feeding pattern to NGT or PEG may explain the improving scores of life quality.

Strengths and limitations

Our study had an advantage over previous studies because, to the best of our knowledge, this is the first study to evaluate the impact of a one-year-long intervention for feeding problems. However, there were some limitations. First, we did not include a control population without neurodevelopmental disorders against which to compare findings. We also had many intervening factors, such as dietary intake, type of feeding, and feeding-related problems; therefore, the evaluation of which parameter affected the quality of life was not possible.

Conclusion

Malnutrition and nutritional disorders are preventable complications with multidisciplinary management in children with neurodevelopmental disorders. These children can thrive appropriately with close monitoring of nutrition, as well as by obtaining feeding support from specialists such as dieticians, and the child's own medical care team involving pediatric neurologists and pediatric gastroenterologists. Finally, the nutritional intervention and treatment of gastrointestinal symptoms contributes to the improvement of caregivers' quality of life.

Disclosure statement

No potential conflict of interest was reported by the authors.

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