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# Impact of an educational program on the feeding of neurologically impaired children

## *Impacto de uma ação educativa na alimentação de crianças neuropatas*

### ABSTRACT

**Purpose:** To verify the impact of an educative program focused on aspects related to feeding developed with a group of caregivers of children with chronic non-progressive encephalopathy. **Methods:** Cross-sectional comparative study conducted with 30 children diagnosed with chronic non-progressive encephalopathy and their caregivers with the use of a questionnaire and video recordings of a meal conducted by the main caregiver. In order to verify the impact of an educational program in the knowledge and conduct of caregivers, patients were divided into two groups: study – consisting of caregivers submitted to a questionnaire and a video recording before and after the educational program; control – group in which caregivers underwent the procedures in two occasions, but without access to the educational program. **Results:** Around 93.33% of caregivers were females, most had low educational level, and only 10% had a professional activity. Previous knowledge of caregivers concerning feeding was restricted, with 66% of caregivers not knowing what aspiration was, 60% being unfamiliar with the complications associated with such occurrence, and 86.66% stating that there is no relation between voice and swallowing. During feeding, only 26.66% of the caregivers used verbal commands related to feeding, and 50% did not realize the difficulties presented by their children. We observed a difference with regard to knowledge and conduct in the study group only. **Conclusion:** The educational program had a positive impact on the knowledge and conduct of caregivers concerning the feeding of their children with chronic non-progressive encephalopathy.

### RESUMO

**Objetivo:** Verificar o impacto de uma ação educativa voltada aos cuidados com a alimentação desenvolvida com um grupo de cuidadores de crianças com encefalopatia crônica não progressiva (ECNP). **Métodos:** Estudo comparativo transversal realizado com 30 crianças com ECNP e seus cuidadores, tendo-se realizado aplicação de questionário e registro de uma refeição conduzida pelo cuidador principal. A fim de se verificar o impacto da ação educativa no conhecimento e conduta dos cuidadores, estes foram divididos em dois grupos: estudo, composto por cuidadores submetidos à aplicação de questionário e registro em vídeo antes e após realização da ação educativa; e controle, grupo submetido aos procedimentos em dois momentos, porém sem acesso à ação educativa. **Resultados:** 93,33% dos cuidadores eram do sexo feminino, a maioria apresentou baixo nível de escolaridade e apenas 10% desenvolviam alguma atividade profissional. O conhecimento prévio dos cuidadores quanto aos aspectos relacionados à alimentação foi restrito, tendo 66% destes referido não saber o que era aspiração, 60% afirmado não saber as complicações associadas a esta e 86,66% terem negado existir relação entre voz e deglutição. Durante a alimentação, apenas 26,66% dos pais fizeram uso de comandos verbais relacionados à alimentação e 50% não perceberam as dificuldades apresentadas pelo seu filho. Observou-se diferença quanto ao conhecimento e conduta de cuidadores apenas no grupo estudo. **Conclusão:** A ação educativa realizada apresentou impacto no conhecimento e conduta dos cuidadores quanto à alimentação de seus filhos com ECNP.

Study carried out at the Universidade Estadual de Ciências da Saúde de Alagoas – UNCISAL – Maceió (AL), Brasil.

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**Conflict of interest:** nothing to declare.

## INTRODUCTION

Chronic non-progressive encephalopathy (CNPE) is described as a developmental disorder of movement and posture — with limitations in activities — secondary to a non-progressive brain injury occurring during fetal or infant development, often accompanied by sensory, cognitive, behavioral, and communicative disorders<sup>(1)</sup>.

Although CNPE has been subject of several investigations, few studies have focused on the primary caregiver's knowledge and behavior as to this specific disorder. The same occurs in the care of this population regarding food, with lack of publications aimed at understanding the impact of the caregiver's dynamics in the performance of neurologically impaired children during feeding. A study on the Brazilian scientific production showed that this theme has not accompanied the growth trend observed in other areas of speech language pathology speech therapy<sup>(2)</sup>.

Based on the proposal by the International Classification of Functioning Disability and Health, there was a breakthrough with regard to the understanding of processes related to a health condition. According to this perspective of health care, disability results from interactions between the dysfunction presented by the individual (be it related to the functions or to the structures of the body), the limitation of activities and the restriction in social participation, considering positive or negative impacts of environmental factors on the performance of activities<sup>(3)</sup>. In this sense, it is necessary to understand the impact of care delivery in the performance of a neurologically impaired individual, in the search for ways to minimize negative impacts and optimize positive ones.

The neurologically impaired child's oral and motor patterns may be atypical or inefficient, impacting on the functions of sucking, chewing, swallowing, and speech, especially in cases of disorders related to voluntary movement. Consequently, feeding difficulties may occur early in life, often before the onset of other signs of movement disorders<sup>(4,5)</sup>.

Although they usually manifest early, swallowing disorders in childhood encephalopathies are often diagnosed and treated late, that is, when clinical complications such as dehydration, malnutrition, and altered lung health are shown. Chronic dysphagia compromises infant growth and development, as well as the quality of life of neurologically impaired children<sup>(6,7)</sup>.

Educational programs for caregivers of patients with dysphagia have been described as part of the therapeutic process and should include their awareness and training, thus preparing them to deal with issues related to functional food (oral handling, type of diet, utensils, supply, posture, signs of difficulty, compensatory strategies) and with daily maintenance of stimuli, optimizing therapeutic results<sup>(8-10)</sup>. However, the effectiveness of educational activities is questioned, because the caregiver may receive too much information and be unable to integrate them into their routine or even to understand the interference of certain conducts in the dynamic of feeding (cognitive process), and

not put them into practice, resulting in the theory - practice dichotomy<sup>(11,12)</sup>. In this context, the aim of this study was to investigate the impact of a speech educational action in the knowledge and conduct of caregivers regarding the nutrition of CNPE children.

## METHODS

This is a cross-sectional comparative study, conducted with 30 children diagnosed with CNPE, registered on the waiting list of three reference services for speech therapy in Alagoas and their primary caregivers, constituting 30 dyads caregiver/child. This study was approved by the Ethics Committee of the University of Health Sciences of Alagoas (UNCISAL) and the Federal University of São Paulo (UNIFESP) under protocols No. 1246/09 and 2065/09, respectively. All caregivers signed the informed consent form to formalize their voluntary participation.

The inclusion criteria were children of both genders, aged between 0 and 12 years, with CNPE; not under speech therapy follow-up, in exclusive oral feeding or mixed (oral and enteral) who had their parents as primary caregivers, regardless of sex and age. Exclusion criteria were children exclusively in alternative feeding (nasogastric tube for enteral feeding, gastrostomy) whose caregivers had already been submitted to educational actions aimed at feeding of their children, and whose caregivers did not participate in all phases proposed by the study.

In order to verify the impact of the educational activity on the knowledge and behavior of caregivers as to food, the study sample was divided into two groups: Group 1 (control), consisted of caregivers submitted to data collection (questionnaire and video recording), in two occasions, with an interval of approximately 30 days, but without access to speech guidance. Caregivers from this group participated in the educational action after reapplication procedures. Group 2 (study) consisted of caregivers who had undergone data collection before orientation and approximately 30 days after the educational action. The distribution of the caregivers was alternate, that is, they were put in one group and in the other as they were selected.

The procedures were divided into six phases:

- Phase 1: Identification of CNPE children registered in a waiting list for reference speech therapy assistance in Alagoas.
- Phase 2: Applying the questionnaire to caregivers – To identify the perception and knowledge of caregivers regarding aspects related to the context of feeding CNPE children, the “Survey on the Perception of Caregivers in the Feeding Context” was applied. The instrument was adopted in a survey of caregivers of adults<sup>(13)</sup> and adapted by the authors, for this study, considering neurologically impaired children.
- Phase 3: Video recording of caregivers feeding their children – The video recording was performed by the same researchers who applied the questionnaire, using a digital camera (Handycam DCR-SR47) and compatible tripod

(tripod for camcorder WT 35501), placed strategically at a distance that would favor the full view of both the caregiver and the child during feeding. At the end of the recording, the digital files were downloaded to a computer (notebook STI IS1253, Windows Vista operating system), saved in files identified by numbers, and subsequently stored on a Digital Versatile Disk.

The Digital Versatile Disks containing the videos of a full meal were then given to two evaluators, speech therapists and specialists in Orofacial Motricity with experience in caring for patients with swallowing disorders. Each of the professionals performed the analysis separately, describing the situation of the video in the "Protocol of Feeding Dynamics Description", an instrument composed of three domains, depending on the nature of the aspects observed: findings related to swallowing, motor, and behavioral aspects, and conduct of the caregiver during the meal.

The protocol was designed by the authors based on functional and behavioral aspects related to the act of feeding children with CNPE commonly described in the literature. In order to avoid interference in assessment, the videos of the first and second collections were given to the evaluators without such information and without informing to which group each dyad belonged. The data were computed considering the rate of agreement in responses by the evaluators.

- Phase 4: Educational program on feeding of neurologically impaired children by caregivers – The educational action aimed at caregivers was carried out at two different moments and consisted of a lecture and individual orientations. The informative talk was held with groups of approximately five caregivers and addressed the following topics: (a) the dynamics of swallowing; (b) swallowing disorders; (c) oral-motor deficits in CNPE children; (d) care of the child with dysphagia; (e) conduct of caregivers facing the child's difficulties. The second part of the educational action was conducted approximately 1 week after the first one, with each caregiver individually, since it was focused on the analysis of the dynamics caregiver/child during feeding (video feedback), with the use of the video from each pair caregiver/child, aiming at discussing with the caregiver features of the ability to feed the child, as well as their perception about possible functional difficulties, compensatory/favoring strategies used by them during feeding and the child's response.
- Phase 5: Reapplying the questionnaire – The reapplication of the questionnaire to the participants in the study group occurred 30 days after the educational program; for the control group, the instrument was reapplied 30 days after the first application, but caregivers had not participated in the educational program.
- Phase 6: Video recording after educational action – The second video recording followed the same rule of reapplying the questionnaire; therefore, with a 30-day interval between the first and second video recordings, being observed the procedures set for the first shot. The statistical analysis was performed using the PASW

Statistics Data Editor application, version 17.0. The normality of the sample was tested by the Shapiro-Wilk and Kolmogorov-Smirnov tests. To compare the distribution of variables between groups, we adopted the Mann-Whitney test, with 0.1 alpha admitted in the data analysis. The comparison of data prior to and after the orientations was made by the non-parametric Wilcoxon test. The significance level of the analysis was set at 5% ( $p < 0.05$ ).

## RESULTS

The sociodemographic characteristics of children and caregivers were described using frequency, mean, mode, standard deviation, minimum and maximum, depending on the nature of the variables. Regarding gender, there was a higher frequency of males in the sample of children (70%), while females accounted for the majority of caregivers (93.33%). Spastic tetraplegia was the most common type of cerebral palsy (73.33%). Caregivers had low educational levels, 80% presenting incomplete elementary school. Comparing the distribution of variables in the control (G1) and study group (G2) we found no statistically significant differences, which illustrate the homogeneity of the sample (Table 1).

The knowledge of caregivers regarding feeding difficulties was restricted in both groups. Choking and fatigue were most frequently cited as signs of difficulties in feeding/swallowing; 66.66% of caregivers reported not knowing the concept of aspiration, while only four (13.33%) defined it properly. Shortness of breath, pneumonia, and death were some of the complications associated with food aspiration. As the issues of this domain were multiple choices, it was not possible to apply an inferential statistical test for these variables. The absence of statistical difference between Groups 1 and 2 for the variable "verbal interaction during feeding" ( $p = 0.1919$ ) and "importance of verbal commands related to food" ( $p = 0.1753$ ) illustrates the similarity of caregivers' conduct as to feeding difficulties presented by their children (Table 2).

As for the changes in voice and breathing during feeding, most caregivers reported not to observe them or never paying attention to it. Hoarseness was the most common voice disorder, while wheezing was cited by only 3.33% of the caregivers. The lack of relationship between voice and swallowing and between breathing and swallowing was mentioned by 86.66% and 43.33% of caregivers, respectively. The comparison of results concerning the relations of voice/breathing/swallowing mentioned by caregivers showed no significant difference between groups ( $p > 0.05$ ) (Table 3).

To verify the impact of the educational action, we compared the knowledge and behavior of caregivers of Groups 1 and 2 at the first and the second data collections (questionnaires and recording of feeding dynamic). The statistical differences observed only in the study group — except for the variables "verbal interaction with the child" ( $p = 0.0544$ ) and "modification of conduct by the caregiver"

**Table 1.** Demographic data of children

Sample characteristics	G1 (control)		G2 (study)		Total		<i>p-value</i>
	n	%	n	%	n	%	
Children							
Gender							0.240
Females	6	40	3	20	9	30	
Males	9	60	12	80	21	70	
CNPE							0.0748
Hemiparesis	1	6.66	4	26.66	5	16.66	
Diplegia	3	20	—	—	3	10	
Tetraparesia	11	73.33	11	73.33	22	73.33	
Age (years)							0.646
Mean	6.2		6.8				
Standard deviation	3.8		3.8				
Min–max	1–12		1–12				
Caregivers							0.150
Females	13	86.66	15	100	28	93.33	
Males	2	13.33	—	—	2	6.66	
Schooling							0.084
Incomplete elementary	10	66.66	14	93.33	24	80	
Complete elementary	1	6.66	—	—	1	3.33	
Incomplete high school	1	6.66	—	—	1	3.33	
Complete high school	3	20	1	6.66	4	13.33	
Professional activity							0.073
Yes	3	20	—	—	3	10	
No	12	80	15	100	27	90	
Age (years)							0.319
Mean	31.9		29.6				
Standard deviation	4.6		8.0				
Min–max	22–45		22–37				

\*Significant values ( $p < 0.05$ ) – Mann-Whitney test.

**Caption:** CNPE = chronic non-progressive encephalopathy.

( $p = 0.0544$ ) — showed the positive impact of the educational programs (Tables 4 and 5).

## DISCUSSION

Children's age group and type of motor impairment coincided with those from previous studies, with prevalence of different ages and the presence of tetraparesia<sup>(14–16)</sup>. In childhood encephalopathy, the level of dependence is also related to lower age and severity of physical, functional, and cognitive limitations of the child, noting that compared to mothers of children with CNPE, mothers of children with normal development tend to act more spontaneously during meals, being less directive regarding the functionality of their children<sup>(17,18)</sup>.

The predominance of female caregivers agrees with other studies on the description of the knowledge and behavior of caregivers of children with CNPE, commonly performed with mothers. It reflects the profile of caregivers of children with neurological disorders, as the care of the child is usually assumed by the mother, while the father is given the responsibility to provide for his family<sup>(19,20)</sup>.

The participants had low educational levels, with most of them not having completed primary education. The only two male participants, besides presenting higher schooling,

referred developing some professional activity. Similar data were observed in a study carried out with mothers of children with CNPE assisted by a public service of physical therapy, low educational level, young age (mean 22.3 years), and professional inactivity being observed among participants<sup>(21)</sup>.

The little importance given by the caretakers to the findings related to vocal and breathing features during swallowing, as well as the ignorance of the relationship between changes in these functions and feeding difficulties, can be justified by the subtlety of the findings and the lack of prior access to information about monitoring signs suggestive of aspiration.

A qualitative study on the mother's perception on this subject found that most of them are unprepared to deal with the activities of hygiene, food, and entertainment with these children, although they are dedicated in care, citing what one of them said: "I feed him slowly and sitting down." The lack of access to specific information about health issues was cited by the authors as one of the factors to support the poor understanding of caregivers about the specificities of CNPE, limiting the care provided to the child<sup>(21)</sup>.

As for complications related to aspiration, a study with caregivers of patients with dysphagia described a similar result, with 76.19% of caregivers stating to ignore the

**Table 2.** Knowledge of caregivers about aspects related to difficulties in feeding

Knowledge	G1 (control)		G2 (study)		Total		<i>p-value</i>
	n	%	n	%	n	%	
Signs of difficulty*							—
Choking	11	73.33	12	80	23	76.66	
Cough	6	40	5	33.33	11	36.66	
Fatigue	6	40	7	46.66	13	43.33	
Anterior exhaustion	4	26.66	6	40	10	33.33	
Stasis in the oral cavity	6	40	4	26.66	10	33.33	
Vomiting	4	26.66	6	40	10	33.33	
Definition of aspiration*							—
Does not know	10	66.66	10	66.66	20	66.66	
Food stuck on mouth	1	6.66	1	6.66	2	6.66	
Food goes to lungs	2	13.33	2	13.33	4	13.33	
Food goes to nose	3	20	2	13.33	5	16.66	
Complications of aspiration*							—
Pneumonia	3	20	2	13.33	5	16.66	
Shortness of breath	5	33.33	4	26.66	9	30	
Increase in secretion	2	13.33	1	6.66	3	10	
Malnutrition	1	6.66	—	—	1	3.33	
Fever	3	20	—	—	3	10	
Sore throat	1	6.66	2	13.33	3	10	
Death	3	20	1	6.66	4	13.33	
Does not know	8	53.33	10	66.66	18	60	
Facing choking							—
Slaps on the back	10	66.66	7	46.66	17	56.66	
Offer something to drink	1	6.66	4	26.66	5	16.66	
Puts the child in standing position	1	6.66	—	—	1	3.33	
Puts the child in sitting position	2	13.33	1	6.66	3	10	
Waits	2	13.33	3	20	5	16.66	
Other	4	26.66	5	33.33	9	30	
Facing food stasis*							—
Waits until they swallow	10	66.66	8	53.33	18	60	
Offers more food	—	—	2	13.33	2	6.66	
Asks to swallow	5	33.33	10	66.66	15	50	
Asks to spit	2	13.33	—	—	2	6.66	
Takes it off the mouth	3	20	3	20	6	20	
Gives water	4	26.66	3	20	7	23.33	
Use other strategies	1	6.66	2	13.33	3	10	
Reasons to give up feeding*							
The child does not open the mouth	5	33.33	6	40	11	36.66	
The child chokes too much	6	40	5	33.33	11	36.66	
The child spits out the food	4	26.66	3	20	7	23.33	
The child cries	4	26.66	6	40	10	33.33	
The child is tired	3	20	6	40	9	30	
The child is asleep or sleepy	—	—	6	40	6	20	
Verbal interaction during feeding							0.1919
No	2	13.33	2	13.33	4	13.33	
Rarely	4	26.66	7	46.66	11	36.66	
Frequently	4	26.66	3	20	7	23.33	
Always	5	33.33	3	40	8	26.66	
Importance of verbal commands about feeding							0.1753
Yes	14	93.33	11	73.33	25	83.33	
No	1	6.66	4	26.66	5	16.66	
Factors that interfere in feeding*							—
To talk with the child	1	6.66	3	20	4	13.33	
Television on	4	26.66	7	46.66	11	36.66	
Parallel talking	8	53.33	5	33.33	13	43.33	
Hurry in feeding	4	26.66	5	33.33	9	30	
The child speaks during feeding	1	6.66	6	40	7	23.33	
The child is fed lying down	4	26.66	5	33.33	9	30	
Other	1	6.66	—	—	1	3.33	

\*Multiple choice question – statistical test not applicable.



**Table 3.** Caregivers' perception about voice, breathing, and swallowing

Functional aspects	G1 (control)		G2 (study)		Total		p-value
	n	%	n	%	n	%	
Perception of change in voice during feeding							
Yes	4	26.66	5	33.33	9	30	0.4098
No	7	46.66	6	40	13	43.33	
Never paid attention	4	26.66	4	26.66	8	26.66	
Change in voice							0.3779
Slight	—	—	1	6.66	1	3.33	
Hoarseness	4	26.66	3	20	7	23.33	
Wet	—	—	1	6.66	1	3.33	
NA	11	73.33	10	66.66	21	70	
Perception of change in breathing during feeding							0.3093
Yes	7	46.66	5	33.33	12	40	
No	5	33.33	7	46.66	12	40	
Never paid attention	3	20	3	20	6	20	
Change in breathing							0.1314
Fast	5	33.33	2	13.33	7	23.33	
Weak	2	13.33	3	20	5	16.66	
Noisy	1	6.66	—	—	1	3.33	
NA	7	46.66	10	66.66	17	56.66	
Relation between voice and swallowing							0.2669
Yes	3	20	1	6.66	4	13.33	
No	12	80	14	93.33	26	86.66	
Relation between breathing and swallowing							0.3779
Yes	9	60	8	53.33	17	56.66	
No	6	40	7	46.66	13	43.33	

**Caption:** NA = not applicable.

**Table 4.** Comparison of caregivers' knowledge in G1 and G2 in the first and second data collections

Caregivers' knowledge	G1 (control group)				p-value	G2 (study group)				p-value
	First collection		Second collection			First collection		Second collection		
	n	%	n	%		n	%	n	%	
Definition of aspiration					0.1587					0.0017*
Inadequate	2	13.33	11	73.33		1	6.66	4	26.66	
Adequate	3	20	2	13.33		2	13.33	9	60	
Does not know	10	66.66	2	13.33		12	80	2	13.33	
Concordance between the definition of aspiration and clinical complications					0.1587					0.0125*
Yes	3	20	4	26.66		5	33.33	2	13.33	
No	12	80	11	73.33		10	66.66	13	86.66	
Relation between voice and swallowing					0.1587					0.0082*
Yes	3	20	2	13.33		1	6.66	10	66.66	
No	12	80	13	86.66		14	93.33	5	33.33	
Relation between breathing and swallowing					0.2965					0.0059*
Yes	6	40	5	33.33		6	40	15	100	
No	9	60	10	66.66		9	60	—	—	
Concordance between perception of voice and relation voice/swallowing					0.2965					0.0082*
Yes	3	20	4	26.66		3	20	12	80	
No	12	80	11	73.33		12	80	3	20	
Concordance between perception of breathing and relation breathing/swallowing					0.2965					0.0455*
Yes	4	26.66	6	40		6	40	14	93.33	
No	11	73.33	9	60		9	60	1	6.66	

\*Significant values (p<0.05) – Wilcoxon test.

**Table 5.** Comparison of behavioral aspects from G1 and G2 during feeding dynamics in the first and second data collections

Behavioral aspects	G1 (control group)				p-value	G2 (study group)				p-value
	First collection		Second collection			First collection		Second collection		
	n	%	n	%		n	%	n	%	
Verbal interaction with the child					0.0899					0.0544
Present	9	60	11	73.33		7	46.66	9	60	
Absent	6	40	4	26.66		8	53.33	6	40	
Commands related to feeding					0.1587					0.0216*
Present	5	33.33	6	40		3	20	8	53.33	
Absent	10	66.66	9	60		12	80	7	46.66	
Perception of child's difficulty by the caregiver					0.2223					0.0139*
Yes	3	20	3	20		4	26.66	9	60	
No	7	46.66	7	46.66		8	53.33	5	33.33	
NA	5	33.33	5	33.33		3	20	1	6.66	
Change in conduct by caregiver					0.5000					0.0544
Yes	3	20	3	20		4	26.66	7	46.66	
No	7	46.66	7	46.66		8	53.33	5	33.33	
NA	5	33.33	5	33.33		3	20	3	20	
Strategy by the caregiver to improve difficulty					0.5000					0.0216*
Yes	3	20	3	20		2	13.33	7	46.66	
No	12	80	12	80		13	86.66	8	53.33	

\*Significant values ( $p < 0.05$ ) — Wilcoxon test;

**Caption:** NA = not applicable.

possible complications secondary to aspiration<sup>(13)</sup>. Although the caregivers from this study have demonstrated limited knowledge regarding the concept and complications of aspiration, when they were asked about which manifestations were signs of difficulties in swallowing, they gave consistent responses, citing coughing, choking, fatigue, and food stasis in oral cavity.

Signs such as choking, coughing, vomiting, or food stasis, depending on the intensity and frequency, may be indicative of difficulty in swallowing, so the caregiver should be able to identify risks of aspiration and adopt preventive measures<sup>(20)</sup>.

In this study, verbal interaction during feeding was investigated in two ways: report on the frequency of use and their occurrence during the video recordings, a behavior that has been observed in the minority of the sample.

The quality of interactions caregiver/child during feeding depends on how the parents are emotionally healthy, sensitive, and responsive, on the child's ability to communicate with the environment, on the maternal representation about children's limitations and possibilities, the severity of CNPE, and on the concern of the parents about their child's nutrition<sup>(22–25)</sup>. They influence the child's ability to feed itself and, in particular, and how much the child enjoy the moments of meal<sup>(20)</sup>.

Although most parents have given importance to the use of verbal commands during meals, such behavior has been identified in a minority of situations analyzed.

The child's ability to ingest adequate amounts of food depends on the positive interaction with caregivers<sup>(23)</sup>. Thus, the use of simple commands related to steps of feeding is considered strategy that supports a safe and efficient oral intake<sup>(26)</sup>.

A comparative study involving 16 children with CNPE and their brothers found that the use of words of praise and coordinates related to oral motor skills during feeding were more used by caregivers during the feeding of children with encephalopathy<sup>(27)</sup>.

Educational interventions for caregivers or the patient with dysphagia have been reported in the literature, but with little depth. Understanding the best way to conduct them and verifying their impact are still challenges, especially when it comes to caregivers who deal daily with functional dependency generated by motor, cognitive, and/or behavioral limitations, as in the case of CNPE.

In this study, the improvement of the level of knowledge about aspects related to swallowing and the implementation of more appropriate conducts by caregivers undergoing the educational action demonstrated the impact of educational programs conducted with caregivers of children with CNPE.

A study conducted with CNPE children described the improvement in postural control and functionality of the stomatognathic system after a program of speech therapy, in which oral sensorial-motor therapy was associated with the training of caregivers. The sessions were observed by the primary caregiver, so that postural maneuvers could be adopted and reproduced during meals, reinforcing the importance of training caregivers responsible for feeding individuals with dysphagia<sup>(28)</sup>. The contribution of the educational program for the knowledge of caregivers was also described by a study conducted with caregivers of patients with dysphagia, which concluded that after the program, 90.48% of the participants could define "aspiration" properly<sup>(22)</sup>.

Bearing in mind the importance of knowledge in the quality of care, it is likely that the children of the sample have been benefited with regard to quality of care related to

feeding; however, one cannot ensure the applicability of this knowledge in daily care, or the maintenance of long-term benefits.

In addition to gradually be given orientation, caregivers should be integrated in the routine of the patient and his family. The family context (availability for following guidelines and emotional state) must be considered in order to avoid conflicts and activity overload to some members<sup>(20)</sup>.

We highlight the contribution of one of the methodologies used in the educational program with the caregivers in this study: the video feedback. Despite being little used in the speech therapy context, the videos have been considered a strategy for feedback to caregivers, allowing reflection on the behaviors and interactions made by them during feeding<sup>(29)</sup>. This resource, employed as observational learning procedure that clearly impacts on behavior changes in children and adults, has been useful in the management of behavioral disorders, social skills training, and advising of parents of children with developmental delay<sup>(30)</sup>.

The socioeconomic and cultural peculiarities of the studied population, as well as the availability and interest of the volunteer caregivers, are noteworthy. Even though their children were not under the follow-up of a speech therapist, several caregivers refused to participate in the study, referring no interest. The motivation and availability to obtain knowledge, as well as the limited knowledge of caregivers about the subject matter, may have been decisive for the impact of the educational program.

## CONCLUSIONS

Caregivers demonstrated limited knowledge regarding the nutritional care of their children with CNPE, besides presenting misconducts when facing difficulties presented by these.

The comparison of caregiver's knowledge and conducts prior to and after the educational action proved the positive impact of the activity.

Although the results were satisfactory, one must understand the implication of educational activities aimed at caregivers of children with neuromotor disorders in routine, beyond theoretical field (knowledge), establishing it in daily care (practice).

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