PROFILE OF PATIENTS WITH CEREBRAL PALSY USING GASTROSTOMY AND EFFECTS ON CAREGIVERS

Perfil de pacientes com paralisia cerebral em uso de gastrostomia e efeito nos cuidadores

Fernanda Pellin Susin [(1)], **Vaneila Bortolini** [(2)], **Ricardo Sukiennik** [(3)], **Renata Mancopes** [(4)], **Lisiane De Rosa Barbosa** [(5)]

ABSTRACT

Purpose: outlining the profile of patients with cerebral paralysis using gastrotomy and investigating the effects of such procedure on caretakers. **Method:** it is a cross-sectional study with a qualitative and quantitative nature. The research was carried out with patients of *Hospital da Criança Santo Antônio – Complexo Hospitalar Santa Casa* who had medical diagnosis of Cerebral Paralysis (CP) using gastrostomy. A questionnaire was applied on the caretakers containing quantitative and qualitative questions and data regarding the sample features. **Results:** there was predominance of monthly income of up to two minimum wages and a family configuration featuring the father as the worker and the mother with no labor activity. Among the reasons for the recommendation for such procedure, deglutition difficulty was present among all the subjects followed by repeated pneumonias and low weight. We could observe a large number of patients who made use of a probe before the gastrostomy with permanence time above one month. The main benefits observed from the settlement of gastrostomy were: weight gain, reduction of respiratory problems and less hospital admittances. From the caretaker´s reports, one perceives the occurrence of feelings like fear of the unknown, resistance and acceptance, difficulties and benefits. **Conclusion:** observing evidences that food problems are frequently found as an indication for the settlement of gastrostomy in children with CP. Caretakers are afraid as for the impossibility of feeding the child via oral. However, after the surgery, most of them reported benefits like weight gain and reduction of hospital admittances.

KEYWORDS: Gastrostomy; Cerebral Palsy; Deglutition Disorders; Rehabilitation

(1) Undergraduate in Speech therapy course of Universidade Federal de Ciências da Saúde de Porto Alegre – UFCSPA.

(2) Undergraduate in Speech therapy course of Universidade Federal de Ciências da Saúde de Porto Alegre – UFCSPA.

(3) Pediatrician, Professor of the Department of Pediatrics, Universidade Federal de Ciências da Saúde de Porto Alegre, UFCSPA, Porto Alegre, RS, Brazil; Doctor in Respiratory Sciences – UFRGS.

(4) Speech therapist, professor of the speech pathology department, Universidade Federal de Santa Maria – UFSM, Doctor in linguistics- UFSC

(5) Speech Therapist, Professor of the Speech Pathology Department, Universidade Federal de Ciências da Saúde de Porto Alegre, UFCSPA, Porto Alegre, RS, Brazil, Master of Arts in language studies at UFRGS

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INTRODUCTION

Cerebral Palsy (CP) is an alteration due to non progressive central nervous system injury, in the early period of brain development, leading to a persistent disorder of movement and posture, that may change in their clinical manifestations over the course of time[1]. The prevalence of CP in developed countries is around 1.2 to 2.3 children per 1000 live births, whereas in countries in development, as it is the case of Brazil, this incidence is much higher, reaching 7: 1000 [2].

Among the most common etiologic factors in the genesis of the CP may be cited, along with extreme prematurity, cerebral malformations, congenital infections, especially toxoplasmosis,

cytomegalovirus and rubella and genetic causes, as well as postnatal causes, such as meningoencephalitis, injuries by drowning, head trauma and strokes[2].

Often, a number of deficiencies, such as mental retardation, seizures and learning difficulties co-occur with the CP. This disease affects the motor development and, frequently, there is an oral motor impairment, with the possibility of the occurrence of dysphagia oropharyngeal or esophageal and / or changes in speech.

Dysphagia is defined as any disorder of swallowing that may result from mechanical disturbances, anatomical abnormalities and neurological lesions [3]. In the case of dysphagia caused by neurological disorders, it involves mainly the first two phases of swallowing, and thus it is defined as oropharyngeal dysphagia [4]. In relation to the oropharyngeal dynamics, the commitments of the oral phase are characterized by the inability to control the food in the mouth, since difficulties in the labial sealing can occur, oral loss of reflexes and loss of movement of the dorsal and anterior parts of the tongue. Thus, in the pharyngeal phase, difficulties to move the palate to the posterior pharyngeal wall can be observed, as well as loss of movement of the posterior pharyngeal wall.

The act of swallowing is the result of a complex neuromotor mechanism, and for the effective passage of food into the stomach, a complete coordination between the four phases of swallowing is necessary. The phases are: oral preparatory phase, oral phase, pharyngeal phase and esophageal phase [5]

The more severe pathophysiological findings in these children may be the lack of coordination between the motor actions necessary to swallowing [6]. This lack of coordination can bring serious consequences such as vomiting during feeding, nasopharyngeal regurgitation, malnutrition, growth retardation, suspected aspiration, the occurrence of coughing during feeding and recurrent pneumonia [7]. Dysphagia is associated with increased risk of aspiration pneumonia, malnutrition and dehydration, which lead to increased morbidity and mortality of patients affected [4-5].

Besides these features, the feeding process of these children is often time consuming and frustrating for both the child and for their caregivers 8. Such difficulties can be extremely stressful and generate problems in family [2].

Gastrostomy is a procedure in which a tube is inserted directly into the stomach through an opening in the anterior abdominal wall. Currently, this procedure can be performed surgically, radiologically or endoscopically [9].

The main indication for gastrostomy is for patients who make use of a nasogastric tube for more than 30 days. Moreover, it is indicated in cases of serious anorexia nervosa, and patients with lifelong perspective [10].

A problem with the placement of the gastrostomy is the predisposition to the occurrence of gastroesophageal reflux [2]. In some cases, the fundoplication is performed in order to stop the reflux, through a combination of anti reflux mechanisms. Surgical treatment is indicated, especially when there is failure in the treatment or with the presence of complicated gastroesophageal reflux disease. Fundoplication is most often recommended for older children and those at risk for severe GERD, including chronic encephalopathy, in particular the non-progressive chronic encephalopathy [11].

The gastrostomy feeding has been shown to lead to weight gain, reducing the feeding time and improving quality of life of caregivers. Nevertheless, for the caregivers, the decision in relation to the insertion of a gastrostomy tube can be difficult, since they have to assess whether the benefits outweigh the risks 12.

Understanding the effects of gastrostomy feeding for children with CP is important for the family's decision to accept or not the use of gastrostomy for their children [6].

The aim of this study is to characterize the profile of patients with cerebral palsy who use gastrostomy and determine the effects of the procedure to the caregivers.

METHOD

This research was conducted through a cross-sectional qualitative and quantitative methodology. It was conducted with patients at the Children's Hospital Santo Antonio – Santa Casa Hospital Complex. The public attended by this institution belongs to the municipality of Porto Alegre metropolitan area and cities of the state of Rio Grande do Sul. The study included patients who were treated at the hospital during the collection period, both in theambulatory and in the hospitalization, which underwent gastrostomy or fundoplication with gastrostomy, who had a medical diagnosis of Cerebral Palsy, and whose respective caregivers agreed to participate in the research. We excluded institutionalized patients and those whose contacts were reported as missing in the records of the service.

Data collection occurred from May to September 2010. The contacts of the patients were obtained through the records of the staff of pediatric surgery and endoscopy of the hospital, conducted between 2008 and 2010. In this search, we tried to include

the word “gastrostomy”, or “gastrostomy with fundoplication.” The choice of the period was due to the emergence of a multidisciplinary group on the management of gastrostomy at the Children’s Hospital Santo Antonio – Santa Casa Hospital Complex.

Thus, we obtained access to the names of patients, medical records and the number of years in which they underwent gastrostomy procedures. Researching the charts, it was identified the term Cerebral Palsy. Then, we made contact with patients and caregivers by telephone calls, and scheduled interviews with those who came to the Children’s Hospital Santo Antonio during the period the collection was being held.

For this purpose, we applied two questionnaires, one containing data that sought to characterize the sample (Figure 1) and another in which there were quantitative questions on how to feed patients, the indication, benefits and complications in the use of gastrostomy. These questionnaires also included two qualitative questions, involving perceptions, feelings and opinions of caregivers regarding the appointment and placement of gastrostomy (Figure 2).

SAMPLE

Name of the child or adolescent_____
Age: ____ years old. DB: ____/ ____/ _____ Gender: ( ) F ( ) M
Type of Cerebral Palsy: _____
Comorbidities: _____

Mother:
Age: _____ years old
Marital Status:
( ) lives with the child’s father
( ) lives with another partner
( ) has no partner
( ) other

Education:
( ) illiterate
( ) elementary school
( ) incomplete elementary school
( ) complete high school
( ) college degree

Occupation: _____
Working hours: ( ) does not work ( ) part time ( ) full ( ) other

Father:
Age: _____ years old
Marital Status:
( ) lives with the child’s father
( ) lives with another partner
( ) has no partner
( ) other

Education:
( ) illiterate
( ) elementary school
( ) incomplete elementary school
( ) complete high school
( ) college degree

Occupation: _____
Working hours: ( ) does not work ( ) part time ( ) full ( ) other

Caregiver:
Age: _____ years old
Relationship or kinship: _____

Monthly income R$:
( ) a salary ( ) two salaries ( ) over three salaries

How many people live in the household: _____

With whom the child or adolescent lives?
( ) parents ( ) mother ( ) father ( ) grandparents ( ) other relatives _____ ( ) other _____

The responsible (s) for the care and transportation of the child or adolescent is (are):
( ) parents ( ) mother ( ) father ( ) grandparents ( ) other relatives _____ ( ) other _____

Figure 1 – Sample Characterization

Questionnaire

1) At what age was the child submitted to gastrostomy surgery?

1.1) How long ago was it?

2) Did your son make use of probes?
( ) no ( ) yes

2.1) How many times _____

2.2) How much time _____

3) Was it the first indication for the use of gastrostomy?
( ) no ( ) yes

4) What is (are) the reason (s) for the use of gastrostomy?:
( ) low weight ( ) recurrent pneumonia ( ) difficulty swallowing
( ) prolonged use of the probe ( ) other

5) What benefits have you noticed after the use of gastrostomy?
( ) weight gain ( ) a decrease in respiratory problems
( ) a reduction in hospitalizations ( ) other which _____

6) The diet that your child receives is:
( ) homemade ( ) industrialized

7) Is the patient currently fed by mouth?
( ) no ( ) yes

7.1) If yes, what kind of food:
( ) liquid ( ) pasty ( ) solid

7.2) How often:
( ) 1-2 x / day ( ) at every meal ( ) eventually

7.3) Amount (ml and / or spoons)

8) With respect to oral hygiene:
( ) Performed before gastrostomy
( ) Performed after gastrostomy
( ) Both situations
( ) Never made

9) It was carried some speech therapy:

9.1) prior to gastrostomy
( ) no ( ) yes ( ) guidelines ( ) therapy

9.2) After the gastrostomy
( ) no ( ) yes ( ) guidelines ( ) therapy

10) Did the child have any trouble with gastrostomy?
( ) no ( ) yes

10.1) If yes, what?
( ) Extravasation of food around the probe
( ) Malfunction
( ) Weight Loss
( ) Granuloma
( ) Displacement or removal of the probe
( ) Dermatitis
( ) Obstruction
( ) Vomiting
( ) widening of the gastrostomy hole
( ) other complications _____

Gastrostomy with fundoplication?
( ) yes ( ) no

11) What was your reaction after the indication of the use of gastrostomy? How did you feel?

12) What message would you leave for a family that receives the indication for the use of gastrostomy to their child?

Figure 2 – Questionnaire on the perceptions and conditions of the use of gastrostomy

Based on data from surveys of sample characterization and quantitative questions, it was set up a database in Excel 2007, used for the statistical analysis using the SAS System for Windows (Statistical Analysis System) version 8.02. SAS Institute Inc, 1999-2001, Cary, NC, USA.

For qualitative data analysis, it was chosen the content analysis. As Laville, Dionne (1999) this type of analysis does not change the form of literal data, due to the fact that the researcher decides to hold the nuances of meaning that exist between the units to its logical links, or to the categories that bound them together, since the meaning of a content resides largely on the specificity of each of its elements and the relationship they establish with each other [13].

The interviews were recorded on Panasonic RR-US430 recorder and, subsequently, transcribed to paper, to be analyzed. After comprehensive and floating reading of data, we sought to observe the processes of meaning construction from the analysis of repetition in the speech of caregivers interviewed. Through the analysis, it was possible to identify some determiners in the discourse of the interviewees, which lead to discursive categories of analysis. The discursive similar sequences were gathered as they produced the same effect of meaning, thus resulting in four categories of analysis.

This study was approved by the Ethics Committee in Research of Santa Casa de Misericordia de Porto Alegre under protocol number 146/010.

RESULTS

The results presented in Table 1 represent the environmental information of caregivers.

Table 2 presents the results for the data on the indication of gastrostomy.

The results shown in Table 3 represent the speech therapy data.

Data quality issues are observed in the categories below:

Category 1: Fear of the unknown

SD1: I freaked out because it was a new thing. It took me four days to accept the idea. And even when the child made the gastrostomy, I had not accepted.

SD2: In the moment we get afraid, but after watching the procedure, we saw that it was the best for the child.

SD3: At first, we get scared with everything, it is pretty stressful in the first few days, but then you understood that it was the best thing to do.

Table 1 – Socio-environmental

MONTHLY FAMILY INCOME	**A minimum wage** 4(30,77%)	**Two minimum wages** 5(38,46%)	**Above of three minimum wages** 4(30,77%)
AGE OF MOTHER	**Average** 29,30 years Variation between 21 and 40 years old		
MARITAL STATUS OF MOTHER	**lives with the child's father** 10(76,92%)	**Has no partner** 3(23,08%)	
MOTHER'S EDUCATION	**Incomplete elementary education** 4(30,77%)	**Complete elementary education** 2(15,38%)	**Complete high school** 7(53,85%)
MOTHER'S WORKING HOURS	**Full time** 2(15,38%)	**Does not work** 10(76,92%)	**Other** 1(7,69%)
FATHER'S EDUCATION	**Incomplete elementary education** 4(30,77%)	**Complete elementary education** 4(30,77%)	**Complete high school** 5(38,46%)
FATHER'S WORKING HOURS	**Full** 9(69,23%)	**Does not work** 3(23,07%)	**Other** 1(7,69%)

Table 2 – Data on the indication of gastrostomy

AGE OF THE GASTROSTOMY SURGERY IN THE CHILDREN	**Less than one year old** 5(38,46%)	**1 to 3 years old** 4(30,77%)	**3 to 5 years old** 1(7.69%)	**5 to 10 years old** 2(15,38%)	**Over 10 years old** 1(7,69%)
HOW LONG AGO	**Less than one year old** 8(61,54%)	**1 to 2 years old** 4(30,77%)	**3 to 4 years old** 1(7,69%)		
IT WAS THE FIRST INDICATION FOR USE OF MEDICAL GASTROSTOMY	**No** 3(23,08%)	**Yes** 10(76,92%)			
THE REASON (S) FOR THE USE OF GASTROSTOMY	**Light weight** 7(53,84%)	**Recurrent pneumonia** 11(84,61%)	**Difficulty swallowing** 13(100%)	**Prolonged use of probe** 5(38,46%)	**Another** 1(7,69%)
BENEFITS YOU OBSERVED SINCE THE USE OF GASTROSTOMY	**Weight gain** 10(72,92%)	**Decreased respiratory** 7(53,84%)	**Hospitalizations** 5(38,46%)	**Other** 1(7,65%)	**No Reduction** 1(7,65%)
DID YOUR CHILD HAVE ANY COMPLICATION WITH GASTROSTOMY	**No** 2(15,38%)	**Yes** 11(84,62%)			
IF YES, WHICH COMPLICATION	**Extravasation of food around the probe** 9(69,23%)	**Malfunction** 2(15,38%)	**Weight loss** 4(30,76%)	**Granuloma** 5(38,46%)	**Withdrawal or displacement of the probe** 9(69,23%)
IF YES, WHICH COMPLICATION	**Dermatitis** 4(30,7%)	**Obstruction** 2(15,38%)	**Vomiting** 4(30,7%)	**Increased bore gastrostomy** 4(30,76%)	

Table 3 – speech therapy

DID YOUR CHILD USE PROBE BEFORE GASTROSTOMY	**No** 1(7,69%)	**Yes** 12(92,31%)
THE PATIENT ARE IS CURRENTLY FED ORALLY	**No** 9(69,23%)	**Yes** 4 (30.77%), and 1 (25%) eat all consistencies and 3 (75%) paste
SPEECH THERAPY PREVIOUS TO THE GASTROSTOMY	**No** 2(15,38%)	**Yes** 11(84,62%)
SPEECH THERAPY HELD AFTER GASTROSTOMY	**No** 4(30,77%)	**Yes** 9(69,23%)

Category 2: Resistance and acceptance

SD1: It took me four days to accept the idea. And even when the child made the gastrostomy, I had not accepted it. Making a hole in the belly was pretty scary, but okay, I saw that everything was fine with my child.

SD2: First, we had a lot of resistance, we were afraid, it is almost unbearable, but for the child it was very good.

SD3: At first it was difficult to accept, but as it was for the benefit of my child I started to accept.

Category 3: Difficulties

SD1: I was very sad because she ate everything by the mouth, sucking in the chest, so it was a shock for me to take the baby from breast. I think the worst thing for a mother is to take the baby from the chest, see her asking to breastfeed and not give it to her.

SD2: For us it is sad to see, but for them it is better, a much better quality of life.

SD3: (...) it sometimes can go wrong, the body may not accept it, there may be other problems related to gastro, and doctors say it is normal and actually it is not. We have to take good care of our children's reaction, because only we know their daily routine, notice that any little thing can become a serious error.

SD4: I felt a feeling quite complicated, so much that I asked the doctor: may I? Even with the gastro feeding him? You can give him something more pasty, that will not make him choke, but over time I saw that every thing we gave him, he would choke.

Category 4: Benefits

SD1: May they do it because it is the only way the child can eat well, gaining weight. It is necessary.

SD2: After she made the gastrostomy, she improved a lot, stopped having pneumonia and stopped vacuuming, much has been resolved.

SD3: When we put the gastrointestinal and now he is 78 lbs, he had a pretty good weight gain, even for him to deal with his breathing problem.

SD4: Fine, the option was better than the nasogastric tube, because it improves the aesthetic appearance.

SD5: Each case is unique. If it is necessary it has an advantage, because it is easier to handle, more comfortable.

DISCUSSION

From the data collected we identified a low monthly family income for the majority, 69.23% earn up to two minimum wages, in addition to the setting of a family where the father works and the mother is not in the labor market. It is believed that the fact that the mother does not work relates to the time required for the care of a child with CP, due the dependence their children have to their families. In addition, the costs of caring for a child with chronic illness or disability manifest financially [14].

In general, children receive an indication of the gastrostomy when they have medical complications, such as recurrent pneumonia and malnutrition. Fathers report on the negative emotional reactions they feel in the introduction of artificial feeding methods, and mothers reported a strong maternal instinct to oral feed [15]. However, this sample showed that 76.92% of the interviewed families accepted the procedure of gastrostomy after the first medical indication, and it is performed in most patients, up to five years old. This finding may be related to the fact that there is a multidisciplinary work in relation to patients who require gastrostomy, since parents who receive better information probably accept and understand better the indication of the gastrostomy.

It appears that much of the population studied had speech therapy before placing the gastrostomy, but 30.77% did not continue with this follow-up after surgery. This can justify the fact that few patients were being fed orally concurrently, because setting the right time to resume oral feeding schedule requires a specific therapeutic strategy, which includes the choice of food to be given and / or rehabilitation planning treatment [4]. Most of these children and adolescents are being fed exclusively by the probe. Traditionally, the speech therapist evaluates and rehabilitates patients with CP, but it seems important to reconfigure their role with patients gastrectomized.

Given this, it is believed that the speech therapists must rethink their role in addressing this clientele, seeking not only to restore the oral route but, failing this, to invest in therapeutic resources that maximize learning and perceptions of oral taste, providing comfort and quality of life to these patients. In this sense, the orientation to family should be the focus of attention of the speech therapist and the multidisciplinary team.

The main benefits observed with the placement of gastrostomy reported by caregivers are: weight gain, decreased respiratory problems and reduced hospitalizations. This corroborates with the literature, since one of the main goals of this procedure is to improve the well being of the patient, preventing or reversing malnutrition [9]. There is a large number of patients who make use of the probe before gastrostomy for over a month, this being one of the main reasons for the indication of such a procedure, because the nasogastric tube feeding is often used for a short term, because the long term can cause discomfort, nasal obstruction or displacement of the

tube, the penetration or irritation of the larynx, recurrent pulmonary aspiration and decreased survival of the individual [10]. However, Table 1 shows that the reason for swallowing difficulties is unanimous among all respondents to the placement of the gastrostomy, followed by recurrent pneumonia and low birth weight.

In addition, most caregivers of children or adolescents reported that there have been complications with the gastrostomy. Table 2 shows the complications mentioned.

However, this data is not much reported in the literature. Knowing the story of the family can minimize the effects of possible complications of gastrostomy and better guide the caregivers about the procedure, which will also result in more appropriate therapeutic choices.

It is observed in data analyzed the occurrence of feelings such as fear, resistance and acceptance. In the category for the "fear of the unknown," we can infer that the lack of knowledge about the procedure can generate such feelings, also present in category 2 "resistance", but resistance is concerning change. In category 3, "difficulties", the fact that the oral route is no longer the only form of feeding is seen as a problem by the caregivers, as parents show anxiety associated with the food problem. Often, mothers found that more time was required in feeding their child, which would imply a lesser involvement in other activities and less attention to other family members [16]. In some cases, after the implementation of the gastrostomy, there is the gain of clinical stability concerning respiratory and nutritional aspects.

Therefore, and as reported by parents in this study, the patient begins to have better conditions for the treatment of dysphagia. Thus, it is possible to demystify the use of gastrostomy as permanent suspension of the oral. The gradual introduction of oral offer may be better suited by the speech therapist, once the caloric needs and the child's breathing are guaranteed.

Parents of children with severe CP are concerned with nutrition and general health of their child. Through the gastrostomy, feeding may improve child nutrition, and it consequently can make life easier for parents [16]. This is reflected in the fourth category, called "benefits" because the caregivers were concerned but acknowledged of the gains from the use of gastrostomy by the subjects. Caring for a chronically ill or disabled child also has a major impact on the financial, professional, social and recreational life of the family, and family functioning [15].

It is important to highlight that in the analyzed sample the majority of children was having the first gastrostomy and were less than five years old. This shows the importance of the multidisciplinary group, which should help in the decision made by the family. Moreover, it is necessary to evaluate the speech therapist's important role in the multidisciplinary team that takes care of gastrectomized patients, because it is up to this professional to make part of the process of indication of gastrostomy after determining specific therapeutic interventions and, if possible, restore the oral feeding.

CONCLUSION

The implications of the use of gastrostomy and the effects it produces in the family and caregivers has received little attention, with studies more focused on medical and nutritional aspects. It has been found that the caregivers are afraid of the unknown and, as a result, they are resistant to accept the surgical procedure. They also have difficulty in accepting that the child does not feed exclusively orally. However, after surgery, most caregivers reported benefits, such as weight gain and reduction in hospitalizations. In addition, the teamwork, in which the speech therapist has a key role, seems to be an important strategy to better approach this issue with family members and caregivers of these patients.

RESUMO

Objetivo: caracterizar o perfil de pacientes com paralisia cerebral em uso de gastrostomia e verificar o efeito que tal procedimento ocasiona nos cuidadores. **Método:** foi realizado estudo transversal de caráter qualitativo e quantitativo. A pesquisa foi feita com pacientes do Hospital da Criança Santo Antônio – Complexo Hospitalar Santa Casa que tivessem diagnóstico médico de Paralisia Cerebral (PC) em uso de gastrostomia. Foi aplicado um questionário aos cuidadores contendo questões quantitativas, qualitativas e dados sobre a caracterização da amostra. **Resultados:** houve predominância de renda mensal de até dois salários mínimos, e uma configuração familiar caracterizada pelo pai trabalhar e a mãe não atuar no mercado de trabalho. Dentre os motivos para a indicação do procedimento, a dificuldade de deglutição esteve presente entre todos os sujeitos, seguido das pneumonias de repetição e baixo peso. Observa-se um grande número de pacientes que fizeram uso de sonda antes da gastrostomia, com tempo de permanência acima de um mês. Destacam-se os principais benefícios observados com a colocação da gastrostomia: ganho de peso, diminuição dos problemas respiratórios e redução de internações. A partir dos relatos dos cuidadores percebe-se a ocorrência de sentimentos como de medo do desconhecido, resistência e aceitação, dificuldades e benefícios. **Conclusão:** observa-se que problemas de alimentação são frequentemente encontrados como indicação para colocação de gastrostomia em crianças com PC. Os cuidadores sentem medo quanto à impossibilidade de alimentar a criança pela via oral. Porém, após a cirurgia, grande parte deles relatou benefícios, como por exemplo, ganho de peso e redução das internações.

DESCRITORES: Gastrostomia; Paralisia Cerebral; Transtorno da Deglutição; Reabilitação

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Mailing Address:
Lisiane De Rosa Barbosa
Av. Protásio Alves 7355, bloco 6, apto 901 – Petrópolis
Porto Alegre – RS
CEP: 91310-003
E-mail: liderosa@terra.com.br
lisianeb@ufcspa.edu.br