

## EXPERIENCES OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY ABOUT THE USE OF GASTROSTOMY

## VIVÊNCIAS DE CUIDADORES DE CRIANÇAS COM PARALISIA CEREBRAL SOBRE A UTILIZAÇÃO DE GASTROSTOMIA

## EXPERIENCIAS DE CUIDADORES DE NIÑOS CON PARÁLISIS CEREBRAL SOBRE EL USO DE GASTROSTOMÍA

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### ABSTRACT:

**Objective:** to understand the needs of caregivers of children with cerebral palsy who use gastrostomy. **Method:** descriptive study with a qualitative approach, carried out at the School of Nursing Unit of the State University of the Midwest, in Guarapuava-Paraná. Data were collected through interviews and analyzed using the content analysis technique. **Results:** Three caregivers participated in the study, with a mean age of 30.6 years, most of them married, all of them with high school education and housework. From the interviews, three categories were raised: family adaptation process and difficulties in using the gastrostomy; needs related to gastrostomy care and the importance of multidisciplinary care. **Conclusion:** The study showed that caregivers were afraid of gastrostomy care and recognized the need for support from the multidisciplinary team. The nurse's role is fundamental in this context, improving acceptance and providing guidance on home care.

**Descriptors:** Child; Cerebral Palsy; Gastrostomy; Home Care Services; Nursing.

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**RESUMO:**

**Objetivo:** compreender as necessidades de cuidadores de crianças com paralisia cerebral que fazem uso de gastrostomia. **Método:** estudo descritivo de abordagem qualitativa, realizado na Unidade Escola de Enfermagem da Universidade Estadual do Centro-Oeste, em Guarapuava-Paraná. Os dados foram coletados mediante entrevista e analisados através da técnica de análise de conteúdo. **Resultados:** Participaram do estudo três cuidadoras, com média de idade de 30,6 anos, a maioria casadas, todas com ensino médio completo e do lar. A partir das entrevistas foram levantadas três categorias: processo de adaptação familiar e as dificuldades ao uso da gastrostomia; necessidades relacionadas aos cuidados com a gastrostomia e a importância do cuidado multidisciplinar. **Conclusão:** O estudo mostrou que as cuidadoras apresentaram medo em relação ao cuidado com a gastrostomia e reconhecem a necessidade de apoio da equipe multiprofissional. O papel do enfermeiro é fundamental nesse contexto, melhorando a aceitação e fornecendo orientações quanto aos cuidados domiciliares.

**Descritores:** Criança; Paralisia Cerebral; Gastrostomia; Serviços de Assistência Domiciliar; Enfermagem.

**RESUMEN:**

**Objetivo:** comprender las necesidades de los cuidadores de niños con parálisis cerebral que utilizan gastrostomía. **Método:** estudio descriptivo con abordaje cualitativo, realizado en la Unidad Escuela de Enfermería de la Universidad Estadual del Medio Oeste, en Guarapuava-Paraná. Los datos fueron recolectados a través de entrevistas y analizados utilizando la técnica de análisis de contenido. **Resultados:** Participaron del estudio tres cuidadores, con una media de edad de 30,6 años, la mayoría casados, todos con estudios secundarios y labores domésticas. De las entrevistas surgieron tres categorías: proceso de adaptación familiar y dificultades en el uso de la gastrostomía; necesidades relacionadas con el cuidado de la gastrostomía y la importancia del cuidado multidisciplinario. **Conclusión:** El estudio mostró que los cuidadores tenían miedo al cuidado de la gastrostomía y reconocieron la necesidad de apoyo del equipo multidisciplinario. El papel del enfermero es fundamental en este contexto, mejorando la aceptación y orientando en el cuidado domiciliario.

**Descriptorios:** Niño; Parálisis cerebral; Gastrostomía; Servicios de Atención de Salud a Domicilio; Enfermería.

**INTRODUCTION**

Chronic non-progressive encephalopathy, a condition called cerebral palsy (CP), occurs as a result of a cluster of physiological changes of a declining nature. It can occasionally cause disorders of cognition, motor skills, functionality and communication. The literature points to possible clinical variables for CP, resulting from a lesion in the central nervous system, which may have its origins during the pre-,

peri- and post-natal phases. The consequences may vary according to the degree of injury, being characterized as mild, moderate or severe.<sup>1</sup>

Worldwide, it is established that 2 to 3 children out of a thousand live births are affected by CP.<sup>2</sup> National data are not available in the literature. In the city of Aracaju (SE), a study found a prevalence of 1.37 in every thousand live births.<sup>3</sup>

The main risk factors are from preventable causes, including: pre-term birth before 28 weeks, low birth weight and Apgar score less than 7 in the first minute, mother's exposure to stress factors, radiation, toxicity, urinary tract infections, violent/traumatic births and situations of fetal or neonatal hypoxia. <sup>4</sup>

A child with CP presents a series of organic, physical, mental and behavioral disorders. Often, there is oral motor impairment, which may lead to oropharyngeal or esophageal dysphagia and/or changes in speech, requiring comprehensive and specific care from healthcare, education, and family social assistance. <sup>5</sup>

When these children are unable to receive oral nutrition, they are subjected to the use of a gastrostomy, which can be a temporary short-term or permanent resource for life. <sup>6</sup> It is a flexible tube that can be introduced surgically, through a stoma that allows access to the gastric region, or through endoscopy, establishing a route for the child's nutrition. <sup>7</sup>

Gastrostomy is a viable alternative, as it supports the maintenance of adequate growth rates for children with limited oral motor problems, also because it can prevent complications, especially malnutrition and bronchoaspiration and other benefits such as comfort, low risk of infections and the appearance of gastric ulcers. <sup>8,9</sup>

However, the indication and use of gastrostomy can generate uncertainty, fears and conflicts between caregivers, causing harm and harm to the child. Caregivers of a child with CP feel great physical and emotional exhaustion due to the attention required in many cases. In this sense, the more support and guidance a caregiver receives, the greater the quality of life of the assisted child. <sup>2</sup>

Therefore, given the above, this study is justified, highlighting the importance of understanding the needs of caregivers of children with CP who use gastrostomy in the home context; bearing in mind that they need to learn care and management, going through a long process until adapting to the use of gastrostomy, in order to reorganize the new routine. Therefore, strategies must be developed to meet the care demands focused on the special needs arising from CP.

## **METHOD**

This is a descriptive research with a qualitative approach, carried out at the Nursing School Unit in conjunction with the Orthosis and Prosthetics Project, which is a Permanent Extension Project, coordinated by the Department of Nursing (DENF), of the State University of the Center-West. (UNICENTRO), in the municipality of Guarapuava, headquarters of the 5th Health Regional of the State of Paraná, which

carries out assessment, adaptation, training, monitoring and supply of orthoses, prostheses to individuals who have some type of physical or motor disability, including children with PC. Data were collected through a semi-structured interview supported by an instrument which contained the following sociodemographic data: age, marital status, number of caregivers, family income, municipality of residence, education and occupation; in addition to questions related to caregivers' perceptions and conditions of use of the gastrostomy.

The interviews took place in the months of May and June 2021, the participants were screened at the Nursing School Unit, belonging to Unicentro, based on appointments made by the Órtese e Prótese Project, a service that serves families.

The research participants were fathers or mothers caring for children with CP with gastrostomy who are registered and undergoing continuous monitoring in the Orthosis and Prosthesis Program. The inclusion criteria were: being parents of a child with CP with a gastrostomy, being over 18 years of age; whose child is aged 0 to 12; with a medical diagnosis of CP; the child must be registered in the Orthosis and Prosthetics Program; resident of any municipality that is part of the 5th Health Region of Paraná; who is present at the

service during the research data collection period. The following were excluded from the research: other family members/guardians of the child, other than the mother or father; child not registered in the Orthosis and Prosthetics Program; who resides in municipalities that do not belong to the 5th Health Region of Paraná; mother/father of children with other neurological pathologies, other than CP; mothers/fathers who do not attend the service during the research period; institutionalized children with CP.

Qualitative data were analyzed using the Content Analysis technique proposed by Bardin<sup>10</sup> and data relating to the sociodemographic characterization of participants analyzed using descriptive statistics. Bardin<sup>10</sup> indicates that the use of Content Analysis foresees three fundamental phases, pre-analysis, exploration of the material and treatment of results, inference and interpretation.<sup>10</sup>

The development of this study occurred in accordance with Resolution 466/2012, of the National Health Council, and the project was approved by the Research Ethics Committee (CEP) of the Universidade Estadual do Centro-Oeste (UNICENTRO), according to opinion 3,185,754. All participants signed the Free and Informed Consent Form.

## RESULTS AND DISCUSSIONS

The data collected made it possible to describe the profile of caregivers of children with CP, in addition to providing results on the use and purpose of the gastrostomy chosen as a therapeutic method for the nutrition of minors.

Interviewee number 1 was 26 years old, lived in a marital situation with her partner, the two are the child's caregivers and the family income was 1 minimum wage from an informal source for 3 people living in the same residence. They lived in São Mateus do Sul (PR) in an urban area, their education was complete secondary education and they were housewives.

Interviewee number 2 was 33 years old, single and the child's main caregiver, family income is 3 minimum wages for 5 people living in the same residence, which is located in Turvo (PR) in an urban area, her education is complete secondary education and occupation of the home.

Interviewee number 3 was 33 years old, lived in a marital situation with her partner, the two are the child's caregivers and the family income was 2 minimum wages for 4 people in the same residence. She lived in Turvo (PR) in an urban area, her education was complete secondary education and she occupied a home.

Based on the statements about the use of gastrostomy by children, it was possible to expand the discussion into three

categories: the process of family adaptation and the difficulties in using gastrostomy; needs related to gastrostomy care; and the importance of multidisciplinary care, which will be discussed below.

### **The family adaptation process and the difficulties in using gastrostomy:**

In this category, it is noted that the caregivers interviewed reported a difficult adaptation process in relation to the use of gastrostomy. A mother's speech indicates initial resistance to the surgical process and fear of a new invasive procedure.

*"I was resistant to having the surgery, at first I was afraid, now I'm used to it, I take great care of my hygiene. He pulls, he pulls, he has to take care.... You have to watch your diet, otherwise it causes diarrhea and vomiting. I'm also afraid of it starting and not being able to see it, afraid of missing the surgery."*(E2)

Result found in this study as verified in the study carried out in Ceará (BR), which states that caring for children who require differentiated attention is a constant challenge for families, in particular, mothers, who are the main involved in caring for the child.<sup>11</sup>

Care for tube maintenance is complex and must be carried out by the caregiver in the best way possible so that it does not interfere with the child's nutrition.

The following statement from a caregiver reveals difficulty:

*“It's a long probe, you have to put tape on it, be careful not to let the probe come out, keep the area clean, protect it so the child doesn't pull or hit it and the probe comes out. I didn't know she would have cerebral palsy and after 3 months I noticed the differences...taking care of her is normal for me, due to the pandemic we are also closer, care at APAE was difficult at the beginning.”* (E1)

A similar result was described in the literature, where it was found that caregivers feel afraid of the unknown and, as a result, become resistant to accepting the procedure, there are reports of difficulties in handling the catheter, feeding and skin care peristomal.<sup>11</sup> To minimize fear, while providing care, the professional must encourage autonomy, encourage acceptance and social support from caregivers so that they feel safe and comfortable in providing care and maintaining the child's life.<sup>12</sup>

Another mother also reports the full work for the child who uses a gastrostomy and the process of acceptance and adaptation that happens slowly, as well as the importance of a support network, be it assistance, family or social.

*“Relax, clean up, position the tube, go well with the diet... I adapted little by little, every day”* (E3)

Time can mitigate the fear that families feel when accepting, handling and caring for a gastrostomy, so much so that the literature recognizes that if care actions are

performed repeatedly, it becomes a habit, with greater ease and normality, to know It is built based on the child's direct care experiences, which incorporates it into the family's social space.<sup>11</sup>

### **Needs related to gastrostomy care:**

The category reflects the content of the statements about understanding the complexity of using a gastrostomy. Some reports show the necessary precautions they took during the entire adaptation process, highlighting hygiene and protection so that the tube is not pulled:

*“...the orifice has to be clean, around the probe, it can't get clogged, there are several precautions, the temperature, the preparation of the diet, so on...(E1)*

*“... I take great care of my hygiene. He pulls it, pulls it out, you have to take care of it. The first thing I look at when I wake up is to see if the probe is there because otherwise it will close the hole.”* (E2)

*“The probe itself is calm, well adapted.... You always have to be careful not to pull, and also allergies around, keep an eye on hygiene.”* (E3)

A study revealed that gastrostomy care requires special attention because it is a technological device that involves: attaching the tube to the child's body; protect the probe inside your clothing so that it does not become loose, move or be removed; in addition to others, for its maintenance and permeability.<sup>13</sup>

The surgical wound must look healthy, clean, dry and free from itching or

surrounding liquids.<sup>14</sup> Therefore, the gastrostomy dressing must be changed every 2 or 3 days, or depending on the appearance of the dressing, in addition to being necessary to pay attention to avoid traction and pulling on the tube.<sup>15</sup>

Another precaution mentioned by the caregivers interviewed is about passing the diet through the tube, alerting them to the speed and diarrhea cases:

*“You have to be careful with the speed of the diet, diarrhea and vomiting.”* (E2)

*“It is necessary to position a probe and go well with the diet, very slowly.”* (E3)

According to Nascimento<sup>16</sup> et al (2015), the diet should be administered at room temperature and slowly, to avoid diarrhea, flatulence and abdominal discomfort.<sup>16</sup>

Although it is a procedure widely performed in health institutions, considered potentially low risk, gastrostomy still presents complications, which can lead to readmissions or prolonged hospitalizations of patients, indicating that possible failures may be occurring in this process. The prevention of these complications is directly related gastrostomy care.<sup>14</sup> To ensure that care is not compromised, the nurse must be involved in the discharge process, to promote continuity of care from the hospital to the home.<sup>12</sup>

Therefore, home care must be carried out in a safe and efficient way, considering

that the literature agrees that the family needs to receive information and support from the nurse, as different doubts arise during the treatment and monitoring of the child; therefore, this dialogical relationship can contribute to the exchange and sharing of care experiences with other members of their social support network.<sup>12,11</sup>

### **The importance of multidisciplinary care**

As previously described, the interviews highlighted the challenges in caring for children with gastrostomy, whether those related to the use of the tube, such as attention to traction, the possibility of developing dermatitis, or management of the diet, when they demonstrated concerns about diarrhea and vomiting.

Therefore, it is clear that caregivers need correct guidance regarding gastrostomy, in the same way, they lack support for positive coping, satisfactory support from the health team, enables mothers to provide safe care at home, giving empowerment to them.<sup>17</sup>

In particular, the concerns highlighted are the frequency described regarding concerns about cleaning care with the gastrostomy, a moment in which the nursing team must be involved, as it is up to them to assist in the care. It is urgent to provide guidance on the correct cleaning technique, providing support so that caregivers know how to recognize signs of complications

with the probe, for example, dermatitis, traction, liquid leakage in the probe balloon. And in case of occurrence, how to proceed. In fact, nursing is responsible for instructing the administration of diet and medications appropriately, in order to avoid episodes of vomiting and diarrhea.<sup>18</sup>

One of the caregivers reveals that she is monitoring the child concomitantly with a speech therapist, as the segment with this professional has a positive impact, even more so with regard to oral food reintroduction. In line with what was mentioned, one hundred percent of the children were recommended the procedure due to swallowing difficulties, therefore, this professional, a member of the multidisciplinary team, is qualified to evaluate and structure the most correct conduct and techniques, aiming for safety and efficiency.<sup>17</sup>

The speech therapist is the professional who can assist in the assistance and feeding difficulties of children, as they can guide the family to prevent complications and provide guidance on practices and essential care in a satisfactory and effective way.<sup>19</sup>

However, the guidance provided is not always incorporated into daily practice, and it is essential to know this reality for families. So much so that the literature highlights that knowing the environment in which people with disabilities live is

extremely important, as it can positively or negatively influence the experience of health and illness. However, one is recognized for the instrumentality and performance of the Social Worker, in the field of rehabilitation of people with disabilities, especially children with CP.<sup>20</sup>

It is worth highlighting the inevitability of working with caregivers, family members and the child regarding the indication of gastrostomy, linking this to the possible change in family dynamics and the child's personal life. Acceptance of the procedure permeates the values and beliefs that that family group carries with it, as well as social values. It is a time of uncertainty, fear, loss of notion of the pleasure of eating. This fact makes it essential for the healthcare team to work on positive reframing and acceptance. A study made it possible to verify the efficiency in dealing with the reframing of the process, as the authors pointed out that optimism in relation to gastrostomy increased the willingness of caregivers to overcome difficulties.<sup>9</sup>

This study demonstrated the importance of comprehensive assistance to these caregivers by health professionals, considering emotional, social and cultural aspects, guiding the development of health practices in monitoring children with CP using a gastrostomy and their families.



## CONCLUSION

It is concluded through the understanding of caregivers of children with CP who use gastrostomy that they present a difficult family adaptation process in relation to the use of gastrostomy, demonstrate specific needs for attention and preparation and recognize the need for multidisciplinary work.

Therefore, the relevance of a multidisciplinary, trained team that can meet the demands that caregivers present in relation to the procedure stands out. Highlighted need for correct guidance on the benefits it brings, the essential care and the resumption of oral feeding.

As a limitation of the study, the particularity regarding the social, cultural, economic and structural characteristics belonging to the population that took part in this study is recognized, which may interfere with the generalization of the study to other locations, as well as the small number of participants that make up the sample. . However, the findings are in line with those presented in the available literature, which can also be considered scarce.

It is hoped that new studies on this topic will be developed, with different methodologies so that the findings can support the clinical practice of nurses and other health professionals and, in this way, qualify the assistance provided to children and their families.

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