

**Family evaluation of children and adolescents submitted to gastrostomy****Avaliação de famílias de crianças e adolescentes submetidos à gastrostomia**Camila Casagrande Mela<sup>1</sup>, Clara Ferraz Lazarini Zacarin<sup>2</sup>, Giselle Dupas<sup>3</sup>

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The study aimed to understand the structure, operation and development families, to identify social support networks for the care of the child and adolescent submitted to gastrostomy, and to describe difficulties and facilities faced in this experience. We used the Calgary Family Assessment Model as theoretical reference, we added it to the semi-structured interview as research instrument; and we used Narrative Analysis as method. The uses of the technological device affect caregivers and their routines, and establish a relationship of renounce and donation with the gastrectomy patient. Difficulty was found to accept that their children are not fed normally. The main setbacks referred to the lack of knowledge and training for specific homecare. Support is limited. This study allowed better comprehension of experiences from families and showed that the use of a technological device brings benefits to the child's health, thus, it is a difficult process to be accepted at first.

**Descriptors:** Gastrostomy; Family; Child; Adolescent; Nursing.

**RESUMO**

O estudo objetivou conhecer a estrutura, funcionamento e desenvolvimento da família, identificar redes de apoio social no cuidado à criança e ao adolescente gastrostomizado, e descrever dificuldades e facilidades enfrentadas nessa experiência. Utilizou-se o Modelo Calgary de Avaliação Familiar, como referencial teórico, tendo sido acrescido da entrevista semiestruturada como instrumento de pesquisa; a Análise de Narrativa foi o método seguido. O uso do dispositivo tecnológico afeta os cuidadores e sua rotina, e estabelece relacionamento de renúncia e doação para com o gastrostomizado. Existe dificuldade em aceitar que os filhos não se alimentam normalmente. Os principais contratempos foram referentes à falta de conhecimento e treinamento para os cuidados específicos no domicílio. Os apoios são limitados. Este estudo possibilitou compreender melhor a experiência dessas famílias e evidenciou que o uso de um dispositivo tecnológico traz melhoras à saúde da criança, porém é um processo difícil de ser aceito inicialmente.

**Descritores:** Gastrostomia; Família; Criança; Adolescente; Enfermagem.

## INTRODUCTION

Gastrostomy is a type of stoma in which occurs the insertion of a tube directly in the stomach, through an opening on the anterior abdominal wall, used to infuse paste and liquid food, besides food formulas to people that cannot contemplate their eating and nutrition by mouth due to diverse causes. In children, it is a concomitant process to treatments of congenital, pathological or traumatic problems, and aims to secure the receiving of good nutrition for an adequate growth and development<sup>(1-2)</sup>.

The gastrostomy time of permanence is undetermined in many cases and it can take months or years for its correction, because the base disease – as well as other factors – can influence the reconstruction of the modified area<sup>(2-3)</sup>. The device is indicated for patients who use nasogastric tube for more than 30 days, being commonly used in cases of severe anorexia nervosa and in people with prolonged life expectancy<sup>(4)</sup>.

The presence of a device generates the need of a continuous professional supervision, considered a chronic condition. Chronicity is characterized by the prolonged course, requiring adaptations to limitations imposed to the individual. Besides that, it provokes important transformations of family dynamics, promoting high compromise from family members as well as the patients themselves and the health system<sup>(5-6)</sup>. In this conception, in many times, mothers leave the hospital needing to provide complex care to their children, causing big changes in personal and family habits. Despite taking a lot of knowledge and experiences from this process, they still have many questions and fears regarding their competencies to deal with the situation<sup>(7)</sup>.

The experience of caring for a child with a chronic condition is very hard for the family since the first moment, with the diagnosis. The despair with the lack of control and frustration with the situations create denial, fear and anguish feelings<sup>(8)</sup>. Slowly, the family starts to have control back, obtaining autonomy to perform the needed care aiming to promote quality of life for the child

as well as for the other members of this group<sup>(5)</sup>. Thus, certain adaptations are needed, availability of financial resources and health assistance for the treatment and to attend possible complications.

In this perspective, parents of children with chronic diseases search for healthcare to obtain knowledge, service efficacy, support and safety transmitted by professionals, to establish a consistent link between the service and patient<sup>(5-8)</sup>. The professional who attends this population should be prepared to interact with the family, establishing a collaborative and respective relationship. Communication and teaching of techniques and care are needed to attend the needs and specificities from each family unit, in order to decrease stress and increase the child's safety and wellbeing.

Few qualitative studies were found in the national and international literature, focused on the experience and feelings from the family that see the need to use a technological device as gastrostomy. Recent research reveals more technical aspects from the procedure, and leaves aside the experience and difficulties faced by the family. However, the study aimed to understand the structure, operation and development of families, identify social support networks in the care for the child and adolescent submitted to gastrostomy, besides, the description of difficulties and facilities faced in this experience.

## METHODS

A descriptive study based on qualitative approach, that tries to comprehend values, meanings, opinions and beliefs of individuals, and has as objective to obtain a more deep and subjective understanding of the study object, without paying attention to numerical and statistical measures<sup>(9)</sup>.

To understand the family structure, operation and development through family ties and social supports, we opted to use the Calgary Family Assessment Model (CFAM)<sup>(10)</sup> as theoretical reference for this study, which allowed it by using the genogram and the eco-map as

instruments for data collection, besides the semi-structured interview. In the structural assessment, we identified family members and their internal and external context. The functional assessment pointed the daily activities and aspects related to behaviors of family members: communication, the affective ties existing and the roles played. On the development assessment, we investigated linkages of the individual and their family in internal and external social environments, characterizing the social support network.

The CFAM allows assessment of family development and operation by the elaboration of a genogram and eco-map. The genogram is a family group diagram that includes at least three generations. Its use serves to differentiate the family's internal and external structure, by the family tree and its amplification. The visualization of the family dynamics as well as the relationships between its members is facilitated by standardized symbols<sup>(11)</sup>.

The eco-map presents the relationship between family and community. It is through this diagram that support networks available for families is represented and evaluated and, in which intensity these supports are used. These networks propitiate the possibility of sharing problems and feelings to families, besides to evidence their socialization and relationships<sup>(10-11)</sup>.

The study was conducted in a city in the interior of São Paulo state, in a municipality healthcare service that offers nutritional service to patients using gastrostomy. This service is entailed to a specialties' center that attends patients through the Unified Healthcare System (SUS). Participants of this research were families of children and adolescents submitted to gastrostomy, meeting the following inclusion criteria: to be family of a child or adolescent with age between zero and 18 years, in accordance with the definition from the 2<sup>nd</sup> Article from the Child and Adolescent Statute (ECA)<sup>(12)</sup>; to be an user of the public ambulatory health service from the city where the study was conducted and to live in the city or region served by the service.

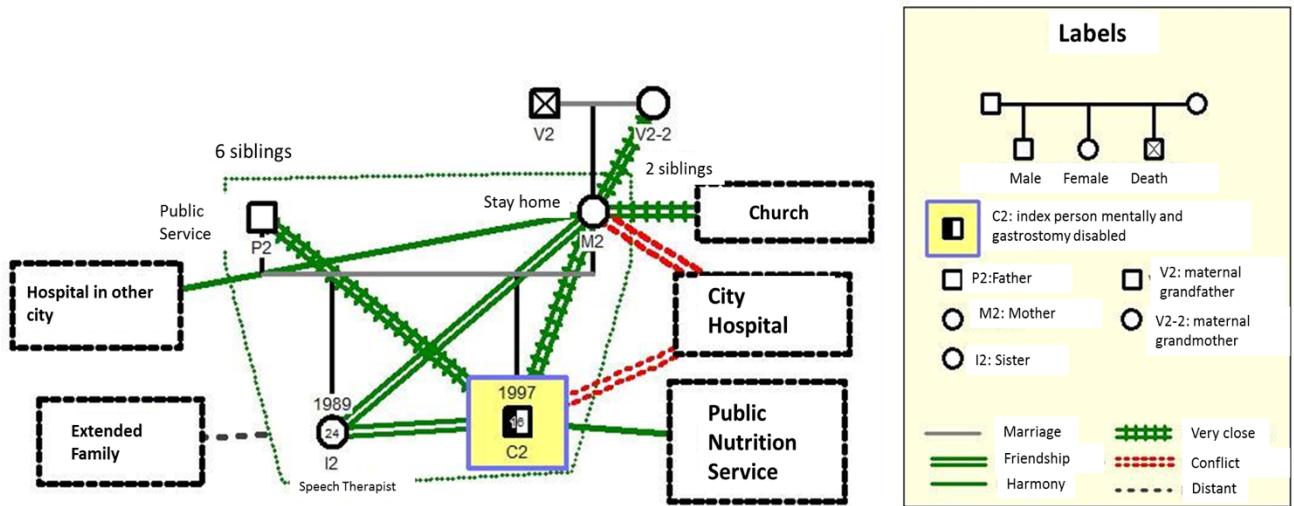
To perform the study, initially 14 families of children and adolescents from zero to 18 years with gastrostomy were raised, with an active registry in the institution where the study was conducted. Some families were contacted at the service at first, after ambulatory consultation with the nutritionist. When it was not possible to do a previous contact, due to absence in scheduled consultations, the families were directly contacted by telephone or at their houses, with the numbers and addresses provided by the health institution. From the 14 initial families, five did not participate in the study: two families were excluded because they did not live in the city or region, another family was not found and one child does not use the device. The fifth family did not want to participate. Accounting that, nine families participated in total.

At the first moment, the study objective was explained, and how would be the interview with family members for those willing to participate. Posteriorly, date and time were scheduled considering availability and particularity of each family to build the genogram and eco-map, and perform the interview. This meeting happened in the family house and it was recorded under consent signed by the present family members. Ethical care followed the Brazilian legislation for research with human beings, and approved by the Ethics in Research with Human Beings Committee, from the Universidade Federal de São Carlos (CAAE:02809512.0.0000.5504 / protocol number: 53018 de 14/08/2012).

Questions were directed initially for the construction of the genogram and the eco-map, as well as to comprehend the experiences lived by the family with the child submitted to gastrostomy, as *"Who is your family?"*, *"How is the relationship among you?"*, *"How do you relate with the health institutions that care for the child?"*, *"Tell me since the beginning how was to hear that it was needed to use the gastrostomy."*, and *"Tell me about the difficulties and facilities found in the daily life."* Data collection was conducted in the period of December of 2012 until June of 2013. After integral transcription of

interviews, Narrative Analysis methodology was used and it allowed identification of common points between experiences and important aspects, besides obtaining information regarding relationships, difficulties and facilities found in the process. The data from interviews were analyzed and pooled in four categories.

To analyze family social support, software (Genopro – 2013) was used and it helped to build the genograms and eco-maps, allowing to identify the relationships and its intensities. (Figure 1).



**Figure 1:** Genogram and eco-map from family two. São Carlos, SP, Brazil, 2013.

**RESULTS**

From the data collection, we created a chart (Chart 1) with the profiles of interviewed families in relation to the gastrostomy time of use, central pathology and the interview participants.

**Chart 1:** Characteristics of families of children submitted to gastrostomy. São Carlos, SP, Brazil, 2013.

Family identification	Child identification	Gastrostomy time of use	Central pathology	Interview participants
F1	<b>Child 1</b>	4 years	Extreme prematurity + Hydrocephalus	Mother, Father
	Female			
	Age: 10 years			
F2	<b>Adolescent 2</b>	13 years	Anoxia (drowning sequel)	Mother
	Male			
	Age: 17 years			
F3	<b>Child 3</b>	3 years	Anoxia (heart surgery sequel)	Mother
	Female			
	Age: 4 years			
F4	<b>Adolescent 4</b>	4 years	West syndrome	Grandmother, Aunt
	Male			
	Age: 16 years			
F5	<b>Adolescent 5</b>	3 years	Microcephaly	Mother
	Male			
	Age: 15 years			
F6	<b>Adolescent 6</b>	14 years	Extreme prematurity	Mother, Father
	Male			
	Age: 17 years			
F7	<b>Child 7</b>	5 years	Cerebral palsy	Mother
	Female			
	Age: 8 years			
F8	<b>Child 8</b>	8 years	Meningococcal Meningitis sequel	Mother
	Female			
	Age: 11 years			
F9	<b>Child 9</b>	5 years	Microcephaly	Mother
	Male			
	Age: 6 years			

Data from the interview were analyzed through Narrative Analysis<sup>(13)</sup> and pooled in four categories. The first was called “Gastrostomy procedure and its care”, and highlights health problems and common causes associated to the device placement, as well as the process of decision-making and family adaptation regarding the gastrostomy and its care. The healthcare team influence on this process and on the guidance for homecare was addressed as superficial and inefficient when the family needs it the most, that is, right after the gastrostomy procedure:

*He received it, because he had gastritis and esophagitis, and his esophagus was really hurt from vomiting. And very skinny. He was 7 years old and weighted only 12 kilos.*

*So the doctor did not even asked us. I even got scared, because he put it. But nowadays I see that it was the best thing he did in his life. (F6)*

The category “Fragilities and potentialities experienced with the device” addresses difficulties faced by the parents on the periods before and after the surgical procedure. In this context, complications, information obtained by family members through health professionals and the change in the family routine are emphasized. Consequently, facilities are also pointed, especially those related to improvement in quality of life for the child or adolescent and the family, besides visible and unquestionable benefits on the child’s growth:

*Ate everything smashed by the mouth. He used to drink milk, eat food, but then started to breathe with trouble, because it used to go to the lungs. He was always hospitalized with pneumonia, but after (the gastrostomy) he wasn't anymore. (F5)*

In “*Support from nuclear and extended family*”, it is presented the importance of family support in all periods of the process. Besides that, it shows the mother as main caregiver and the help coming from the father and their children in the care with the child. Regarding the extended family, it is noticed the process of getting distant and not feeling responsible of the family member with the device and the parents:

*Who takes care of her it's me here at home and my mother when she is with her. My husband helps, but if we are passing milk into her, then I connect her. He just passes it and then I go there and remove it. (F8)*

Referring to the category “*Support networks*”, it is observed the family need to look for help beyond the family context. In this perspective, between the main searched services, ambulatory health is noticed, as the Health Basic Units and Family Health, the nutrition service, Assistance Institutions for special children and Religious Institutions:

*At the beginning, he was hospitalized for a long time. We had support from many people, from the church especially. There were the priests from the church here that would come to visit, and still nowadays, they come to visit us, they participate. (F2)*

## DISCUSSION

The data analyzed in this study helps to comprehend the family experience in the care with children and adolescents submitted to gastrostomy.

The base health problems of children and adolescents were all from neurologic impairment and consequently

compromising swallowing and the ability to eat by mouth. The low weight, undernutrition and aspiration pneumonias, caused by swallowing dysfunction, were the main causes to perform the gastrostomy, agreeing with contributions from another study<sup>(14)</sup>. Those scenarios request the children to stay hospitalized for long periods, accumulating more concerns to parents. With the gastrostomy device placement, those adversities are reduced at the rate that the need for hospitalizations decreases.

The decision to go on with the gastrostomy to substitute or to complement oral eating can be very hard for parents. At the first moment, most caregivers did not want to accept the procedure, because they believed that besides hurting the child's development and not providing adequate nutrients, it would bring a risk to their lives. A study conducted in Italy revealed that parents feels anguished with the device and refuse it initially<sup>(14)</sup>. By these aspects, it is noted that families do not receive sufficient information about how the surgery is performed, the care needed to the child and the risk and benefits of the procedure.

The physical health, the nutritional status and respiratory diseases are considered in the process of parents related to the gastrostomy procedure. The research conducted is similar to the contributions of these studies<sup>(15)</sup>, because the parents are only convinced to accept the procedure from the explanation provided by the health team, broadening the devices used as well as the improvement in the child's quality of life. Besides that, for patients who used nasogastric tube, gastrostomy was also indicated and accepted promptly. It is worthy to note that the nasogastric tube cannot be used for prolonged time because it causes nose, oropharynx, esophagus and gastric lesions. As consequence, it unfavorably contributes in the clinical evolution if used in long term. Another study, conducted in Spain, showed that parents interpret gastrostomy as a final step of their child's evolution and for this reason, delay the acceptance of the procedure<sup>(16)</sup>.

Incentive from friends or people who experienced the same situation also accounted for their decision. It is noted that is relevant the health team incentivize and propitiate opportunities for families facing the same difficulties with their children to meet. Orientations about needed care with gastrostomy and diet, post-surgery, are partially given by professionals, although when they get at home, they have trouble with the new demand. Thus, it is a need for the health team to be prepared to conduct guidance, and clarify doubts of families.

Difficulties permeate this experience, before as well as after the gastrostomy. Frequent hospitalizations due to aspiration pneumonia and other harms as gastritis, esophagitis and weight loss, were the main situations faced by families before the gastrostomy. After the device placement, the lack of information and unknowing care were mentioned as main difficulties. Families who did not know the device and its functionality found it strange. The removal or disconnection of the device from the abdominal opening caused surprise and panic for some parents. It would be easier and faster if caregivers would leave the hospital knowing what should be done with their children in those situations.

Hospital discharge with the caregivers and follow-up home visits become important sources of support. Through them, it is possible to share technical-scientific knowledge and common sense, offering individualized attention and minimizing fear feelings and anxiety experienced by the family<sup>(17)</sup>.

Another fragility found refers to social life. A family tends to decrease or avoid outings, because there is a series of attributions, as to prepare and administer the diet, besides transport issues with the patient and the needed material. Only one family mentioned travelling with their son. Prejudice is present in the family reports. From this perspective, esthetic sequels from the procedure as well as the base pathology have strong influence in the behavior of family members, as people find it strange, causing feelings of embarrassment<sup>(18)</sup>.

It was evident the suffering from mothers seeing their child not being able to eat orally, as well as from other family members. This fact is similar to what was found by other authors<sup>(1-15)</sup>, in which eating orally is seeing by the family as a pleasurable activity, an important social process that create bonds. Therefore, gastrostomy represents a sign of impairment, a deprivation from eating pleasure and interruption of affection and union that occurs in the interaction mother-child during feeding.

Although not really evident, another mentioned difficulty was financial<sup>(19)</sup>. The special conditions from those patients require spending with specific materials, as tubes, food formulas, wheelchairs, besides medical assistance. Most caregivers do not have a paid activity, mentioning to be forced to leave their jobs to fully dedicate themselves to the child. Thus, they use benefits from the patient who depends on this technology or from the income of other family members.

Regarding difficulties during the experience with the gastrostomy, many potentialities were mentioned. The main one refers to the practicality and quickness of the food offered in the device, facilitating care promotion for the family and the patient. Thus, with time, it became an easy execution procedure for caregivers, meeting the information found in another study<sup>(15)</sup>.

Another facility propitiated by the device consists of the reduction of pathological scenarios and hospitalizations, as the ones caused by aspiration pneumonia, for example, previously frequent due to reflux. The tiredness and stress experienced by family members in hospitals, especially caregivers, were avoided, thus increasing their quality of life.

Participants also remembered the weight gain, similar to other study<sup>(20)</sup>. Gastrostomy allowed those children and adolescents to have a significant increase in weight and adequate nutrition. The food is used better when offered by the device, propitiating better satiety sensation. It also stops the emesis caused by reflux.



Family members mentioned that the gastrostomy brought health improvements as well as development improvements for their child, less frequent visits to doctors and increase in quality of life. It is noteworthy that the comparison with the nasogastric tube was inevitable. Corroborating with a research<sup>(21)</sup>, nasogastric tube was considered high maintenance, because it is too easy for the child to take it off and its constant obstruction, besides lesions caused by it. Those situations could be avoided with the early use of gastrostomy.

A study<sup>(20)</sup> demonstrate a significant improvement in weight, feeding time reduction and stress, besides improvements in social functioning after the gastrostomy placement, agreeing with results found in the present research. The cost-benefit of placing the device is effective due to diverse positive aspects on the patient's health, being also a safer method, with low incidence of complications.

The support offered to the family propitiates safety and strength to proceed with care. When there is no support, families search for alternatives, trying to promote the child and adolescent wellbeing. Support can be provided by the nuclear or extended family, religion, health professionals or public and private assistance, for example<sup>(19)</sup>.

Mostly, the mother was noted as main caregiver<sup>(1)</sup>. Generally, she receives help related to diet administration, shower and other cares, besides psychological support from other nuclear family members, as their husbands and other children. As found in research<sup>(19-22)</sup>, the abnormality of the child or adolescent is perceived as favoring higher interaction between nuclear family members, narrowing their bonds while facing challenges.

In what concerns the extended family, it was observed the constant presence of the maternal grandmother in the reports, similarly to other studies in the literature<sup>(22)</sup>. They are the main support to the family when the child is goes home and need care, or even when the main caregiver needs to be absent to solve issues

outside the family environment. This generally happens due to the fact of women being more connected to care and for being someone that mothers trust and feel comfortable with. Other family members helping with care cited were aunts and other grandparents. However, little help from those family members is noted, as they believe that caring is not part of their role. Over time, they get distant and absent. It is emphasized that help and support provided by other family members are extremely important to the nuclear family that is caring for the patient with gastrostomy to face the situation.

Some mothers mentioned that they do not work or abandoned their profession to be exclusively dedicated to their child. Thus, it is inferred a fear to delegate functions to others, believing that the responsibility is their priority. This fact, associated with little support from other extended family members, can culminate in overload for the nuclear family, causing isolation from family members from social life, especially the motherly figure. Also, it can let the caregiver more vulnerable to tiredness, stress, sadness and depression, in times, evolving to the a break of the family balance<sup>(23-24)</sup>. A study conducted in United States with families with special healthcare needs children, traced the profile of caregivers and found that in general lines, families face a high demand of healthcare, great financial load, increase of underemployment and unemployment as more than half of parents do not work to care for their child with high medical complexity<sup>(25)</sup>.

The networks of intra-family support are insufficient to the family and to the technology dependent. It is important to look for help outside the family context. Differently from what is observed in a study<sup>(24)</sup> that mentioned not existing any kind of follow up after surgery, we found support for those families in this research, although scarce.

When parents need healthcare for their child, we noted a common search for medical insurance, allowing activities as physical, occupational, speech therapy and other services besides consultations and medical monitoring. Some parents mentioned that only their child



has health insurance and other family members use the Unified Healthcare System. This fact demonstrate worries from parents to offer more options of services to their child, caring for some sort of agility and quality normally present in health insurance plans. Thus, they do not care to spend a little more money to get this improvement.

Within the resources searched by families, it is highly noticed ambulatory healthcare, represented by Basic Health Units, in special the teams from the Family health program<sup>(7)</sup>. This units, associated to the public nutritional service offer medications, food and equipment needed to conduct care. Although the public healthcare system is not excellent, it offers important financial support, independently of monthly family income. Materials, as equipment, medications and dietetic formulations, especially developed for this reason, are high value products when compared to the same expenses of people who do not use the device.

Institutions of assistance to especial child also frequently appeared in interviews as social support networks. Most of technology dependents goes there and keep good relationships. Only one family did not adapt to the institution. Over there, they do school activities, physical therapy among others. Parents that cannot bring or pick up their children counts on the support from the transport service from the institute, free of charge. It is important to note that this type of institute and other places where activities are developed with those children help families and especially, the caregivers, avoiding healthcare overload. Besides that, they help on the development and socialization of those children and adolescents.

It is also important to mention that religion institutions work as a big social, psychological and spiritual support network for families. We noted that people who follow a religion, independently from frequency, are more resilient when facing adversities. Thus, the family finds support in religion to look for significance in their experience and to feel supported in suffering moments<sup>(19-22)</sup>.

## FINAL CONSIDERATIONS

The present study found that the need to use a technologic device directly affects the family, by the decision process to conduct the gastrostomy surgery, or by the routine change.

After gastrostomy procedure, there were increases in health and development of children and adolescents with reduction in pathological scenarios, better nutrition and food use, as well as increase in quality of life. However, most parents have difficulties to accept gastrostomy and they suffer because they cannot feed their child orally, considering that this is an important activity for the social process. Outings become scarce, caregivers leave their jobs, material needs, financial difficulties arise, and dedication to the child or adolescent with gastrostomy is intense, causing a possible overload and family imbalance.

Facing this situation becomes easier when the family finds people offering support and strength to go on with the healthcare. In accordance with the study, the biggest sources of support, outside the nuclear family context, is concentrated in the maternal grandmother figure, health insurance, health units, assistencial institutions for special children and religious. These supports are extremely important to face the challenges encountered by the family.

However, it is important to highlight that social support environments visited by those families and their technology dependent members, although being a big help, are still limited and common. We observed that the life of those children and adolescents are restricted to the school, home and health services. Thus, it is important to create new environments to attend these individuals and their families, and inform parents about other existing support networks. To engage in activities involving leisure and outings can be one alternative.

At last, it is important to remember that there are a reduced number of national scientific studies in nursing addressing children and, especially, adolescents with gastrostomy. In this perspective, it is needed to increase

visibility to this population that lacks attention and support, by the amplification and deepening of studies from this nature, that can constitute in subsidizes to think

about the healthcare process for children and adolescents submitted to gastrostomy and their families.

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