







## MATERNAL EXPERIENCES IN CARING FOR CHILDREN WITH GASTROSTOMY: SUBSIDIES FOR THE HEALTH TEAM PERFORMANCE

VIVÊNCIAS MATERNAS NO CUIDADO À CRIANÇA GASTROSTOMIZADA: SUBSÍDIOS PARA ATUAÇÃO DA EQUIPE DE SAÚDE

EXPERIENCIAS MATERNAS EN EL CUIDADO DEL NIÑO OSTOMIZADO: APORTES AL TRABAJO DEL EQUIPO DE SALUD

 Vanessa Medeiros da Nóbrega <sup>1</sup>  
 Maria Gildete de Freitas Araújo <sup>2</sup>  
 Liandra Roberta Pinho da Cunha Coutinho <sup>3</sup>  
 Clécia Kelly do Nascimento Oliveira <sup>4</sup>  
 Jaqueline Costa Dantas <sup>5</sup>  
 Neusa Collet <sup>1</sup>

<sup>1</sup> Universidade Federal da Paraíba – UFPB, Programa de Pós-Graduação em Enfermagem. João Pessoa, PB – Brazil.

<sup>2</sup> UFPB, Hospital Universitário Lauro Wanderley, João Pessoa, PB – Brazil.

<sup>3</sup> Universidade Federal de Pernambuco – UFPE, Programa de Pós-graduação em Engenharia Biomédica. Recife, PE – Brazil.

<sup>4</sup> Centro Especializado de Nutrição, Hospital Nossa Senhora das Neves. Aracajú, SE – Brazil.

<sup>5</sup> Universidade Estadual da Paraíba – UEPB, Programa de Pós-graduação em Saúde Pública. Campina Grande, PB – Brazil.

**Corresponding author:** Vanessa Medeiros da Nóbrega  
**E-mail:** nessonobregam@hotmail.com

### Author's Contributions:

**Conceptualization:** Neusa Collet; **Data Collection:** Vanessa M. Nóbrega; **Funding Acquisition:** Vanessa M. Nóbrega, Liandra R. P. C. Coutinho; **Investigation:** Vanessa M. Nóbrega; **Methodology:** Vanessa M. Nóbrega; **Project Management:** Vanessa M. Nóbrega; **Supervision:** Vanessa M. Nóbrega; **Validation:** Neusa Collet; **Visualization:** Vanessa M. Nóbrega; **Writing – Original Draft Preparation:** Vanessa M. Nóbrega, Maria G. F. Araújo, Liandra R. P. C. Coutinho, Clécia K. N. Oliveira, Jaqueline C. Dantas; **Writing – Review and Editing:** Vanessa M. Nóbrega, Neusa Collet.

**Funding:** Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES) and Fundação de Amparo à Ciência e Tecnologia do Estado de Pernambuco (FACEPE).

**Submitted on:** 2018/10/08

**Approved on:** 2019/09/24

### ABSTRACT

**Objective:** to analyze maternal experiences in caring for a child with gastrostomy and to reflect on the performance of the multiprofessional team regarding the identified care demands. **Method:** descriptive, exploratory, qualitative study, conducted between December 2015 and May 2016 with six mothers, through semi-structured interview. The thematic analysis supported the interpretation of the data. **Results:** maternal experiences regarding the needs of a child with gastrostomy indicate that the fears change along the trajectory and that the ways of care are being built in daily practice. Thus, inadequate care is developed at home due to lack of support and knowledge, which may result in harm to the child's health. **Conclusion:** the care for children with gastrostomy should be continuous, collaborative and shared between the multiprofessional team and family in the hospital and home environment. Meeting the unique demands of this population prevents readmissions and promotes better quality of life for children and families.

**Keywords:** Child Health; Adolescent Health; Gastrostomy; Family; Patient Care Team.

### RESUMO

**Objetivos:** analisar as vivências maternas no cuidado à criança gastrostomizada e refletir sobre a atuação da equipe multiprofissional frente às demandas de cuidado identificadas. **Método:** estudo descritivo, exploratório, de natureza qualitativa, realizado entre os meses de dezembro de 2015 e maio de 2016 com seis mães, por meio de entrevista semiestruturada. A análise temática subsidiou a interpretação dos dados. **Resultados:** as vivências maternas diante das necessidades da criança gastrostomizada indicam que os receios mudam ao longo da trajetória e que os modos de cuidar vão se construindo na prática cotidiana. Desse modo, cuidados inadequados são desenvolvidos no domicílio por falta de apoio e conhecimento, podendo resultar em prejuízos para a saúde da criança. **Conclusão:** o cuidado à criança gastrostomizada deve ser contínuo, colaborativo e compartilhado entre equipe multiprofissional e família no ambiente hospitalar e domiciliar. Atendendo às demandas singulares dessa população, evitam-se reinternações e promove-se melhor qualidade de vida à criança e família.

**Palavras-chave:** Saúde da Criança; Saúde do Adolescente; Gastrostomia; Família; Equipe de Assistência ao Paciente.

### RESUMEN

**Objetivo:** analizar las experiencias maternas en el cuidado del niño ostomizado y reflexionar sobre el desempeño del equipo multiprofesional con respecto a las demandas de atención identificadas. **Método:** estudio descriptivo, exploratorio, cualitativo, realizado entre diciembre de 2015 y mayo de 2016 con seis madres, por medio de una entrevista semiestructurada. La interpretación de datos se efectuó en base al análisis temático. **Resultados:** las experiencias maternas con respecto a las necesidades del niño ostomizado indican que los temores cambian a lo largo del tiempo y que las formas de cuidado se construyen en la práctica diaria. Por lo

### How to cite this article:

Nóbrega VM, Araújo MGF, Coutinho LRPC, Oliveira CKN, Dantas JC, Collet N. Maternal experiences in the care of a child with gastrostomy: subsidies for health team performance. REME – Rev Min Enferm. 2019[cited \_\_\_\_];23:e-1250. Available from: \_\_\_\_ DOI: 10.5935/1415-2762.20190098

*tanto, cuando la atención en el hogar es inadecuada por falta de apoyo y conocimiento, la salud del niño puede resultar perjudicada.*

*Conclusión: el cuidado de los niños ostomizados debe ser continuo, colaborativo y compartido entre el equipo multiprofesional y la familia, tanto en el hospital y como en el hogar. Al satisfacer las demandas especiales de esta población se evitan los reingresos y se promueve una mejor calidad de vida para los niños y las familias.*

*Palabras clave: Salud del Niño; Salud del Adolescente; Gastrostomía; Grupo de Atención al Paciente.*

---

## INTRODUCTION

The number of children with temporary and/or permanent special health care needs (CSHCN) is growing worldwide due to medical and technological advances in pediatrics and neonatology. This population has diversified health care demands, depending on the underlying disease, and part of it needs to make prolonged use of medications and devices, temporary or definitive, to maintain and ensure a better quality of life, which requires team monitoring, multi and interdisciplinary in the hospital and home environment.<sup>1</sup> Among the most commonly used technological devices are gastrostomy tubes (GTT).

The GTT, which consists of a surgical procedure through which a tube is inserted into the abdominal wall to the stomach, is indicated for children unable to receive the adequate caloric intake orally in the long term, even with intact gastrointestinal tract.<sup>2,3</sup> Study found that, among the main situations and indications for performing GTT in Pediatrics, are neurological health problems, which compromise swallowing and the ability to eat orally, causing low weight, malnutrition and aspiration pneumonia, requiring use nasogastric and nasogastric tubes.<sup>3</sup>

These comorbidities in the pediatric population can trigger worsening of the clinical condition, causing long periods of hospitalization and/or intensive care unit hospitalization, besides bringing inconvenience and concerns to caregivers. The expectation with the placement of GTT is the reduction of these adversities and, consequently, the reduction in the number of hospitalizations<sup>4</sup> and the improvement of the child's quality of life, which now receives adequate nutritional support.

However, ostomy demands care and adaptations of the family to the new condition of life, because upon discharge from hospital, the latter will take care of a child with gastrostomy and not always, in the first moment, the main caregiver will be able to perform this task.<sup>4</sup>

Study reveals that, in addition to the lack of openness of the professional to listen and dialogue with the family, the actions developed by professionals are focused on aspects that they believe the caregiver needs to be aware of. As a result, families have not been adequately prepared and supported to answer their questions and encourage positive coping.<sup>5</sup>

Thus, the need to know the experiences of these families in caring for a child with gastrostomy emerges, in order to reflect on the role of the multidisciplinary team in face of the care demands identified in the home and hospital routine, when appropriate.

In this context, the question was: how has the family been developing care for the child? How can the multiprofessional team empower and support the family in this care? Thus, this study aimed to analyze maternal experiences in caring for a child with gastrostomy and to reflect on the performance of the multiprofessional team regarding the identified care demands.

## METHOD

Exploratory-descriptive study of qualitative nature, with the purpose of, from the experiences of mothers of children with gastrostomy, reflect on the role of the multidisciplinary team facing the demands inherent in the care of this population.

Data collection took place between December 2015 and May 2016 at the pediatric clinic of a reference university hospital for chronic juvenile disease in *Paraíba*. Inclusion criteria were being of age and primary caregiver of a child aged between one month and 12 years old, with gastrostomy and hospitalized in the pediatric clinic during the data collection period. And as an exclusion criterion: being a caregiver of a child with GTT who was not discharged after the procedure. All people who met the selection criteria and were invited by the researcher agreed to participate in the study.

The technique used with family members was the semi-structured interview. Firstly, a structured characterization script was completed containing data on the child (age, gender, GTT time, schooling, weight, height), caregiver (age, marital status, religion, profession, income) and living conditions (type and status of housing, area of residence, number of rooms, water used). Then, the interview was conducted guided by the following questions: "tell me about the care you give to a child with gastrostomy; what questions do you have regarding the care of your child with gastrostomy?" The interviews lasted an average of 15 minutes, were recorded with the consent of the participants and transcribed in full.

The empirical material was subjected to thematic analysis<sup>6</sup>, following three steps: pre-analysis, in which the interviews were exhaustively read to obtain an overview of the collected data; codification of the excerpts in units of records with subsequent grouping for the elaboration of themes and nuclei of meaning; and final analysis with interpretation of results, using the grouped data from the structured script (presented in the characterization of families) to discuss the findings with the support of relevant literature.

The study followed all the recommendations provided for in Resolution N° 466/127 of the *Conselho Nacional de Saúde* and

was approved under Opinion Report N° 2.143.546 of June 28, 2017 and CAAE 49375115.5.0000.5183. All participants signed the Informed Consent Form and, to ensure their anonymity, were identified by the letter “E” accompanied by a numeral corresponding to the chronological order of the interview.

## RESULTS

### CHARACTERIZATION OF FAMILIES

Six main caregivers of children with gastrostomy participated, all of them mothers, aged between 18 and 36 years. Of these, three were single (E2, E3, E4); two married (E5, E6); and one divorced (E1). The average monthly income of most families was one minimum wage, and only two of the parents were formally employed (telemarketing – E2; saleswoman – E4); three declared themselves housewives (E3, E5, E6); and one, unemployed (E1).

Regarding children, there was parity in relation to females and males, age ranged from three months to nine years, while time with the GTT tube ranged from one to 10 months. The main health problems for GTT insertion were neurological (cerebral palsy, microcephaly, neurological complications due to meningitis and intracranial hemorrhage) and, in one case, structural basis of the gastrointestinal system (esophageal atresia).

According to the mothers’ report, only half of the families received home visits from family health unit (FHU) professionals, and one resident in the rural area was visited by the entire team, one was visited only by the community health worker (CHW) and the other by the doctor and CHW.

The results of the interviews, after analysis, were grouped into the thematic categories presented below.

### FEARS IN CARING FOR A CHILD WITH GASTROSTOMY

The joy at the hospital discharge of the child after the insertion of the GTT tube became anxieties, worries and despair, as the mother began to experience difficulties at home in relation to the care previously performed by professionals in the hospital environment:

*When I went home, I put her to bed, I said, “Ready, now what? How is it going to be?”. Other than the days I despaired, I cried. Then, I researched and when I went to see, she began to get used to me and my way of being and I with hers (E2).*

There were gaps in the guidelines regarding GTT care in various areas during hospitalization, which caused insecurity in some mothers regarding the care of their children at home:

*I had no opportunity to perform gastrostomy cleaning. Just witnessed the change, the cleaning of the tube I follow. [...] I was not instructed after the gastrostomy (E1).*

*When she [child] came home, I didn't know what to do, despite all the teachings I had here [at the hospital]. I was still suffering a lot [pause], so I needed to raise my head and (pause) I searched a lot on the internet, [...] how to take care of the gastro (E2).*

As a result, the caregivers had many difficulties and doubts regarding the management of possible complications with GTT:

*I came home and had difficulty [...] When I bathed him, I was afraid to rub my hand because I thought I was going to leave [...] I keep thinking like this: “when she [referring to the GTT tube] going out, how am I going to do?!” Because if she goes out she'll be just the little hole... What if she's eating?! (E4).*

*I already thought about the tube leaving home, if it would have any technique to put on without having to go to the hospital, to help ... Because, well, the second time it left, it didn't burst. I was already imagining this, but every time I left, I would take him to the hospital, [...] because if I put in and not stay in the right place [...] (E6).*

The possibility of leaving the abdomen tube is one of the main concerns of caregivers, as it triggers insecurity regarding the correct attitude regarding this situation. However, one of the mothers, who is from the health area and has technical knowledge, even nervous about leaving the tube, was able to intervene in the unexpected situation and developed new knowledge about GTT care:

*I'm a Nursing technician, but I had difficulty at home when the tube came out. The first time I was nervous, it was early in the morning, I was leaving, I put in quickly, I sucked the rest of the water I had and normal [filled the balloon], everything worked out. There was a time when the nurse filled the balloon with serum, and the doctor said she couldn't [...] because the serum pierces the tube. So, what happened?! The balloon punctured; it was straight out, straight out. When I looked right there was a little hole and the other day I went to the hospital. The doctor changed and that's when she said she couldn't fill with serum (E5).*

Some complications or complications related to GTT appeared in children, distressing the caregiver:

*For one thing, the gastro helped him gain weight, but I think it's bothering him, because when he eats there are times when he wakes up crying. The surgeon came to look ... and said that when he was discharged, he would come back with 15 days to have surgery because he created a hernia over the gastro. [...] There was diarrhea after the gastro, which goes and then comes back again (E4).*

## EXPERIENCES WHEN PERFORMING CARE WITH THE PERISTOMAL REGION

Mothers emphasized home experience about technical care and assessment of the GTT peristomal region in children:

*Clean with gauze and saline. First, I put on a glove, pick up the gauze and serum, soak the gauze, or put the serum on it, and feel the gauze to remove any excess dirt or secretion without rubbing, and dry with the gauze. If necessary, I put the ointment, if not just put the gauze not to get dirt (E5).*

*On the outside, normal cleaning as I was explained [...] whenever it's dirty to clean. Because I clean it when I bathe it, but occasionally, it gets a little yellowish discharge, which really releases in the tube over the hours, then I clean it with gauze and water (E6).*

After the insertion of the GTT, most mothers did not receive practical preparation in a hospital environment to clean the peristomal region:

*I did not perform at the hospital. [...] the cleanliness of the place, I only witnessed. They wash with a serum, put a little powder, which I do not know the name, gauze and adhesive (E1).*

*I do not clean much not [in the hospital], because the girl cleans. When she comes, I help by pouring water for her to clean (E3).*

Some mothers developed autonomy for care that gave them the ability to assess the situation and make decisions based on observations in daily practice:

*[...] when they do [the gastrostomy] it is well scarred, then after a while is ... it's because ... it's the stuff that muffles [...] I think the bandage muffles it, because afterwards I started to take off the bandage, I was just treating there, passing that barrier cream, that's when it was getting better (E2).*

## FEEDING THE CHILD THROUGH THE TUBE

In daily life, when feeding the child through the GTT, the mothers developed adaptations and variations in the technique according to their experiences:

*I feed through a 20 ml syringe, which I attach to the tube and put the milk without the plunger and wear gloves. Before finishing the diet, I wash with a measure of water of 20 mL and then I remove the syringe, the glove and throw in the trash (E1).*

*I put [the feed] in a 20 mL syringe and I keep put it in, I don't force it, I let it go down normal, because I think that force hurts. The stomach is a very delicate thing, if you put pressure on it will of course hurt. And after the diet ends, I put 10 mL of water to wash, because if you do not wash ..., there was a time that I did not wash, and when I went to give the milk was clogged, because the milk is a little greasy. If you do not wash it will clog the gastro (E2).*

*At home, I take the plunger out of the 20 mL syringe, fit the tip of the syringe into the tube and the milk I put in the bottle I put it in the syringe and it goes down spontaneously, sometimes I push it just to push the milk to go down, sometimes goes down and does not have to (E6).*

The mothers expressed doubts about the cleaning and changing of the tube and about the type of food to be administered over time:

*My biggest question is how to clean the tube and possibly change it or if it leaves or enters. [...] Regarding the issue of food, I have the doubt if it will be left in this formula. According to the nutritionist she would stay for six months until she gained weight, because she became very thin (E1).*

When mothers receive satisfactory support from the health team, they can provide safe care at home. In general, the guidance received during hospitalization and the observation of how the team handled the GTT were experiences that empowered them to care for their child, including correcting inappropriate practices:

*One time I administered the milk at 21h, when it was midnight, I went to give the milk and did not go down. The tube had clogged. I had to come here [hospital] to clear at dawn [...]. I had the nurses' teachings on how to handle, the cleanliness, everything. They explained to me how to handle the tube, washing it with water always before and*

*after feeding so that there is no residue on the tube wall and obstruction (E6).*

The role of the multiprofessional team in the reintroduction of oral foods was emphasized by one of the mothers, who had initial resistance to the procedure and was hopeful in the successful return of oral feeding:

*I didn't want them not [to do the gastrostomy], because she chewed, swallowed all the blended food ... she ... swallowed. She got the flu, with a lot of phlegm, so they said she couldn't swallow [...]. Now, three times a week she swallows and chews during speech therapy (E2).*

## DRUG ADMINISTRATION THROUGH THE TUBE

In general, children with GTT use various medications that must be administered via the tube. However, the caregivers did not receive the guidelines to perform this procedure and had doubts about the correct way to perform it:

*It makes use of gardenal and clonazepan. Liquid, droplets. Administer by gastrostomy. I think if it was a pill I would have to dilute. [...] I was not instructed after the gastrostomy on how care should be taken in administration (E1).*

*It makes use of rivotril, luftal, dipyrone. I put the amount of the drops, with 1 mL of water, make the medicine, then I wash with a little water to enter the amount of the drop. No one taught me how to administer the medicine. I do as you say in the recipe. I press the plunger gently to lower it (E4).*

*He makes use of vitamins and iron through the syringe tube. In the case of iron, I administered it an hour before feeding it, I took those measuring cups, put the six drops of the neutrofer with 5 mL of water. Then I aspirated with the syringe and put it in the tube and then put water to clean. Already the vitamin I put along with the milk. They didn't explain how I did it, I saw them doing it. Thus, when they came with the syringe, they observed [that they learned to administer the drugs by GTT] (E6).*

Due to lack of guidance, there are inadequate practices in the management of the GTT tube, as some mothers administered medication along with their diet. This behavior can provoke interaction and decrease the absorption of the drug and its effectiveness:

*She takes vitamin C, ferrous sulfate and depakote. Every morning I give sulfate and vitamin C, along with milk through the tube. [...] The depakote I put in a 3 mL syringe, fill three and put, then I wash with 5 mL of water, must wash the tube every time, either with milk or with water (E5).*

The caregiver, when guided by the team, feels safe at home and develops strategies regarding drug administration:

*The girls here at the hospital taught how to prepare and administer [...]. I always use my cell phone to remember the [medication] schedules, because otherwise I forget. They have in my fridge the schedules and have in my cell phone to keep waking up (E2).*

## SUPPLIES FOR PERFORMING GTT CARE

There is significant expenditure on inputs for maintaining GTT care and the proper diet for the child. Although some families have financial difficulties in providing this material in enough quantity, they do not always have access to inputs in public health services:

*When I leave here [hospital] I ask and the girls [Nursing] give me some gloves ... When it ends at home, I buy at the pharmacy. We put in court to see if she [daughter] can receive the medicines, can receive these things: gauze, syringe ... But for now, nothing (E2).*

*Syringe, tube, so far no one helped. Like I told you, I even buy the syringe from the pharmacy. Usually, I only pick up gas at the public clinic if I have it there. They give me a part, like the tube and the syringe, which is what I spend the most (E4).*

*When I came back [Secretaria de Saúde] with the medical reports, they said they could do nothing to get the syringes for his food, I had to go to court. [...] When they gave me the negative, I had to look for a point to get the syringes for his food. [...]. This all takes time. At first, I got a box [of syringe], urgently, and the others, my mother who is a health agent, goes to the clinic, picks up some, my husband also buys [...]. The only syringe I reuse is water, which the doctor said could spend the day, but milk with each administration is a clean syringe (E6).*

## DISCUSSION

Given the numerous demands on health and obstacles experienced by mothers of children with GTT to provide care



at home, it is necessary to reflect on the performance of the multiprofessional team.

Upon discharge from the hospital, families take care of a child with gastrostomy and, at this moment, they will not always be able to appropriate this responsibility. At home, mothers performed this care without professional support, including in the initial phase of adaptation after device insertion and hospital discharge. For this reason, in certain situations, inadequacies may arise since this family nucleus is not technically and emotionally prepared nor has received support from the HFU (Health Family Unit) for self-care.

The multiprofessional teams of USF and the Family Health Support Center (FHSC), being inserted in the home context, have the possibility to know the family dynamics, the psychological, housing, socioeconomic and access to the healthcare network (HCN) that may have repercussions on the care process developed by family members. Thus, they could accompany and guide the caregiver in the therapeutic process to face this new phase experienced with the child, who now depends on this technological device to receive medicines, be nourished and hydrated.

In this process, the use of clear and efficient communication from the health team to guide family members in the practice of caring for these children and their involvement in the planning of this assistance brings safety and enables them with the necessary skills to perform the procedures.<sup>5</sup>

Although sometimes HFU and HCN are unable to provide the family with material resources to meet the needs of children, they have the potential to facilitate access to appropriate and timely care.

A study conducted in *Minas Gerais* also showed a gap in this level of care in CSHCN care, due to the non-resolving care of the demands presented by the family and the difficulty of access.<sup>8</sup> This reality corroborates the findings of this study, indicating the inefficiency of primary care in effecting care management and supported self-care.

After the transition from hospital to home, family members build experiences, new knowledge in another reality, prevailing some doubts and fears about their ability to deal with the situation.<sup>9</sup>

The most frequent doubts and difficulties regarding GTT found in this study refer to cleanliness, period of change of the tube, how to act when it is externalized, type of diet and who to resort to in case of complications during the handling of the device.

It is recognized that the fear when faced with the device is due to lack of skill, lack of knowledge of its operation, unfavorable reality for the development of necessary care and to act against complications with the GTT. This fact may be linked to the predominance of focus by professionals involved in care in a hospital environment, in the technicality

of their activities, forgetting that they are training lay people to provide complex health care in their homes to CSHCN.<sup>10</sup> In this perspective, it is necessary to insert, during the hospitalization period of children with gastrostomy, health education and family training for care in the health care routine of health professionals since their admission.

It is necessary to establish this dialogue between health professional and family, using participatory methodologies that favor a critical-reflexive process of both, because together they will have to build knowledge, adapting it to the unique context of each situation.<sup>11</sup>

One aspect that may interfere with the health education process refers to the psychological condition. One of the caregivers reported that, despite the teachings of the team, she felt distressed by the difficulties experienced at home in the face of care. It is noticed that the psychological unpreparedness of the mother had a negative influence on her empowerment.

It is understood that the time for dialogue with the caregiver in carrying out such guidelines should be appropriate and, depending on the psychological and emotional conditions, there may be a need for prior work on these conditions that will influence the ability to understand information and openness to dialogue with the team.

In health education, caregivers' openness to this critical-reflexive process is necessary,<sup>11</sup> and this condition will only be met if they are well and psychologically and emotionally balanced to gain confidence in their potential to perform care.

In the search for this trust and autonomy, the multiprofessional team can use, during training and guidance on GTT care, multiple methodologies, including active ones. In this way, it strengthens the set of knowledge, practices and skills needed by caregivers, in order to ensure better quality of life for these children and reduce their dependence on health services.<sup>1</sup>

It was found that, during the period they remained in the hospital, the mothers did not perform the peristomal hygiene technique under the supervision of health professionals, an indispensable action in preparing them for hospital discharge, because in this process, in addition to training Technically, professionals can identify fears and insecurities that may interfere with home care.

Families of children with gastrostomy have increasingly assumed responsibility for care, needing to overcome the weaknesses identified here. Nevertheless, it is necessary for professionals to involve caregivers in care, establishing a dialogical relationship that prepares them for hospital discharge after the insertion of GTT.<sup>12,13</sup>

It is noteworthy that this is not a transfer of daily care performed in the hospital environment to the companion, with delegation of duties, making him or her a "team member",

but rather being together in this process to equip him/her with the necessary skills home care.

The preparation for hospital discharge initiated with the family upon admission is consolidated at the final moment of hospitalization. And this work should be continued in the post-hospital period, through the follow-up of the other services of the HCN and home visits.<sup>12</sup> Therefore, the need for the hospital team to refer this family with the necessary guidelines emerges, enabling the FHU team. assume the responsibility of supporting this family for continuing care at home.

Regarding GTT care, the maintenance of dry and clean skin in the peristomal region was the most cited by the interviewees of this study, an action that, together with the maintenance of intact skin, is considered a gold standard in device care.<sup>14</sup>

However, other precautions also considered relevant were not reported, such as fixation of the tube to the skin to avoid accidental traction and displacement,<sup>2,14-16</sup> gently rotate the tube clockwise and counterclockwise to avoid adherence to the skin and facilitate cleaning, and the evaluation of the underlying skin, except for sutured catheters that had radiological insertion,<sup>14-16</sup> daily assess the peristomal skin, looking for signs of irritation or infection,<sup>2,14,16</sup> monitor how much of the catheter is externalized,<sup>16</sup> and perform device inspection to identify leaks.<sup>14,16</sup>

At discharge, the technology-dependent child sometimes receives a prescription for a significant number of medications to continue therapy at home. Due to various factors, caregivers mismanage them, causing interactions that can result in treatment problems, with possible return to hospital.<sup>17</sup>

All children in this study used two or three GTT medications, such as anticonvulsants, antipyretics, vitamins, and iron. Such administration requires prior specific guidance to avoid dosing and timing errors, as well as food interaction and drug dilution. It was found that some caregivers expressed doubts and difficulties to explain how they performed the administration of drugs at home. There is evidence of lack of pharmacotherapy and unpreparedness for the safe and correct administration of medicines, which the health team is required to prepare family members to perform the procedure.

Also in relation to the use of enteral drugs, the use of liquid formulations is recommended, due to the great ease of diffusion and to avoid obstruction of the tube; and administration with a minimum interval of 30 minutes of the diet, to avoid drug versus nutrient interaction,<sup>17</sup> care not emphasized by mothers.

It is desirable that the preparation and follow-up of mothers for drug administration should be performed both in the hospital and at home. Therefore, the HCN needs to be organized and structured to ensure support to CSHCN families.<sup>18</sup>

Regarding food, it is understood that the caregivers performed the administration relatively correctly, but none of

them explained about important aspects in performing the procedure to prevent complications. These include checking gastric residue before diet,<sup>14</sup> not administering diet if abdominal distension, nausea and vomiting are observed; slowly administer the diet to prevent diarrhea, flatulence and abdominal pain; raise the headboard between 30 ° and 45 ° when administering the diet and so remain for about 30 minutes to an hour to avoid aspiration and regurgitation,<sup>14-16</sup> when there is no contraindication; and proper cleaning of the reused materials (equipment, syringe and diet bottle) with warm water and then placing them in a 5 liter water solution to 50 mL of 1% sodium hypochlorite for disinfection, which may be used for 24h.<sup>15</sup> Other important factors that were not mentioned refer to oral hygiene three times a day,<sup>14,16</sup> checking the volume of fluid in the tube cuff every seven or 10 days and its readjustment; adequate volume of water to wash the tube.<sup>14,16</sup>

These results reveal that the transition of these children from hospital to home requires action planning prepared by the multidisciplinary health team, with the participation of family members from the moment of insertion of the device until the child's discharge, to ensure continued quality assistance.<sup>8</sup> Thus, preparing for hospital discharge with active family participation, identifying priorities in planning, is a prerequisite for successful return-to-home adaptation.

It is necessary for the health professional to look at the mother and recognize her as a person who will have a great responsibility to take care of her child, without necessarily having a training for this care, as well as the context in which she is inserted and the difficulties experienced.<sup>4</sup>

It is acknowledged that by assuming the responsibility of assisting a CSHCN with GTT, both at home and in the hospital environment, significant changes occur in the family from the physical, emotional and psychosocial point of view, increasing the responsibility of health professionals in the field. support for these families. Nevertheless, an international study identified a reduction in professional support after discharge, which impacted on caregivers' learning, a process that should be based on family experiences in care management, to overcome the daily adversities that change over time.<sup>19</sup>

Regarding difficulties/complications, the most cited by mothers were inflammation or infection at the site of insertion of the device, obstruction of the tube, episodes of diarrhea and hernia in the peristomal region, culminating in the early return to the hospital environment.

Depending on the severity, complications can be classified as major or minor. The smallest are those directly connected to the tube insertion region and peristomal region (granuloma formation in the peristomal region, infection at the tube insertion site, tube displacement and gastric obstruction); the major ones, in turn, are aspiration pneumonia, bleeding in the

digestive tract, internal organic lesion, necrotizing fasciitis and ischemic necrosis of the gastric wall with migration of the tube towards the abdomen.<sup>20</sup>

In this regard, a study identified low occurrence of complications in GTT, the most common and in decreasing order of appearance being gastric contents leakage, inflammation, obstruction, granuloma, tube exit and secretion and infection.<sup>3</sup>

Regarding complications up to six months after the GTT, the most frequently identified were gastric leakage and local inflammation.<sup>3</sup> This finding may be justified by the fact that, over time, there may be enlargement of the stoma, which favors the extravasation of gastric contents, whose contact with the skin causes peristomal inflammation.

With proper training, there is a possibility that the child will gradually feed back orally if she has the caloric and breathing needs restored, as GTT is a reversible condition. In this work of oral food reintroduction, the importance of the speech-language pathologist in the multiprofessional team is highlighted, as the professional can evaluate and diagnose the swallowing disorders, as well as define the most appropriate, safe and efficient conducts and techniques.

The mothers revealed that, in relation to the inputs, they did not have enough material to perform care for their child at home, so that they often need to buy, which suggests lack of support from the HCN, as well as prejudice to family budget. In this context, there may be double financial burdens for the family, since most of the time, besides the mother abandoning her paid activity to care for her child, she needs to pay the purchase of inputs to meet the demands of the family. CSHCN.<sup>4</sup>

According to Law No. 13.257/2016 of the Civil House, in its article 21, item 2: "it is incumbent upon the public power to provide, free of charge, to those in need, medicines, orthoses, prostheses and other assistive technologies related to the treatment, habilitation or rehabilitation for children and adolescents, according to the lines of care that address their specific needs".<sup>21</sup>

Despite the legal allowance, many families are unaware of the rights of CSHCN, and the provision of necessary inputs to a child with GTT by HCN is often inconsistent and irregular.

In this study, it was found that the children and their family did not receive due attention from the municipality's HCN, through the Health Departments and FHU. Thus, in the search for their rights, some resorted to judicialization, because family income does not cover the acquisition of inputs for the maintenance of care to be performed at home. This need may be met by the social worker during hospitalization, because the lack of adequate material to perform the care leaves this child vulnerable and brings greater risks, which may lead to readmissions, caused by the lack of basic conditions to maintain their health.

This strenuous scenario of struggles experienced by CSHCN families exposes them to individual, social and

programmatic vulnerabilities, as recognized by a previous study<sup>22</sup>, causing damage to the health of these children.

In this sense, the need for the involvement of the multiprofessional team in the preparation for hospital discharge is emphasized, which besides the nurse and the doctor, is composed by the clinical pharmacist, speech therapist, nutritionist and social worker, with a view to the construction of a discharge plan. care that guarantees the continuity of care. Thus, it enables the empowerment of the family to manage the situation at home, resulting in better quality of life for those directly involved in the process of caring for children with GTT.

## CONCLUSION

The relevance of the longitudinal and continuous follow-up of CSHCN with GTT is understood from the perspective of a multi- and interprofessional look, which should be initiated when identifying the need for insertion of the device and lasting even after discharge, following the child's follow-up time.

There were gaps in the care and self-care supported offered by the multiprofessional team to children with gastrostomy, weakening the health care and empowerment of mothers to take care safely and effectively at home. This reality has contributed to the emergence of unnecessary and preventable readmissions, generating fear and insecurity in family members when taking care of children with gastrostomy.

In this sense, it is recognized the fundamental role of nurses in supporting these families, so that they empower themselves with the knowledge necessary for decision-making at home in relation to experienced situations related to GTT.

In addition, as it is a population in need of continuous care, HCN flows and counterflows should be clearly established in order to highlight the competencies of each service in this process, as well as to effectively refer cases to FHU, with the summary containing the necessary information for the staff of this service to be able to continue the care and support to families. Thus, unnecessary mismatches and wear to family members are avoided when they need assistance, whether related to the periodic change of the device, support for home care or even intervention in the event of complications and complications.

Despite the limitation recognized by the number of participants, the study made significant contributions by reflecting on the multiprofessional role in the process of caring for children with GTT, based on their daily maternal experiences.

## ACKNOWLEDGMENT

We thank the *Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES)*, for the PhD scholarship and



the *Fundação de Amparo à Ciência e Tecnologia do Estado de Pernambuco* (FACEPE), for the Masters scholarship.

## REFERENCES

1. Cabral IE, Moraes JRMM. Family caregivers articulating the social network of a child with special health care needs. *Rev Bras Enferm*. 2015[cited 2018 Feb 15];68(6):769-76. Available from: [http://www.scielo.br/pdf/reben/v68n6/en\\_0034-7167-reben-68-06-1078.pdf](http://www.scielo.br/pdf/reben/v68n6/en_0034-7167-reben-68-06-1078.pdf)
2. Nascimento NG, Borges EL, Donoso MTV. Assistência de Enfermagem a pacientes gastrostomizados baseada em evidências. *Rev Enferm Centro-Oeste Min*. 2015[cited 2018 Feb 15];5(3):1885-97. Available from: <http://www.seer.ufsj.edu.br/index.php/recom/article/view/743/940>
3. Soutinho LAR, Fontes DA, Carvalho YSV, Brendim MP, Marques CHD. Perfil, critérios de indicação e desfecho da inserção de gastrostomia em um hospital pediátrico universitário. *Acta Fisiátr*. 2015[cited 2018 Feb 15];22(3):123-9. Available from: <http://portaldeboaspraticas.iff.fiocruz.br/wp-content/uploads/2019/07/v22n3a04.pdf>
4. Mela CC, Zacarin CFL, Dupas G. Avaliação de famílias de crianças e adolescentes submetidos à gastrostomia. *Rev EletrônicaEnferm*. 2015[cited 2018 Jan 24];17(2):212-22. Available from: <https://revistas.ufg.br/fen/article/view/29049/19524>
5. Esteves JS, Silva LF, Conceição DS, Paiva ED. Families' concerns about the care of children with technology-dependent special health care needs. *Invest Educ Enferm*. 2015[cited 2018 Feb 15];33(3):547-55. Available from: <http://www.scielo.org.co/pdf/iee/v33n3/v33n3a19.pdf>
6. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. São Paulo: Hucitec; 2014.
7. Ministério da Saúde (BR). Conselho Nacional de Saúde. Resolução nº 466, de 12 de dezembro de 2012. Dispõe sobre diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. *Diário Oficial da União*, Brasília, 13 June 2013[cited 2018 Feb 25]. Available from: [https://bvsms.saude.gov.br/bvs/saudelegis/cns/2013/res0466\\_12\\_12\\_2012.html](https://bvsms.saude.gov.br/bvs/saudelegis/cns/2013/res0466_12_12_2012.html)
8. Reis KMN, Alves GV, Barbosa TA, Lomba GO, Braga PP. A vivência da família no cuidado domiciliar à criança com necessidades especiais de saúde. *CiêncEnferm*. 2017[cited 2018 Feb 15];23(1):45-55. Available from: <https://scielo.conicyt.cl/pdf/cienf/v23n1/0717-9553-cienf-23-01-00045.pdf>
9. Mota MA, Silveira CRM, Mello ED. Children with cerebral palsy: how can we assess and manage their nutritional. *Inter J Nutrol*. 2013[cited 2018 Feb 15];6(2):60-8. Available from: <http://docplayer.com.br/17348813-Criancas-com-paralisia-cerebral-como-podemos-avaliar-e-manejar-seus-aspectos-nutricionais.html>
10. Fontana G, Chesani FH, Menezes M. As significações dos profissionais da saúde sobre o processo de alta hospitalar. *SaúdeTransf Social*. 2017[cited 2018 May 21];8(2):86-95. Available from: <http://incubadora.periodicos.ufsc.br/index.php/saudeettransformacao/article/download/4230/4994>
11. Severo VRG, Neves ET, Jantsch LB, Zamberlan KC. Health education with families of children with special health needs: literature review. *Rev Enferm UFPE Online*. 2014[cited 2018 Apr 13];8(supl.1):2455-62. Available from: <https://periodicos.ufpe.br/revistas/revistaenfermagem/article/viewFile/9937/10238>
12. Okido ACC, Pizzignacco TMP, Furtado MCDC, Lima RAG. Technology-dependent children: the maternal care experience. *Rev Esc Enferm USP*. 2012[cited 2018 May 24];46(5):1066-73. Available from: [http://www.scielo.br/pdf/reusp/v46n5/en\\_05.pdf](http://www.scielo.br/pdf/reusp/v46n5/en_05.pdf)
13. Góes FGB, Cabral IE. Discourses on discharge care for children with special healthcare needs. *Rev Bras Enferm*. 2017[cited 2018 Apr 13];70(1):154-61. Available from: <http://www.scielo.br/pdf/reben/v70n1/0034-7167-reben-70-01-0163.pdf>
14. Lino AIA, Jesus CAC. Cuidado ao paciente com gastrostomia: uma revisão de literatura. *Rev Estima*. 2013[cited 2018 Jan 20];11(3). Available from: <https://www.revistaestima.com.br/index.php/estima/article/view/333>
15. Oliveira RG. *Blackbook-Enfermagem*. Belo Horizonte: Blackbook; 2016.
16. Sociedade Brasileira de Nutrição Parenteral e Enteral (SBNPE). *Cuidados de pacientes com gastrostomia*. Rio de Janeiro: SBNPE; 2014.
17. Kurien M, Penny H, Sanders DS. Impact of direct drug delivery via gastric access devices. *Expert Opin Drug Deliv*. 2015[cited 2018 Feb 15];12(3):455-63. Available from: <https://doi.org/10.1517/17425247.2015.966683>
18. Ramos LDC, Moraes JRMM, Silva LF, Góes FGB. Maternal care at home for children with special needs. *Invest Educ Enferm*. 2015[cited 2018 Feb 15];33(3):492-9. Available from: <http://www.scielo.org.co/pdf/iee/v33n3/v33n3a13.pdf>
19. McDonald J, McKinlay E, Keeling S, Levack W. The 'wayfinding' experience of family carers who learn to manage technical health procedures at home: a grounded theory study. *Scand J Caring Sci*. 2017[cited 2018 Feb 15];31(4):850-8. Available from: <https://onlinelibrary.wiley.com/doi/full/10.1111/scs.12406>
20. Rahnemai-Azar AA, Rahnemaiazar AA, Naghshizadian R, Kurtz A, Farkas DT. Percutaneous endoscopic gastrostomy: indications, technique, complications and management. *World J Gastroenterol*. 2014[cited 2018 Feb 15];20(24):7739-51. Available from: <https://www.wjgnet.com/1007-9327/full/v20/i24/7739.htm>
21. Congresso Nacional (BR). Lei nº 13.257, de 8 de março de 2016. Dispõe sobre as políticas públicas para a primeira infância e altera a Lei nº 8.069, de 13 de julho de 1990 (Estatuto da Criança e do Adolescente) [...] e a Lei nº 12.662, de 5 de junho de 2012. *Diário Oficial da União*, Brasília, 8 de março de 2016[cited 2018 Feb 09]. Available from: [http://www.planalto.gov.br/ccivil\\_03/\\_Ato2015-2018/2016/Lei/L13257.htm](http://www.planalto.gov.br/ccivil_03/_Ato2015-2018/2016/Lei/L13257.htm)
22. Dias BC, Arruda GO, Marcon SS. Vulnerabilidade familiar de crianças com necessidades especiais de cuidados múltiplos, complexos e contínuos. *REME - Rev Min Enferm*. 2017[cited 2018 Sept 30];21:e1027. Available from: <http://www.reme.org.br/artigo/detalhes/1163>