CHILD CAREGIVER'S EXPERIENCES WITH GASTROSTOMY
VIVÊNCIAS DE CUIDADORES DE CRIANÇAS COM GASTROSTOMIA
VIVENCIAS DE CUIDADORES DE NIÑOS CON GASTROSTOMÍA

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ABSTRACT

Objective: to understand the experience of caregivers of children with gastrostomy. **Method:** this is a qualitative, descriptive, exploratory study with 15 caregivers. The data were collected in a semi-structured interview. The content analysis was performed for the interpretation of the findings, resulting in three thematic categories: daily care of the caregivers of children with gastrostomy; challenges of caregivers in the care of the child with gastrostomy and experiences experienced by the caregivers of children with gastrostomy. **Results:** it was evidenced, through the results, that the main difficulties encountered by caregivers were fear and catheter management. Advantages after catheter use were also reported, such as the reduction of hospitalizations and the improvement of quality of life, confirming the importance of the educational and care role of the health professional, among them, the nurse, for the effectiveness of this process. **Conclusion:** it was possible, through the study, to understand the experience of these caregivers, identifying the difficulties and the paths covered to face everyday situations. **Descriptors:** Gastrostomy; Children; Caregivers; Nursing; Pediatric Nursing; Nursing Care.

RESUMO

Objetivo: compreender a vivência dos cuidadores de crianças com gastrostomia. **Método:** trata-se de um estudo qualitativo, descritivo, exploratório, com 15 cuidadoras. Coletaram-se os dados no por meio de uma entrevista semiestruturada. Realizou-se, para a interpretação dos achados, a Análise de Conteúdo, resultando em três categorias temáticas: cuidados cotidianos dos cuidadores de crianças com gastrostomia; desafios dos cuidadores no cuidado da criança com gastrostomia e experiências vivenciadas pelos cuidadores de crianças com gastrostomia. **Resultados:** evidenciou-se, pelos resultados, que as principais dificuldades encontradas pelas cuidadoras foram o medo e o manejo do cateter. Relataram-se, também, vantagens após o uso do cateter, tais como a redução das internações e a melhoria da qualidade de vida, confirmando a importância do papel educativo e assistencial do profissional de saúde, entre eles, o enfermeiro, para a efetivação desse processo. **Conclusão:** possibilitou-se, pelo estudo, compreender a vivência dessas cuidadoras, identificando as dificuldades e os caminhos percorridos para o enfrentamento das situações cotidianas. **Descritores:** Gastrostomia; Criança; Cuidadores; Enfermagem; Enfermagem Pediátrica; Cuidados de Enfermagem.

RESUMEN

Objetivo: comprender la vivencia de los cuidadores de niños con gastrostomía. **Método:** se trata de un estudio cualitativo, descriptivo, exploratorio, con 15 cuidadoras. Se recogieron los datos en el marco de una entrevista semiestructurada. Se realizó, para la interpretación de los hallazgos, el Análisis de Contenido, resultando en tres categorías temáticas: cuidados cotidianos de los cuidadores de niños con gastrostomía; desafíos de los cuidadores en el cuidado del niño con gastrostomía y experiencias vivenciadas por los cuidadores de niños con gastrostomía. **Resultados:** se evidenció, por los resultados, que las principales dificultades encontradas por las cuidadoras fueron el miedo y el manejo del catéter. Se reportaron también ventajas después del uso del catéter, tales como la reducción de las internaciones y la mejora de la calidad de vida, confirmando la importancia del papel educativo y asistencial del profesional de salud, entre ellos, el enfermero, para la efectividad de ese proceso. **Conclusión:** se possibilitó, por el estudio, comprender la vivencia de esas cuidadoras, identificando las dificultades y los caminos recorridos para el enfrentamiento de las situaciones cotidianas. **Descriptor:** Gastrostomía; Infantil; Cuidadores; Enfermería; Enfermería Pediátrica; Cuidados de Enfermería.

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INTRODUCTION

It is pointed out that with the advancement of surgical techniques, the increase in life expectancy and the incidence of chronic degenerative diseases, gastrostomy catheters are increasingly used in children unable to maintain nutrition through oral feeding.

A gastrostomy is conceptually defined as an opening, that is, the formation of a stoma that connects the stomach to the external environment by means of a stomach access catheter in the abdominal wall, to ensure a safe route of nutrition, hydration and administration of medicinal products in patients whose oral route is impossible or at risk of feeding.¹

It is emphasized that the permanence and the exchange of the gastrostomy catheter do not have a defined period in the literature, but, generally, the instrument remains in use for a long term, due to the necessity of nutritional support of the patient, being this exchange limited to the complication situations and the substitution decision based on the criteria of the surgeon and staff, such as rupture, deterioration and occlusion of the catheter.²

It is known that caring for a child with gastrostomy causes impacts on the family, revealed through family disorganization in various dimensions of living, including emotional, social, financial and daily activities, that is, those that are related to the instrumental aspect of family functioning.³

In this context, caregivers are required to adapt to the new condition of life, since family members need to be instrumental in dealing with this diverse and challenging universe in order to visualize in the procedure the advantages offered by the catheter.

In this perspective, the caregivers of children with gastrostomy seek the knowledge, support and safety transmitted by professionals in the health service, in order to form a consistent link between the service and the patient. Thus, professionals working with this population should provide information related to the procedure and other care that involves changes in the new health condition, providing a collaborative and respectful assistance and considering the context in which each family is inserted. It is also understood that understanding the experiences of these caregivers may contribute to the targeting of care to be given to these children and families, therefore, this study aimed to understand the experience of caregivers of children with gastrostomy.

OBJETIVO

- Understanding the experience of caregivers of children with gastrostomy.

METHOD

This is a descriptive, exploratory, qualitative study that allows the investigation of focus groups, social experiences from the participants' point of view, and which, in addition to having a theoretical basis, allows the deepening of social issues related to small groups knowledge, offering a subsidy for the construction of new approaches, concepts and hypotheses during research.⁴ The research was carried out in a public hospital of the State Department of Health of Ceará, Brazil, for tertiary care, specialized in the clinical-surgical and outpatient care of pediatric patients.

As participants of the study, caregivers of children with gastrostomy who attended the following inclusion criteria were selected: being the main caregiver of the child and having a record of medical records in the institution. The caregivers who attended the outpatient clinic with their children were excluded for the definitive withdrawal of the catheter, due to medical discharge.

The study was carried out with 15 caregivers, during the care of the children with gastrostomy, performed in the Nursing clinic, from June to July, 2016. Data was obtained for using an interview with a semi-structured script, consisting of the identification data of the participants and the following guiding question: "Could you tell us how you have been experiencing the care of the child with gastrostomy?".

The interview was conducted individually, explaining the purpose of the study; after accepting to participate in the research, the respondents signed the Free and Informed Consent Term (FICT). The interviews were recorded, which lasted approximately ten minutes and were later transcribed, constituting the corpus of the research.

The analysis was systematized according to the Thematic Content Analysis technique. Three steps are proposed for the operationalization of this method: pre-analysis; exploitation of the material and treatment of results; inference and interpretation.⁵ Thus, three categories of the daily information of the caregivers of children with gastrostomy were constituted from the corpus of information collected from the interviews; challenges of caregivers in the care of the child with gastrostomy and

experiences experienced by caregivers of children with gastrostomy.

The research was approved by the Research Ethics Committee (REC) under number 1,580,334, in accordance with Resolution 466/12, which deals with human research.⁶

RESULTS

The study participants were all female, with a mean age of 35.5 ± 7.4 years, with a minimum of 22 years and a maximum of 49 years, being the motherhood the degree of kinship with the patient care in all cases. It was observed that the majority of caregivers resided in the city of Fortaleza (8; 53.2%); followed by Maranguape (2; 13.3%) and Trairi, Pentecoste, Crateús, Itapipoca and Fortim, with a resident (6.7%) in each.

It was recorded, as far as the schooling of the participants, that six (40%) had complete Elementary School; five (33.4%) had incomplete Elementary School; two (13.3%), complete secondary education and two (13.3%), incomplete higher education. It was pointed out, in relation to professional performance, that 12 (80%) were housewives; two (13.3%) were domestic and one (6.7%) was a farmer. It was added that nine (60%) caregivers reported having assistance for the care of the patient, being provided by their husbands (3; 33.3%), daughters (3; 33.3%), maternal grandparents (2; 22.2%) and a cousin (1; 11.2%).

It was verified that, when asked about the orientation of gastrostomy care before surgery, eight respondents (53.5%) reported having received guidelines, most of which were performed by the nurse (5, 62.5%); the medical professionals and nutritionists were cited by three (37.5%) and one (12.5%) participants, respectively. From the speeches of the participants, the following categories were listed.

♦ Daily care of caregivers of children with gastrostomy

In this category, the care provided by the caregivers in their homes is highlighted, highlighting their doubts, anguish and difficulties in handling and maintaining the catheter. Among the main difficulties mentioned, care was taken to feed the children with gastrostomy as the greatest challenge, since the caregivers need numerous knowledge and practices that were not part of their routine. It was also evidenced the need for a continuous follow-up able to solve the doubts found by the family, as is observed.

In relation to food, which usually leaks and because it is a very large child, it moves a lot, becomes loose and it happens this

leakage of the stomach fluid, which burns the skin and becomes unbearable. (C6)

The food, she is being accompanied by the nutritionist, but I'm starting to get scared because she will be six months old and will start to eat other types of food. (C9)

I was only taught to give milk, and then only put water. Only, whenever I put water in, the milk would come back and I did not know that he had to be relaxed so that the milk would not come back and everything went right. (C1)

The management of the catheter in the cleaning of the equipment and of the peristomal skin was also evidenced in the interviews. In this context, the lack of knowledge and insecurity of the caregivers regarding the indispensable care in the preservation of the catheter were revealed. It was pointed out, therefore, the precariousness in the guidelines offered to the caregivers when the patient is discharged, evidencing that the health professional, acting in the care of these patients, should develop the sensitivity to conduct such guidelines, according to the demand of the patients. caregivers, in order to flexibilize professional relations, favoring the exchange of knowledge for the improvement of the life of being cared for.

When he got home, my biggest difficulty was just to put the protection on so he could not rip the probe and clean it, which I did not know. I was only taught to give milk, and then only put water. (C1)

The care and cleanliness I do. When it's red, I bring it here [hospital]. (C3)

The difficulty of doing the cleaning is, mainly, because it moves much, mainly, when she is without clothes. (C13)

♦ Challenges of carers in the care of the child with gastrostomy

The importance of family preparation in the care and management of the catheter, especially in the preoperative period, was shown in this category. It was observed that, although there was a history of hospital stay with repeated hospitalizations and practices in the care of their children, nonetheless, the caregivers reported negative emotional reactions, with emphasis on the fear of caring for the child with gastrostomy. It was also observed that the children received the indication of gastrostomy when they already had clinical complications, such as repetitive pneumonia or malnutrition. It is emphasized that, prior to the surgery, all the children used the nasointestinal catheter for long periods of months or even years.

The first time he started, I was desperate. I thought the boy was going to die [laughs] ... there, he had not blown the balloon and the whole probe came, and I was desperate because I saw that ball inside and I did not

know it was that way [laughs] . (C1)
My biggest difficulty was when the probe came out, I get scared, because with that hole you have, I get scared, because there comes blood mixed with food, when your stomach is full. (C15)

Reports were found, although feelings of fear were present in all the interviewees' speeches, to improve children's quality of life, as verified.

Do you think this probe was the best? Better than the other of the nose [nasointestinal tube] because, of the nose, it was only suffering. She used it for almost three years, she started it, right, and when it was time to put it on, the poor little girl came in change of color, until she gained weight, the other one did not gain weight. (C8)

◆ Experiences lived by child caregivers with gastrostomy

It is observed in this category that, in addition to physical changes after surgery, the challenges faced by caregivers occurred in the periods before and after the surgical procedure. Anxiety related to the artificial introduction of gastrostomy feeding methods was demonstrated, with a strong maternal instinct for oral feeding. Some of these experiences were identified in the interviewees' statements.

Who can say that you feel happy with a child with the probe? No mother, right? If God made the little mouth is to feed by that organ that God put, but, unfortunately, it is so. (C6)

By the time he was hospitalized, the nurses only taught me how to give milk ... there, over time, I learned. His probe was able to clean and disassemble and I did not know [...] there, I was learning everything by myself, trying to learn [...] there, when one day the probe came out and I saw a ball inside and I was desperate . Oh, my God, I killed the boy. And today, I've learned the basics, but it's calmer. (C1)

There were moments of uncertainty in the performance of gastrostomy due to the initial idea that the child could have problems related to the surgery and could cause serious damage to his health, including death; however, these reactions were gradually replaced by a different way of looking at the facts marked by the confidence, courage and will to learn, as observed.

My fear was when I left, and I had to open the girl again, I was scared to death, those things. So [...] I was not alerted at all, right, but, thank God, it's being normalized and I'm learning from day to day. (C11)

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day the probe came out and I saw a ball inside and I was desperate. Oh, my God, I killed the boy. And today, I've learned the basics, but it's calmer. (C1)

DISCUSSION

It is pointed out that caring for children who need differentiated attention is a constant challenge for families, particularly mothers, who are the main actors in child care. Thus, the mother becomes the most involved in this role, since, more broadly, she carries the greater responsibility in the emotional, physical and financial spheres.⁷

It is assessed, as observed in the speeches of the study participants, that there is still much fear and difficulties to be faced with regard to home care. It is emphasized, even though, during the hospitalization time of the child, gastrostomy care has been performed, that the fear of not performing them correctly still occurs.

It is known that the child with gastrostomy requires, from their caregivers, the responsibility for the performance of highly technical procedures that, formally, should be performed only by qualified professionals; these procedures include preparation and administration of medication, enteral feeding, and peristomal skin hygiene.⁸ Thus, the way in which each family faces the new condition is related to their beliefs and care is constructed in a process that varies according to socio-cultural experiences and experiences.⁹

It is noticed that the actions of care with the child are performed with recurrence, becoming a habit, and they receive the tone of ease and normality of the caregiver; however, knowledge is constructed based on the experiences of direct care of the child, which incorporates it into the social space of the family. It is argued that, over time, the caregiver's experience overcomes attempts at correctness and automation, because they learn over time, very automatically, without the establishment of a plan.¹⁰

It is argued that the family and those involved in care need time to assimilate this new way of caring for the maintenance of the child's life. It is described, therefore, that the passage of the time and the daily reproduction of the procedures make that they acquire more confidence and security.¹¹

Despite the difficulties encountered by mothers after the insertion of gastrostomy in their children, the report of the improvement of the child's condition was reported. It is observed in other studies, reinforcing this finding that gastrostomy feeding provides a significant weight gain, reduces feeding time and improves the quality of life of caregivers;

¹² however, the caregivers' decision regarding the insertion of a gastrostomy catheter can be difficult, in order to assess whether the benefits outweigh the risks of performing the surgical procedure.

The catheter also facilitates the administration of medications and stabilizes the nutritional demand and pulmonary function, as well as the preservation of the digestive hormonal responses and the administration of a larger volume of food formula.¹³ It is pointed out the ponderal evolution, mainly, in the first six months after its placement, as a positive point that confers utility to this catheter and suggests that it should be used early.¹⁴

However, the mother's suffering was evidenced when her child can not be fed by the oral route, a fact that can also be observed in other studies,¹⁵ in which oral feeding is seen by the family as normal, pleasant and an important social process and formation of affective bond. Gastrostomy is therefore characterized as a sign of deficiency, with deprivation of the desire to feed and an interruption of affective bonds that occur in the interaction between mother and child during feeding.¹⁶

It is verified, when it comes to the relationship of this family with the professional, before the hospital discharge, that the caregivers feel helpless. It is emphasized that guidelines for hospital discharge should not constitute a one-way moment, in which the professional provides the information and the family/caregiver only consents, but an opportunity for the exchange of knowledge, since the caregiver has also become knowledge of the activities performed with the child during hospitalization.

It is identified that the family caregivers of these children expect a relationship with the healthcare professional based on negotiation and mutual trust, since this alliance, established between family and professional, helps the family in the new and complex care required by a child in need health at home.¹⁰ It is suggested, therefore, that it is up to all the professionals involved, and in particular the nurse, to set goals so that this child and his family are accompanied and adequately assisted. It is necessary to train the caregivers, since the care will be part of their routine care of the child at home.

It is known that, originally, the practice of care may be related to any person who helps another to ensure the maintenance of his life, and not to a trade or profession, however, there are situations in which individuals need professional care for the maintenance of life.

In this way, when referring to children with chronic health conditions, such as gastrostomized patients, the information and guidelines must be carried out by qualified professionals, including nurses. However, it is pointed out in the scientific literature that there are inconsistencies between the guidelines made by the health team and the demands of the families, since they present difficulties to understand the language used by the professionals in the preparation for home care.¹¹

It was also pointed out the support of a network of care by caregivers, highlighting the importance that health professionals have for people's lives. It is believed that mothers find this link necessary, in order to obtain trust, because a professional is available who will give support at any time.⁷ It is therefore emphasized that the social support network to which they have access and the sharing of information, experiences and experiences in social interactions and with health professionals in a dialogical relationship can contribute to the exchange and sharing of experiences of care with the other members of their social support network.

CONCLUSION

It was noticed, through the understanding of the experiences of the caregivers, that they presented difficulties in the manipulation of the catheter, although it was part of their daily life. Between the main difficulties, the peristomal skin care and feeding are listed. It was verified that the caregivers feel fear of the unknown and, as a result, they have resistance to the acceptance of the surgical procedure, however, after the surgery, advantages such as weight gain and reduction of hospitalizations.

As a limitation of the study, the scarcity of literature related to the care of patients with gastrostomy is considered, especially in Pediatrics, since research has shown that there is a greater concern regarding the description of the surgical technique. It is hoped, therefore, that this topic will arouse interest in the area, instigating the carrying out of research regarding the care directed to the child with gastrostomy.

REFERENCES

1. Forest-Lalande L. *Gastrostomias para nutrição enteral*. Campinas: Editora Lince; 2011
2. Conselho Federal de Enfermagem. Parecer nº 06/2013/COFEN/CTAS. Emite Parecer sobre o exercício legal e competência do

profissional enfermeiro referente a troca da sonda de gastrostomia e jejunostomia [Internet]. Brasília: COFEN; 2013 [cited 2018 June 13]. Available from:

http://www.cofen.gov.br/parecer-no-062013cofentas-2_28109.html

3. Rodrigues LN, Borges AFB, Chaves EMC. Experienced feelings by mothers of gastrostomized children. *Rev Enfermagem Atual* [Internet]. 2017 [cited 2018 June 15];83(1):24-9. Available from:

<https://docplayer.com.br/68975179-Sentimentos-vivenciados-por-maes-de-criancas-com-gastrostomia.html>

4. Minayo MC. O desafio do conhecimento: pesquisa qualitativa em saúde. 10th ed. São Paulo: Hucitec; 2010.

5. Bardin L. Análise de conteúdo. 7th. ed. Lisboa: Edições 70; 2011.

6. Ministério da Saúde (BR), Conselho Nacional de Saúde. Resolução nº 466 de 12 de dezembro de 2012. Aprova as diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos [Internet]. Brasília: Ministério da Saúde; 2012 [cited 2018 Jan 12]. Available from:

http://bvsms.saude.gov.br/bvs/saudelegis/cns/2013/res0466_12_12_2012.html.

7. Assis FAG, Pinto MB, Santos NCCB, Torquato IMB, Pimenta EAG. Family child with special needs of health: the process of coping and adaptation. *Ciênc Cuid Saúde*. 2013 Oct/Dec ;4(12):763-43. Doi:

<http://dx.doi.org/10.4025/ciencucuidsaude.v12i4.18826>

8. Okido ACC, Hayashida M, Lima RAG. Profile of technology-dependent children in Ribeirão Preto-SP. *J Human Growth Develop* [Internet]. 2012 Mar [cited 2018 June 15];22(3):291-6. Available from:

http://pepsic.bvsalud.org/pdf/rbcdh/v22n3/p_t_03.pdf

9. Zacarin CFL, Alvarenga WA, Souza ROD, Borges DCS, Dupas G. Vulnerability of families with children with intestinal stomas. *Rev eletrônica enferm*. 2014 Apr/June;16(2):426-33. Doi:

<http://dx.doi.org/10.5216/ree.v16i2.26639>.

10. Pinto JMS. Cuidados habituais modificados no cotidiano dos cuidadores de crianças com necessidades especiais de saúde: interfaces com o saber de enfermagem [dissertation] [Internet]. Rio de Janeiro: Universidade Federal do Rio de Janeiro; 2013 [Internet]. Available from:

<http://objdig.ufrj.br/51/dissert/799729.pdf>

11. 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 Sept/Dec;33(3):235-43. Doi:

<http://dx.doi.org/10.17533/udea.iee.v33n3a19>

12. Susin FP, Bortolini V, Sukiennik R, Mancopes R, Barbosa SDRP. Profile of patients with cerebral palsy using gastrostomy and effects on caregivers. *Rev CEFAC*. 2013 Sept/Oct;14(5):933-42. Doi:

<http://dx.doi.org/10.1590/S1516-18462012005000016>

13. Parada KLD. Gastrostomía en la nutrición enteral domiciliaria. *Rev Gastrohup*. [Internet]. 2012 [cited 2018 June 15];14(2):77-82. Available from:

<http://revgastrohup.univalle.edu.co/a12v14n2/a12v14n2art8.pdf>

14. Carido J, Santos C, Ferreira MG, Fonseca J. Enteric nutrition through percutaneous endoscopic gastrostomy in pediatric patients - retrospective evaluation in 40 consecutive patients. *J Port Gastrenterol*. 2011 Nov;18(1):273-8. Doi:

<http://www.scielo.mec.pt/pdf/ge/v18n6/v18n6a03.pdf>

15. Cruz AC, Angelo M, Gamboa SG. The views of the family about the experience of having a child with gastrostomy. *Rev Enferm Referência*. 2012 Dec;3(8):147-53. Doi:

<http://dx.doi.org/10.12707/RIII1216>

16. Mela CC, Zacarin CF, Dupas G. Family evaluation of children and adolescents submitted to gastrostomy. *Rev eletrônica enferm*. 2015 Apr/June;17(2):212-22. Doi:

<http://dx.doi.org/10.5216/ree.v17i2.29049>.

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