ORIGINAL ARTICLE

REVISTA ENFERMAGEM ATUAL IN DERME

DIFFICULTIES IN CARE OF CHILDREN WITH INTESTINAL OSTOMY FROM THE PERSPECTIVE OF FAMILY CARERS

DIFICULTADES EN EL CUIDADO DEL NIÑO CON ESTOMÍA INTESTINAL DESDE LA PERSPECTIVA DE LOS CUIDADORES FAMILIARES

DIFICULDADES VIVENCIADAS PELOS FAMILIARES CUIDADORES DE CRIANÇAS COM ESTOMIA INTESTINAL

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ABSTRACT

Introduction: Intestinal ostomies are the result of a surgical procedure in which part of the small or large intestine is brought out through the abdomen. In children, they are generally performed to correct congenital anomalies. As a result, families are faced with the need to understand the associated pathology, the surgery itself, and its specific care requirements. **Objective:** To analyze the difficulties experienced by family members regarding the guidance received from stoma therapists on caring for their child's intestinal stoma. **Methodology:** Qualitative descriptive and exploratory research, conducted through semi-structured interviews in the homes of nine mothers of children with stomas, whose data were submitted to Bardin's content analysis. **Results and Discussion:** After analyzing the data, we found fear of the unknown, bleeding of the intestinal mucosa, difficulties in handling, cutting, and cleaning the bag, and a lack of or conflicting guidance on care. **Conclusion:** In the context of hospitalization, family caregivers did not receive effective guidance from the health team on how to care for their child's ostomy, thus experiencing difficult moments, leading to feelings of fear, despair, concern, and helplessness, aggravated by the lack of psychosocial support.

Keywords: Ostomy; Child; Nursing Care; Family.

RESUMEN

Introducción: Las ostomías intestinales son el resultado de una intervención quirúrgica en la que se exterioriza parte del intestino delgado o grueso en el abdomen y, en los niños, suelen tener como objetivo corregir anomalías congénitas. De este modo, la familia se enfrenta a la necesidad de comprender la patología asociada, la propia cirugía y sus cuidados específicos. **Objetivo:** analizar las dificultades experimentadas por los familiares en relación con las orientaciones recibidas por los enfermeros estomaterapeutas sobre el cuidado del estoma intestinal de su hijo. Metodología: Investigación cualitativa de tipo descriptivo y exploratorio, realizada mediante entrevistas semiestructuradas en el domicilio de nueve madres de niños con ostomías, cuyos datos se sometieron al análisis de contenido de Bardin. **Resultados y discusión:** tras el análisis de los datos, se constató miedo a lo desconocido, sangrado de la mucosa intestinal, dificultades en el manejo, recorte e higiene de la bolsa, ausencia y divergencias en las orientaciones sobre los cuidados. **Conclusión:** En el contexto de la hospitalización, los familiares cuidadores no recibieron de manera eficaz las orientaciones adecuadas del equipo de salud para cuidar la ostomía de su hijo, por lo que vivieron momentos difíciles, lo que les provocó sentimientos de miedo, desesperación, preocupación e impotencia, agravados por la falta de apoyo psicosocial.

Palabras clave: Ostomía; Niño; Cuidado de Enfermera; Familia.

RESUMO

Introdução: Estomias intestinais são o resultado de um procedimento cirúrgico onde parte do intestino delgado ou grosso é exteriorizado no abdome, e, em crianças, objetivam, geralmente, corrigir anomalias congênitas. Dessa forma, a família se depara com a necessidade de compreender a patologia associada, a prórpia cirurgia e seus cuidados específicos. **Objetivo:** analisar as dificuldades vivenciadas pelos familiares acerca das orientações recebidas pelos enfermeiros estomaterapeutas sobre o cuidado com o estoma intestinal de sua criança. **Metodologia:** Pesquisa qualitativa do tipo descritiva e exploratória, realizada por entrevista semi-estruturada no domicílio de nove mães de crianças com estomias, cujos dados foram submetidos à análise de conteúdo de Bardin**.** **Resultados e Discussão**: após análise dos dados constatou-se medo do desconhecido, sangramento da mucosa intestinal, dificuldades no manejo, recorte e higiene da bolsa, ausência e divergências de orientações sobre os cuidados. **Conclusão:** No contexto da hospitalização, os familiares cuidadores, nao receberam de forma eficaz as devidas orientações da equipe de saúde para cuidar da estomia de sua criança, dessa forma, vivenciaram momentos difíceis, levando a sentimentos de medo, desespero, preocupação e impotência, agravadas pela falta do apoio psicossocial.

Palavras-chave: Estomia; Criança; Cuidados de Enfermagem; Família.

INTRODUCTION

An intestinal ostomy is a surgical procedure in which the small or large intestine is diverted to the abdominal surface. These ostomies are intended to divert fecal contents, mainly due to obstruction, trauma, or acute pathology, and, depending on the intestinal portion involved, may have different names, such as ileostomy in the case of the ileum, the final portion of the small intestine, and colostomy in the case of the colon (1).

Enterostomies can be temporary, when they aim to protect intestinal anastomoses until they heal, to rest a specific intestinal segment that has an inflammatory process or fistula, or even in cases of intestinal obstruction for various reasons. Permanent enterostomies are performed when it is not possible to restore intestinal transit due to the loss of a large part of the affected area, usually in cases of rectal cancer near the anal margin (2).

In this sense, intestinal ostomies can evolve with early complications (necrosis, retraction, hemorrhages, and infections) and late complications (prolapse, stenosis, and parastomal hernia). Peristomal chemical dermatitis, resulting from direct skin contact with enteric effluent, can also be a breeding ground for fungal or bacterial infections (1,2).

When present in children, intestinal ostomies are usually temporary, related to the cause of the ostomy, and have particularities related to the child's developmental stage, requiring health professionals, especially nurses, to consider these characteristics (3-4).

It is worth mentioning that, in 1940, the mortality rate associated with colostomies in children was approximately 90%, and currently it is less than 1%. However, the number of people with ostomies in Brazil is still poorly known, and when it comes to the child population, the data is even more obscure (5).

According to the World Health Organization, the prevalence of ostomies may reach 0.1% of the world population, and in Brazil, more than 100,000 adults and children live with an ostomy. Brazilian studies on the pediatric population indicate a higher prevalence of males with neurological diseases (6).

Nursing care for people with enterostomies, whether adults or children, is a challenge for nurses, who are one of the main members of the multidisciplinary team, providing technical care, psycho-emotional support, and personalized guidance to cover the entire process involved in ostomy (4).

Regularly, information about the need for intestinal ostomy is met with resistance by the family. In this sense, the healthcare team, being responsible for the first contact with the family, must be trained and provide the necessary support to face this situation. It is worth noting that the family needs to develop new skills that were not part of their routine, such as handling the technological device (7-8).

In this context, the literature points to numerous difficulties experienced by family caregivers, which include information about the pathology, the need for the surgical procedure itself, the care required in the postoperative period, and the process of social (re)integration when the child returns to their social environment (1).

Specific stoma care must be taught to the family caregiver so that it can be successfully performed at home. Such care involves procedures for organizing the collection equipment and replacement material, removal, measurement of the cutout, and application of the collection bag, peristomal skin and stoma hygiene, in addition to specific care with the collection equipment (9).

In view of the foregoing, the lack of records on pediatric ostomy data and the scarcity of literature on this topic highlight the relevance of this study, considering its impact on the quality of life of children and their families, as well as the contributions and care required by these family members in the daily lives of their children with intestinal ostomies at home.

METHODOLOGY

This is a qualitative, descriptive, and exploratory study, which was conducted as part of a master's thesis entitled "Guidelines for stoma therapists for the care of children's intestinal stomas at home: from the perspective of family caregivers," which emphasized the difficulties listed by family members in dealing with intestinal ostomies in their children (10).

The development of this study is guided by the COREQ (Consolidated Criteria for Reporting Qualitative Research), which provides parameters for the planning, execution, and elaboration of the qualitative research (11).

Participants were recruited through a database of a private company, which, in addition to manufacturing collection and adjuvant equipment, develops a free program to provide guidance on such materials and ostomy care by a stoma therapist nurse. This nurse works in hospitals, clinics, or homes, registering patients on a specific platform that contains sociodemographic and clinical data.

In this manner, the inclusion criteria were defined as follows: children aged 0 to 24 months who underwent colostomies or ileostomies and who reside in the municipality or metropolitan region of Rio de Janeiro. In addition, the exclusion criteria were as follows: children whose family members did not provide direct care after hospital discharge, having access to homecare services or private health professionals.

It should be noted that these family members were contacted by telephone, presented with the research proposal, and asked about their interest and availability to voluntarily participate in the study. For those who accepted the invitation, a date and time were scheduled for a semi-structured interview at their home. The sample size consisted of a preselection of 21 children, but 12 of them did not participate in the study for the following reasons: two had urinary stomas and did not use collection equipment; three did not agree to participate in the research (one due to embarrassment and the other two did not want to comment on the reasons); four lived outside the metropolitan region of Rio de Janeiro, and three lived in a risk area.

Nine family caregivers participated in the study, and data collection took place at home from June to November 2019 through semi-structured interviews, covering sociodemographic characteristics, clinical data on the child, and the following guiding questions: “What care guidelines were provided by the stoma therapist nurse regarding stoma care?”; “Did you consider the guidelines for caring for your child’s stoma important? Why?”; “How did these guidelines help in the daily care of your child’s stoma?”; “Did you have any difficulty putting these guidelines into practice at home?”. Other questions were added in order to deepen the responses received

The interviews with family caregivers were audio recorded using a mobile app and each lasted an average of 45 minutes. They were then transcribed in full so that content analysis could be performed based on Bardin's literature, which consists of breaking down the text into Units of Records (UR), following analogical regroupings. These operations aim to discover the core meanings or themes that make up a communication, focusing on the frequency with which these cores appear, in the form of segmentable and comparable data, rather than on their dynamics and organization, in order to subsequently grasp the categories (12).

The research was approved by the Research Ethics Committee (CEP) of the State University of Rio de Janeiro under Opinion No. 3,304,621. Based on ethical principles, the primary caregiver family member was informed about the research and consulted about their interest in participating on a voluntary basis, and the Free and Informed Consent Form (FICF) was presented, in accordance with the criteria of the guidelines and regulatory standards involving human beings, Resolution 466/2012 of the National Health Council. To ensure anonymity, family members were identified in the study by acronyms referring to their child's favorite toy or drawing.

RESULTS AND DISCUSSION

All nine participants in the study were mothers of children with enterostomies, who were their primary caregivers, which coincides with the literature, where caregiving is culturally linked to the mother figure (13). The mothers' ages ranged from 22 to 30 years. Regarding education, the following information was obtained: Seven mothers had completed high school; one mother had incomplete higher education, and one mother had a postgraduate degree.

It is worth noting that only three mothers were in paid employment at the time of the interview, while the others were exclusively caring for their children and attending to household demands.

Among the surgical procedures, seven were colostomies and two were ileostomies, which were performed for the following reasons: three for congenital malformation of the megacolon type; one for necrotizing enterocolitis; and five for imperforate anus.

Accordingly, for a clearer presentation of the results related to the various difficulties faced by mothers in their new life situation, as well as in caring for their children, two categories were constructed: a) Fear of the unknown and the repercussions of intestinal ostomy and b) The absence/divergence of guidance in the hospital setting.

Category 1 - Fear of the unknown and the repercussions of intestinal ostomy

In an initial analysis, this category sought to describe the multiple feelings experienced in the face of the new situation. The mothers' statements discuss the lack of guidance on the possibility of bleeding during cleaning of the stoma mucosa, generating feelings of despair, fear, and doubt, as reflected in the following statements:

> *They didn't explain the blood part to me. [...] Sometimes, a little blood comes out and we get a little desperate, you know, but with the information they gave me, we now know more or less how to control the situation, you know why it is, how it happens, why it happens (Spider-Man's mother).*

> *And also, what scared me the most was, nowadays it's normal, but in the beginning, was that I would clean [the stoma] and it would start bleeding around the edges, wow, that was absurd to me! I thought something was wrong, I wanted to take him back to the doctor and stuff... then I realized [...] I didn't have this information [...] That it could bleed and that it would go back to normal. (Bear's mother).*

In this context, as this is a fundamental care issue that concerns the intestinal anatomy exposed through the stoma, it is extremely important to ensure that family caregivers are aware of the possible clinical findings that may occur when caring for an intestinal stoma so that they can feel more confident and at ease.

In addition to providing guidance on identifying bleeding caused by ostomy cleaning, nurses should advise caregivers to seek care at a hospital or referral center for the child when the bleeding is abnormal (14).

It is essential to observe the color of the stoma, as well as its functioning and the child's general appearance. In addition, it is necessary to use transparent collection equipment to optimize visualization of the stoma (2,14-15).

Therefore, we reiterate the need to prepare those responsible for the care of children with intestinal ostomies, both for the proper care of the ostomy and peristomal skin, and for the prevention of complications. Considering that some of these complications may develop later, often weeks or months after surgery, contact with a healthcare professional or referral service should also be part of the comprehensive care received by these family members (16).

Faced with the necessity to handle their child's intestinal stoma, feelings of fear and concern arise, feelings that are inherent, especially when caring for their child for the first time, as reported by Neném's mother below.

> *I had [difficulty] because I was afraid. So I used that thing [tongue depressor] and was terrified to touch it [the stoma and hurt it [...] I think the first month was the hardest because I had to be so careful and I was*

> *afraid. He would cry, and I would think something was wrong, then the bag would come off, and I would say, "Oh my God!" Then I would think, "Is this normal?" But, as I said, after the first month, everything was fine (baby's mother).*

It is worth noting that these difficulties can be mitigated if mothers have the opportunity to perform the procedures under the supervision of the nursing team while their child is still hospitalized, which is essential for the dehospitalization process. Thus, in the face of doubts and difficulties, which are individual and particular, there is a need for dialogue and adaptations in teaching and learning to incorporate new concepts in a non-verticalized manner by the nurse (16-17).

Furthermore, the mothers of Frozen, Bear, and Butterfly also describe difficulties related to the adhesive base in terms of adhesiveness, removal, and cutting, as follows:

> *So, what started to cause us problems? Because her bag kept coming loose, I don't know if it was because of the urine [vesicostomy near the colostomy] [...] I think it was because the feces were getting underneath [seeping in], making it damp [the adhesive base] and causing it to come loose (Frozen's mother).*
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> *At first, I think it was normal for everyone, because cutting it is very difficult, I think it should have come pre-cut [...] it didn' [t...] Cutting it was very difficult, because one day I would cut it too big, another day it would be too small, and the boy would cry, and then, sometimes, there was no one to help me, so I had to hold the child because children move around a lot (Bear's mother).*
>
> *Then there was the issue of feces seeping in, because I didn't have the necessary skill to cut the circle so that it fit perfectly over the stoma. So there was always a little gap, and feces would seep in there and end up hurting her skin (Butterfly 's mother).*

Based on the above excerpt, mothers describe the difficulty in cutting the adhesive base, both in relation to the lack of support during the procedure and in relation to their own individual ability to perform the cut. Given this, there is a clear need to work on the teaching-learning process, and the healthcare team, especially nurses, must respect each stage of adaptation gradually, as parents need to feel confident in performing the procedures (15-17).

From this perspective, there is an urgent need for training in new skills related to the care of the child's intestinal stoma while still in the hospital environment, since, in addition to the general care required by this age group, the care of the intestinal stoma raises numerous questions and difficulties. The procedure of cutting the adhesive base is characterized as a manual and technical task, which must respect the size and shape of each intestinal stoma. In this sense, the adjustment of the adhesive base aims to promote adequate sealing to prevent effluent infiltration and the onset of chemical dermatitis (18-19).

In addition, it should be emphasized that promoting maternal tranquility and security in caring for their children should be achieved during the child's hospitalization, when guidance is provided and questions are answered, since the mother's early participation in caring for her child translates into skills for this purpose, reducing her anxiety in the process of discharge (13,16,18).

Regarding the internal hygiene of the collection bag, where feces are collected and stored before emptying, mothers reported that they did not receive clear guidance on how to perform this procedure, leading them to adapt the cleaning technique according to their reality.

> *I think we used to clean it with cotton wool or wash it directly under the tap... I know we used to make good use of the bag, wash the bag (Baby's mother).*
>
> *My advice is different now, much milder, which is just to wash [the two-piece bag] with soap. That's what we do now. (butterfly's mother).*
>
> *And cleaning it is also very difficult; even today, I find it very difficult to clean! If I have to clean it... nowadays I take it to the bathroom... How am I going to clean the bag that's there on a child? (Bear's mother)*

In the above reports, it is evident that some mothers, despite having received guidance on the internal hygiene of the collection bag from the health professionals, had to adjust at home to perform this care on their children.

Although there is no standardization in the literature regarding the care of the plastic collection bag, not receiving any type of guidance hinders the dehospitalization process, as it is basic care for the collection equipment, helping to prolong its durability by preserving the synthetic resin from wear and tear. In addition, it contributes to the promotion of physical and psychological comfort, not only for the child but also for the family.

Thus, the bag should be emptied when it reaches 1/3 of its capacity, which is usually much more frequent in babies, as they not only evacuate more frequently, but the bag is also smaller than the adult one. This prevents excessive and prolonged weight of the collection equipment on the child's skin, which can promote early detachment. If the frequency of emptying is too high, the use of adult collection equipment may be considered (15,20-21).

The assessment of learning by family members requires attention from health professionals, considering that intervention actions are based on situational diagnosis. The identification of flaws in the conduct of the dehospitalization process allows for its early readjustment and should be acquired through observation (13,18).

In addition to the difficulty with the two-piece collection equipment, Butterfly's mother discusses the difficulty of providing care due to her daughter's behavioral characteristics.

> *Today, I can no longer change her on my own. I need her father to hold her legs because she always puts herself in a defensive position. Sometimes, even in this defensive position, she hurts her stoma a little, but then, when it's time to put the bag on, I sprinkle the powder on top and the next day there's nothing left. [...] Today I have [difficulty] because she won't stay still, not because I don't know what to do. I know exactly what to do, but she won't let me anymore! [...] I had problems later, as I said, when she started crawling and climbing things, because it was a matter of her development (Butterfly's mother).*

The literature shows that a baby's restlessness and incessant movements can hinder the adaptation of the collection equipment and cause trauma to the stoma. Therefore, a one-piece system is recommended, as it has a more malleable resin and more easily accommodates the peristomal skin (2,13). Thus, continuous health education is necessary, considering the dynamics involved in the process of caring for the child's intestinal stoma during all stages of the child's development, which involve different activities, body structure, diet, and the use or non-use of medications.

Category 2 - Absence and/or discrepancies in guidance in the hospital setting

In this category, some family members reported that they did not receive any guidance in the hospital setting on how to care for their child with an ostomy, while others pointed out discrepancies in this guidance among professionals.

> *There is zero information at the hospital! The first time I changed it in the presence of a stoma therapist, the first time I did it right was with stoma therapist M., because I was doing it, but I was doing it the way they taught me at the hospital. I only knew that there was a stoma therapist nurse through this mother, not through the nurses at the hospital. [...] If we go to the emergency room, there is no one prepared to guide you on this. I received all kinds of wrong guidance at the hospital (Butterfly's mother).*
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> *At the hospital, there was a big difference in the guidance. It was totally different at first. They cut the bag in a circle and don't make the little balls. In this case, his stoma has two openings. They are not careful at all. They take the bag off and put it on. If it is dirty with feces, they leave it, because they say that it is already a contaminated place, so there is no need to keep cleaning it, only when bathing. The treatment is totally different (Bita's mother).*

Therefore, it can be seen from the excerpts from the mothers' reports above that there is a lack of guidance or standardization regarding the care of the child's intestinal stoma received by family caregivers, as well as discrepancies in this guidance.

Moreover, due to the creation of the ostomy, both the family and the child undergo a long adaptation process. Therefore, family support is needed as a coping mechanism for the difficulties encountered in daily life, and training with the nurse for the care of the child's stoma should be carried out progressively, so that the mother and/or family member are able to perform them until hospital discharge (13-15).

It should be noted that, among the guidelines to be provided, it is of utmost importance to provide guidance on hygiene and observation of the collection equipment, seeking to choose the one that best fits the body contour of the abdomen and paying attention to the correct cut of the adhesive base, so that there is no accumulation of effluents between the adhesive base and the skin, infiltration of these effluents, and chemical dermatitis with early and unpredictable detachment of the collection equipment (13).

In line with the findings of this study, another study pointed out that most parents caring for children with intestinal ostomies did not receive guidance on caring for their child's ostomy (18). Therefore, conducting the guidance process, it can minimize the family's anxieties, and caring for the child with an ostomy, healthcare professionals must have technical and humanized training, which is an essential requirement for building a relationship of trust with families (23).

Considering that family caregivers, mostly mothers, are the first to identify changes in their children's health patterns, the healthcare team must remain attentive when evaluating the child, in addition to valuing the information provided by mothers to identify abnormalities and make an early diagnosis (7,15,18).

The difficulties experienced in the hospital setting in relation to the guidelines also emerged in the mothers' reports related to receiving the guidelines only on the day of discharge, in addition to there being many guidelines in a short period of time, thus making it difficult to learn how to care for the child at home

> *I only had one orientation, which was on the day he was discharged. Until then, I didn't even know... She only visited him at the hospital. I had to wait a long time because she was already on her way. Her "teaching" there was great, but it wasn't enough for someone who had never done anything like that before... I needed at least a week of follow-up, at least the second change [...] I was scared, so I [thought]: "Ah! I'll take it easy, but when I got home, things got complicated." (Bear's mother)*
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> *I think it's absurd for people to learn on the spot when they're discharged, because we must learn how to clean the bag, not hurt the child's intestine, put the bag on properly so as not to hurt the child's intestine. [...] Unfortunately, they couldn't give us much information because there were many children there, not just my son (Pocoyo's mother).*

In this manner, it was possible to highlight, in the statements of Bear and Pocoyo's mothers, that discharge preparation is specific and not procedural. Furthermore, the guidance received was provided in a short period of time. The institutions mentioned centralize discharge guidance in a single professional. In this context, there is a loss in the learning of these family members, which came to light when the family members found themselves alone with their child at home.

The importance of preparing parents for their child's hospital discharge is recognized in the literature, mainly because it is a strategy that facilitates this process of dehospitalization. Children with intestinal ostomies have specific needs, requiring some adjustments on the part of the family, who need to feel confident in providing this care.

Complementing these statements, Pocoyo's mother also reports a lack of knowledge about caring for the child's intestinal ostomy on the part of health professionals, also alerting to the need for these professionals to be trained

> *I think there are many who are lacking, I'm not generalizing about all nurses, but there are some who don't know, OK? In a large hospital, you are likely to encounter people who have colostomies and worse things [...] the nurse cleans them up and the child is discharged from the hospital and must learn in the hospital how to do it at home. So, it's not just adults, but children too, because nurses must be able to learn anything and teach the mothers who are in the hospital. [...] And I'll tell you, there are nurses, nursing technicians who don't even know how to cut a bag, OK? They didn't even know how to put a bag on, they waited for someone else who knew how to cut the bag (Pocoyo's mother).*

Thus, the mother's account expresses indignation at the unpreparedness of some nurses in the face of their lack of knowledge about intestinal ostomy care and at the lack of preparation of family members to perform this care.

Correlating with the literature, it is the nurse's responsibility to plan and interact with the multidisciplinary team and the family regarding the hospital discharge process, which begins at the time of admission, continues through the construction of the stoma, and ends with discharge to the home (7).

In this process, nurses must understand the individual characteristics of family members in terms of physical, mental, psychological, religious, and socioeconomic aspects. Readaptation to daily life activities is necessary, especially regarding ostomy and peristomal skin care (2,22-23).

The family of a child with a stoma must acquire skills that were not part of their daily routine, which requires multidisciplinary follow-up. It is also necessary to strengthen the family so that they can find their way to participate in daily care and develop their potential. Nurses are health professionals capable of providing care that meets the needs of individuals and families (1).

The nurse is the link between knowledge, information, and practices. However, due to the limited specific information provided to mothers about peristomal skin care and the correct handling of collection equipment, the performance of procedures generates feelings of fear and insecurity (23). It should be emphasized that, unlike adults, children's skin tends to suffer more damage from exposure to effluents (13).

The guidance provided by nurses, whether they are stoma therapists or trained generalist nurses, should involve observation of the characteristics of stoma, local hygiene, appropriate selection of collection equipment according to the child's age, and the use of adjuvants, when necessary, such as skin protectors, adhesive remover wipes, adjustable elastic belts, among others. The physical and psychosocial aspects of the child, the capacity for self-care (depending on age), and the participation of parents and/or guardians in providing care should also be considered, thus preventing the emergence of complications or facilitating their management (15,22).

Mothers discuss the search for additional information on the internet, mainly on social networks by family members of children with ostomies

> *I participated a lot in groups of mothers who had colostomized babies [on the internet, on Facebook], so it helped me a lot (Frozen's mother).*
>
> *But I went online, on YouTube, and saw how to clean a bag properly. So, the way I'm doing it is perfect! [...] That was important, because sometimes not everything you find on the internet is true, you know? Not everything we see on the internet is true, so it helped me a lot! (Bear's mom).*
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> *I sought guidance on the internet, in groups of mothers with ostomized babies, groups of ostomized adults... I discovered several tips, especially when she was bleeding and started to hurt a lot, so I got a lot of guidance that I didn't have before. (Butterfly's mother)*

For this reason, mothers' statements revealed that family members often had to seek information on stoma care independently. However, much of the online guidance available lacked scientific and technical rigor, consisting instead of advice shared by other family members based on their own adaptations and personal experiences with caring for children with intestinal stomas.

In this way, it can be understood that, as a virtual environment, the internet functions as a learning link that promotes social interaction, providing students with sources of analysis, guidance, awareness, understanding, and scientific breadth. In this way, autonomy is promoted, in addition to self-regulation of behavior by the student (17).

However, despite being a source of knowledge where family caregivers exchange their experiences, it is important to have a professional reference to confirm the accuracy of the guidance received, so as not to absorb behaviors that could harm the health of their child (3).

To sum up, it is worth mentioning that this study was limited by the low number of people who met the inclusion criteria. This fact is reinforced in the study by Nkiruka and Unebike (25), who report that over a 10-year period, only 112 ostomies were created in children, with an average patient age of 5 years.

CONCLUSION

It can be concluded that, in the context of hospitalization, the lack of effective guidance from the healthcare team on stoma care led mothers to experience difficult moments characterized by fear, despair, concern, and helplessness. Furthermore, some family members received only sporadic instructions at the time of hospital discharge, which hindered their learning of specific procedures, as they lacked access to training and supervision from the nursing team.

This gap in care highlights a weakness in the health education process and underscores the urgent need for the development of a protocol to be implemented in health facilities. Such a protocol should address the specific needs of this population, ensuring appropriate reception, continuous monitoring, and effective knowledge acquisition by families within the institution, so that care can be safely continued at home after discharge, thereby reducing the risk of physical and psychological harm to both child and family.

In this context, the study contributes to nursing care by suggesting health education strategies that are better aligned with the reality of this clientele. From a teaching perspective, it may support the training of nurses, preparing them for professional practice. Moreover, in the field of extension, it offers a basis for proposing nursing interventions that strengthen the support provided to family caregivers of children with ostomies, facilitating home care, minimizing potential health complications, and improving the quality of life of the child–family dyad.

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Declaration of Conflict of Interest

Nothing to declare.

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