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The importance of the stomal therapy nurse for the care of children with intestinal stoma: the maternal perspective

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ABSTRACT

Objective: To analyze, from the maternal perspective, the importance of the guidance provided by stomal therapy nurses for the care of children with intestinal stomas. **Method:** This qualitative, descriptive-exploratory study collected data through semistructured interviews conducted from June to November 2019. The data were subjected to thematic content analysis as suggested by Bardin. **Results:** Nine mothers of children with stomas were interviewed. They emphasized the importance of guidance from stomal therapy nurses, which contributed to their confidence in performing specific stoma care and using specific products correctly. In addition, an improvement in peristomal dermatitis was noted. Mothers also expressed satisfaction with the information they received about the surgical procedure. **Conclusion:** The guidance received by the mothers was crucial due to the lack of information about the disease and the specific care required for their child with a stoma. This guidance fostered a sense of gratitude, especially for the redirection provided by the stomal therapy nurse in addressing care difficulties.

DESCRIPTORS: Surgical stomas. Enterostomal therapy. Nursing care. Child.

A importância do enfermeiro estomaterapeuta para o cuidado com a criança com estomia intestinal: óptica materna

RESUMO

Objetivo: Analisar, por meio da óptica materna, a importância das orientações fornecidas pelo enfermeiro estomaterapeuta para o cuidado de crianças com estomia intestinal. **Método:** Estudo qualitativo, descritivo-exploratório. Dados produzidos por meio de entrevista semiestruturada, no período de junho a novembro de 2019, submetidos à análise de conteúdo temática proposta por Bardin. **Resultados:** Foram entrevistadas nove mães de crianças com estomias intestinais, as quais destacaram a importância das orientações do enfermeiro estomaterapeuta, as quais contribuíram para a segurança na execução dos cuidados específicos com a estomia das suas crianças e do manejo correto dos produtos específicos, além da evolução satisfatória das dermatites periestomais. Também se constatou satisfação em receber informações sobre o procedimento cirúrgico. **Conclusão:** As orientações recebidas pelas mães foram fundamentais diante da escassez de informações sobre a doença e o cuidado específico de sua criança com estomia, fazendo emergir o sentimento de gratidão, principalmente no redirecionamento pelo estomaterapeuta dos cuidados necessários na dificuldade apresentada.

DESCRITORES: Estomas cirúrgicos. Estomaterapia. Cuidados de enfermagem. Criança.

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La importancia del enfermero estomaterapeuta en el cuidado del niño con ostomía intestinal: perspectiva materna

RESUMEN

Objetivo: Analizar, desde la perspectiva de las madres, la importancia de las orientaciones brindadas por el enfermero estomaterapeuta para el cuidado de niños con ostomía intestinal. **Método:** Estudio descriptivo-exploratorio, cualitativo. Datos recolectados a través de entrevistas semiestructuradas, desde junio hasta noviembre de 2019, sometidas al análisis de contenido temático propuesto por Bardin. **Resultados:** Se entrevistaron nueve madres de niños con ostomía intestinal, quienes resaltaron la importancia de las orientaciones del enfermero estomaterapeuta para contribuir a la seguridad en la realización de cuidados específicos de la ostomía de sus hijos, y el correcto manejo de productos específicos, además de la evolución satisfactoria de las dermatitis peristomales. También hubo satisfacción al recibir información sobre el procedimiento quirúrgico. **Conclusión:** Las orientaciones recibidas por las madres fueron fundamentales ante la escasez de información sobre la enfermedad y los cuidados específicos de su niño con ostomía, resultando en un sentimiento de gratitud, especialmente en la reorientación por parte del estomaterapeuta de los cuidados necesarios ante las dificultades presentadas.

DESCRIPTORES: Estomas quirúrgicos. Estomaterapia. Atención de enfermería. Niño.

INTRODUCTION

The surgical creation of an opening from a hollow organ to the outside environment is defined as a stoma. Enterostomies are procedures designed to divert intestinal flow to the abdominal surface. This is done to decompress, protect anastomoses, or restore the function of an organ affected by the sequelae of a pathological or traumatic process.

When this surgery involves the ileal segment of the small intestine, it is called an ileostomy. In children, the procedure is used to correct conditions such as necrotizing enterocolitis, meconium ileus, granulomatous ulcerative colitis, etc.

A colostomy is an opening made in the large intestine. Colostomy is indicated in cases of congenital malformations such as anorectal malformations such as anal atresia and Hirschsprung's disease (or congenital megacolon), which are characterized by intestinal obstruction in children[1,2].

Currently, there is a lack of data on the number of people with stoma in Brazil, and data on the pediatric population is even more unclear due to the lack of a unified national registry. In developing countries, congenital anomalies and male sex are known to be predominant factors in the need for stoma creation. This is consistent with the results of the few national studies available[2].

Nursing care for a child with a stoma requires special measures to provide comfort, safety, and control over the new situation the child and family will experience. The team must act quickly, safely and efficiently when surgery is indicated and involve the family in the process of diagnosis and care of the child[1,3].

The nursing specialty that focuses on the care of people with wounds, stomas, and fecal and/or urinary incontinence is known as stomal therapy. Studies highlight the unique support this specialty provides to this population, which extends beyond specific stoma care products to include health education aimed at planning care beyond the hospital setting[1,4].

In addition, there is a notable gap in the scientific literature regarding the role of generalist nurses and stomal therapy nurses in the care of children with elimination stomas, particularly in relation to family involvement. This gap highlights the need for the present study[5].

Despite the multiple demands faced by children with stomas and the need for holistic care by stomal therapy nurses, this study focused on the specifics of technical care. This focus is due to the lack of evidence-based literature on the subject and the negative impact on quality of life and development of complications caused by lack of knowledge about such care[2].

OBJECTIVE

To analyze the importance of guidance provided by stomal therapy nurses in the care process of children with intestinal stomas from the perspective of mothers of these children.

METHODS

This is a qualitative, descriptive, exploratory study designed to delve into the history, relationships, beliefs, perceptions, and opinions of individuals about how they live, feel, and think[6].

Since this research collects data through interviews and aims to maintain the integrity of the study, the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was used as a support tool. This tool consists of 32 items covering the following areas: research team and reflexivity, study design, and analysis of findings[7].

Participants were recruited from a patient database of a private company based in São Paulo. This company manufactures stoma collection devices and, besides marketing its products, provides care to people with stomas nationwide through stomal therapy nurses. The goal is to provide guidance on stoma care and the use of stoma management devices. After this care, the individual's sociodemographic and clinical data are registered on the company's platform.

In this context, given the inclusion criteria (children between 0 and 24 months of age who have undergone colostomy or ileostomy and who reside in the city or metropolitan region of Rio de Janeiro), data were extracted from the company's database with the consent of the coordinator of the patient assistance program.

The choice of the age range of patients and the specific type of stoma is justified by the fact that the majority of operations for the creation of intestinal stomas are performed in this period, since the most common causes are congenital malformations, necrotizing enterocolitis, etc[3].

Besides, the primary caregiver was defined as the person responsible for the child's direct care, who received instruction from a stomal therapy nurse regarding the child's stomal care and who provided this care. Exclusion criteria were families whose children received postdischarge care from public health services or private health insurance.

By using data from the list of preselected children, families who met the inclusion criteria of the study were contacted by telephone. The purpose was to present the research proposal and to inquire about their interest and availability to voluntarily participate in the study. For those who accepted the invitation, a date and time were arranged for the semistructured interview to be conducted at their home.

The initial sample size consisted of 21 preselected children; however, 12 did not participate in the study for the following reasons: two had urinary stomas and did not use collection devices; three refused to participate (one because of embarrassment and the other two did not give reasons); four lived outside the metropolitan area of Rio de Janeiro; and three lived in high-risk areas. Thus, nine primary caregivers participated in the study.

Data were collected in the homes of the primary caregivers of children with stomas. This process involved the researcher, the mother as the primary caregiver, and in one specific case, the father who was directly involved in the child's care.

Data were collected through semistructured interviews that first recorded the sociodemographic characteristics of the primary caregiver and the clinical data of the child with the stoma. Open-ended questions were then asked about the guidance provided by the stomal therapy nurse to the family members regarding the care of their child's stoma.

Data collection was conducted from June to November 2019 by using the following guiding questions: "What instructions did the stoma nurse give you regarding stoma care?"; "Did you find the instructions important for caring for your child's stoma? Why?"; "How did these instructions help with the daily care of your child's stoma?"; "Did you encounter any difficulties in implementing these instructions at home?". Additional questions were added to further explore the responses received.

Interviews with primary caregivers were audio-recorded by using a mobile app, and each interview lasted an average of 45 minutes. They were then fully transcribed for content analysis. There was no need to repeat interviews.

Data analysis was conducted by using Bardin's thematic content analysis. This type of analysis involves breaking down the text into units of record (RUs) through analogical regrouping. The goal of these operations is to uncover the core meanings or themes that make up the communication, focusing on the frequency with which these core elements appear as segmentable, comparable data, rather than on their dynamics and organization, to subsequently identify the categories[8].

This study was registered on Plataforma Brasil and submitted for review to the Research Ethics Committee (CEP) of Universidade do Estado do Rio de Janeiro, the sponsor of this study. Data collection began only after receiving approval, with opinion number 3.304.621.

Based on ethical principles, primary caregivers were informed about the research and asked about their interest and availability to participate voluntarily. Those who agreed were presented with the Informed Consent Form (ICF) in accordance with the guidelines and regulatory norms for research involving human subjects — Conselho Nacional de Saúde Resolution No. 466/2012 for research involving human beings, ensuring privacy and individuality.

To ensure anonymity, the family members were identified in the study by codes corresponding to the interview number, with F1 for the first interviewee, F2 for the second, and so on.

RESULTS

This study included only mothers of children with stomas, a total of nine participants. These mothers were the primary caregivers for their children, which is consistent with the cultural association of caregiving with the maternal role[9].

Mothers' ages ranged from 22 to 30. In terms of education, seven reported having completed high school, one had some college education, and one mother had a postgraduate degree. Three mothers reported being employed at the time of the interview, while the others were solely devoted to caring for their children and managing household demands.

Regarding the clinical data related to surgical creation of stomas, seven mothers reported that their children had undergone colostomy and two had undergone ileostomy. These procedures were performed for the following reasons: three for congenital malformations, one for necrotizing enterocolitis, and five for imperforate anus.

Upon analyzing the statements, two thematic categories were identified: peristomal skin care: the importance of stomal therapy nurses' guidance and stomal therapy nurses' guidance on the management of collection devices and accessories.

Families of children with stomas were instructed by stomal therapy nurses on how to care for their child's stomas. Seven families received instruction during the child's hospital stay, while two families received instruction at home after the child was discharged.

> [the guidance from the stomal therapist] helped me to do everything properly […] I had good instruction, and I was able to do [the care] properly. [The guidance was important because] I don't have to worry that it's giving me fungus [on the peristomal skin], […] because I know that [the skin] is well looked after. (F1)
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> The stomal therapist explained everything beautifully. I followed everything she said to the letter. She said everything, you do it step by step, so whenever I looked, I knew what to do. I remembered everything I had to do. (F2)

Mothers expressed satisfaction with the guidance they received from the stomal therapy nurse, which contributed to their sense of security, understanding, and ability to cope with the situation. This guidance facilitated the incorporation of the specific care needed for the proper management of their children's stomas.

The following statements emphasize the importance of the counseling in helping to regenerate and maintain the tissue integrity of the peristomal skin affected by dermatitis, thereby reducing the child's suffering.

> I thought the guidelines helped my daughter a lot so that she wouldn't burn her skin anymore. It was important because there was always burning around the stoma. […] It eased some of the suffering she already had with it. It's because you're already seeing the child there suffering with the stoma and still burning and not knowing what to do. (F3)

> The guidelines helped me to maintain the integrity of the skin. To keep the stoma looking healthy at all times, to be able to see if there's anything wrong. Whenever I went to the stomal therapists, they gave me advice. The skin was really badly damaged, so the stomal therapist had the opportunity to give me all the guidance in every case, and there she saw me doing it, and she guided and led the actions. (F4)

Guidance on maintaining vigilance for peristomal skin integrity was important for primary caregivers, as home stoma care requires both maintenance of skin integrity and early detection of potential complications.

Regarding the importance of instruction on how to use the collection devices and supplies, mothers reported many benefits from the instructions. They emphasized gaining knowledge about the products, their proper use, and the importance of properly cutting the adhesive base for their child's stoma.

> This cut-out has made it much easier for me, because before his skin was always red, as if it had formed a wound, and now it stays intact. Before, I used to change a bag every time I changed my diaper, now I can remove the stool and I don't have to change the bag every time. As I said, we're out and about a lot because of the treatment, so all this guidance, all this help has made my day-to-day life easier. (F1)

> The advice was important because the skin around the stoma always burned. Even if I applied the skin protection paste, it would come off over time, because of the secretion, and it would burn a bit. […] after the guidance, it got much better. At first, it would come off a bit, but then it would stay on for two or three days. (F3)

The previous statements highlight the importance that mothers place on the instruction on how to use stoma products for their child. The instruction they received gave them a sense of security in performing the care. This led to improved care of the peristomal skin, as evidenced by regeneration and maintenance of skin integrity. This improvement was due to better adherence of the adhesive base to the skin, which facilitated the daily routine and reduced the frequency of changing the collection devices.

In F4's account, the supervision of the stomal therapist during the care process contributed to the security.

> I applied the powder [skin protection product] according to her instructions, because she was there, by my side, guiding me, but I was the one carrying out the change. So, as I'd already had initial contact with the change at the hospital and at home, it was good that I did it with her guidance, because she was directing me. Not to mention that I never had any problems, there was an episode when I called the nurse because I couldn't use the paste. She did a good job of explaining it to me. I sent her a photo of the stoma and she said: "Put it on like this, put it on like this, it sticks". And three days later, the skin was intact. (F4)

In this account, it was evident that caregiver F4, when faced with difficulties in the procedure, was redirected by the stomal therapy nurse on the proper use of the product, resulting in successful healing of the child's peristomal skin. The connection between the professional and the caregiver was also evident as the caregiver sought further guidance when in doubt or in difficulty and received prompt assistance.

Guidance provided by the stomal therapy nurse was important for the mothers because of their initial lack of knowledge about the clinical and surgical condition as well as the necessary care for their children.

> As I said, we don't know how to take care of it, how to do it. I thought the guidelines were important, because I'd never seen this before in my life. It was the first time I'd seen this case, and then I wondered, right? Because I'd never heard of such a case." (F5)
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> Her advice was fundamental, because I had never heard in my entire life that a child was born with this problem. How was I going to take care of it? How was I going to change the bag? This information was very important. What would my life have been without this information? That was my fear. At the hospital, I always asked if there was going to be someone to teach me, how am I going to do it, how am I going to change it? "There is [the hospital said]. The stomal therapist will come and explain it to you, don't worry." Then I felt calmer". (F2)

There was unanimous agreement on the importance of the guidance given to mothers by the stomal therapy nurses. This guidance was crucial since the lack of information about the child's condition and how to care for a child with a stoma. In addition, there was a strong sense of gratitude for the guidance received.

DISCUSSION

Counseling is recognized as one of the most important tools in the teaching-learning process. Therefore, health care workers must be available to exchange information with primary caregivers during the hospital stay. This underscores the need for clear, concise, easy-to-understand instructions[2].

The quality of care for a person with a stoma is related to early access to counseling, especially when the impact of that care is related to the proper selection of collection devices and accessories. Direct skin contact with stoma waste can cause skin conditions known as chemical or contact dermatitis. However, this education is a gradual process that begins in the hospital to enable the primary caregiver to provide proper care after discharge[1].

In addition, reflecting on past practices that may have worsened their child's health status allows mothers to change their reality through a critical analysis of their situation. In this sense, health education for the families of children with intestinal stomas is based on new care practices tailored to the specific needs of each child. The support of a specialized nurse is fundamental in this process. The nurse must be closely involved with the family caring for the child in order to provide professional support and to understand the family's prior knowledge, their experience with the disease, and their biopsychosocial conditions in coping with the disease[1,9,10].

The quality of life of a child with a stoma is related to a well-executed surgical construction as well as clear instructions about the stoma, its function, its management, and daily care needs. Emphasizing the benefits and positive aspects will help the family cope with the challenges of this condition[11].

An important point emphasized by the primary caregivers is the value of guidance from the stomal therapy nurse regarding care focused on regeneration and maintenance of peristomal skin integrity affected by dermatitis. The stomal therapy nurse should enable the caregiver to identify the specific characteristics of an "intact" stoma to prevent complications and guide the nurse in the ongoing assessment of this skin. Caregiver should be able to recognize the normal color of the stoma, which is bright red or dark pink as well as aspects related to the moisture and integrity of the mucosa (without ulcerations, granulomas, or tumors) and the integrity of the peristomal skin[5].

Peristomal skin lesions, or peristomal dermatitis, are characterized by a pathologic process that includes all skin lesions around the stoma, whether acute or chronic, manifested by classic inflammatory signs: erythema, heat, pain, and redness, sometimes with deeper tissue damage. These lesions can not only delay the reversal of the stoma but also reduce the quality of life of the child with an intestinal stoma and their primary caregivers[5,12–14].

Therefore, the nurse should educate families on how to care for the peristomal skin, including how to clean it gently and carefully, and how to select appropriate collection devices and accessories available on the market. This care aims to strengthen the relationship between the family and the child as well as to align expectations and necessary care practices[5,15,16].

Before training the primary caregivers of a child with a stoma, the stomal therapy nurse or specialist should assess the caregivers' perceptions of the main complications and how to intervene appropriately. Caregivers also need to be educated about when to seek help from a health care worker, such as when stoma stenosis occurs[1].

On the other hand, the lack of information on stoma care for children has led to insecurity and fear among primary caregivers in handling and performing procedures, resulting in postoperative complications[11].

Dialogue with the family, especially during the initial contact, aims to promote empathy and provide resources to build a solid foundation of health education. This approach respects the pace of each family and addresses not only the pathology itself but also the main concerns that may arise. A study by Faria and Kamada shows that although preoperative counseling was provided, it focused on the pathology and its treatment, and did not include information about the impact of living with a stoma in the biopsychosocial postoperative context[17].

As evidenced by the mothers' testimonies, the guidance provided by the stomal therapy nurse helped them to use the collection devices safely and to use the ancillary products appropriately, respecting their correct indications. The mothers also emphasized the importance of the instruction on how to properly cut the adhesive base for their child's stoma, which they considered critical in caring for a child with an intestinal stoma.

Collection devices consist of devices with an adhesive base designed to protect the skin and attach to the collection bag. The purpose of the bag is to collect and store urinary or fecal waste. The system may be one-piece, where the adhesive base is attached to the collection bag, or two-piece, where the adhesive pad is separate from the bag and attached later[5]. Pediatric adhesive bases are thinner, providing more flexibility for children; however, they are less resistant to waste erosion and require more frequent replacement than adult bases[18].

Despite the increased availability of pediatric products today, options for neonates and children with high or fluid output are still limited. The selection of products for pediatric care should generally consider several factors: the child's age, weight, and abdominal surface area; the location and type of stoma (urostomy, ileostomy, colostomy); the height of the stoma (protruding, flat, or retracted); the consistency and daily volume of the output; the child's body profile; and the child's activity and mobility levels[18].

Ancillary products are used to facilitate the use and durability of collection devices with the goal of caring for the peristomal skin. A common and widely used example is the hydrocolloid protective skin paste. This paste is malleable and is used to fill and smooth irregularities on the peristomal abdominal surface, such as wrinkles and folds. It helps to accommodate the adhesive base and reinforce its seal, thus preventing premature infiltration of the effluent[5,18].

Synthetic resin powder is composed of hydrophilic polymers (e.g., gelatin, pectin, carboxymethylcellulose, and hydrocolloids) that absorb moisture from peristomal dermatitis exudate and promote skin regeneration. It also acts as a protective barrier against imminent contact with new exudate[5,18,19].

Therefore, guidance on the indication and correct use of the adjuvant products contributed to the revitalization of the injured skin and prevented premature infiltration of the effluent into the adhesive base by properly sealing the collection devices. In this regard, the expertise of the stomal therapy nurse, derived from clinical practice and mastery of specific products, stands out as a key factor in the rehabilitation of the child-family unit[1,15,18,19].

Another important aspect of caring for children with stoma is their body profile. Babies have a rounded abdomen with skin folds and their lower abdomen is very close to the groin, which can cause the thigh to rub against the collection device. The nurse must consider these factors when selecting products to avoid discomfort during the baby's activities and mobility, and to prevent premature dislodgement of the collection device[18].

Therefore, guidance on the proper use of each stoma product is of paramount importance, as there is a wide range of materials with different compositions and presentations available on the market. The prescription of collection devices should be individualized, respecting the characteristics of each type of stoma and considering the patient's skin characteristics.

This approach aims to prevent leakage, infiltration, and deterioration of the peristomal skin, thereby promoting a better quality of life for these children[5,18,19].

In this context, the role of the specialized nurse is crucial in the personalized selection of collection devices that meet the clinical needs of each child. In addition, providing appropriate guidance to help the family use these devices correctly is essential to facilitate the family's daily life, as demonstrated in this study. A critical perspective based on scientific evidence is fundamental in guiding assertive care and contributing to skin recovery and health promotion.

Regarding the information about the adhesive base, the composition includes hydrophobic substances that promote adhesion and hydrophilic substances designed to interact with moisture, whether from wastewater or perspiration[5].

For better adhesion, the adhesive base should extend 1 cm beyond the edge of the stoma, and the cutout should match the size and shape of the stoma. The gap between the stoma and the adhesive plate should not exceed 2 mm to avoid unnecessary exposure of the skin to the fluid. This measurement should be taken each time the collection device is changed for up to six to eight weeks after surgery. This is necessary because the postoperative inflammatory process causes edema in the stoma during these first few weeks, requiring adjustments in the size of the collection device and the adhesive base cutout. Nurses also need to counsel families to be aware of the physical changes their child is experiencing as he or she grows and develops.[20].

Testimonials emphasized that proper cutting of the adhesive base contributes to adequate skin protection, thereby reducing the incidence of leakage, infiltration, and consequently, peristomal dermatitis.

Finally, families emphasized the importance of the nurse's guidance for safe care. In this regard, the demonstration technique was recognized as a useful method for understanding new ways of caring, with the knowledge gained being relevant to everyday care situations[21,22].

In addition, caregivers should be allowed to handle the collection equipment and supplies prior to surgery to avoid anxiety and unfamiliarity in the postoperative period as well as difficulties with handling these specific materials. Family members must be recognized as an active, critical participants, and the health care worker should answer their questions fully and effectively[11].

Health education is a dynamic, dialogic process that allows nurses to develop and share knowledge with families about the best care for a child with a stoma. This collaboration aims to support the daily practice of such care. This process requires the empathy, expertise, and teaching skills of the professional to more effectively address the health needs of this population[2].

The limitation of this study is that data were collected from a small group of primary caregivers, primarily mothers. With a greater diversity of family members as caregivers and a larger sample size, more generalizable results could be obtained. Therefore, similar studies should be conducted in other contexts to increase knowledge on this topic.

Among the contributions to the field, giving voice to the families of children with stomas allows for the identification of the significant role of the nurse and stomal therapy nurse in providing educational guidance and health education to patients with intestinal stomas.

The present study also contributed to the body of knowledge on this topic. Based on the findings, nurses and stomal therapy nurses can reflect on their roles as health educators and agents of change in health care to minimize potential health complications in these children, promote safe care, and improve the quality of life for these patients.

FINAL CONSIDERATIONS

Families identified the guidance provided by the stomal therapy nurse as critical to stoma care practices, especially in the absence of basic information about the surgery and specific care needs. Statements reflect a remarkable satisfaction of the families, especially regarding the revitalization of the injured skin.

In this context, it is essential to consider the specific characteristics of the child and to ensure that the guidance provided to the primary caregiver is personalized and addresses their concerns and questions. This approach should consider the type of stoma and its clinical characteristics, thereby reducing complications and promoting the quality of life of the child with an intestinal stoma.

Finally, considering health education as an important tool to guide families in the management of a child's stoma, it aims to create an interface between the stomal therapy nurse and the family. The result of this interaction is a learning process that promotes a change in the family's reality and, above all, improves the child's quality of life.

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