

Maternal challenges in care for the child with intestinal ostomy grounding the proposal of a booklet

Desafios maternos do cuidado ao filho com estomia intestinal fundamentando a proposta de uma cartilha
Desafíos maternos en el cuidado del niño con ostomía intestinal fundamentando la propuesta de cartilla

RESUMO

Objetivo: Descrever os desafios enfrentados pelas mães para o cuidado ao filho com estomia intestinal, propondo cartilha educativa. Método: Estudo descritivo exploratório qualitativo, com doze mães em um serviço de Unidade de Referência Especializada. Coletou-se em janeiro e fevereiro de 2018 por entrevista semiestruturada e posterior análise de conteúdo de três etapas. Resultado: Emergiram 1) Superar o medo de cuidar da estomia; 2) Aprender passo a passo a troca do equipamento; 3) Superação da falta de orientações; e 4) Necessidade de possuírem um material educativo. A cartilha contou com 19 folhas e imagens coloridas sendo dividida em sete partes, instruindo a troca, a higiene e explicitando adjuvantes e acessórios. Conclusão: As ações educativas prestadas pelos enfermeiros no nível terciário ainda são insuficientes. Espera-se que a coprodução da cartilha contribua tanto com as mães quanto com os profissionais tencionando a qualidade de vida e a inserção da criança com estomia.

DESCRIPTORIOS: Criança; Estomia; Ânus Imperfurado; Anormalidades Congênicas; Relações Mãe-Filho.

ABSTRACT

Objective: To describe the challenges faced by mothers in caring for their children with an intestinal ostomy, proposing an educational booklet. Method: Descriptive exploratory qualitative study, with twelve mothers in a Specialized Reference Unit service. It was collected in January and February 2018 by semi-structured interview and subsequent three-step content analysis. Result: The following emerged: 1) Overcoming the fear of taking care of the ostomy; 2) Learn step by step how to change the equipment; 3) Overcoming the lack of guidance; and 4) Need to have educational material. The booklet had 19 sheets and color images, being divided into seven parts, instructing the exchange, hygiene and explaining adjuvants and accessories. Conclusion: The educational actions provided by nurses at the tertiary level are still insufficient. It is expected that the co-production of the booklet will contribute to both mothers and professionals, aiming at the quality of life and the insertion of the child with ostomy.

DESCRIPTORS: Child; Ostomy; Anus Imperforate; Congenital abnormalities; Mother-Child Relations.

RESUMEN

Objetivo: Describir los desafíos que enfrentan las madres en el cuidado de sus hijos con ostomía intestinal, proponiendo una cartilla educativa. Método: Estudio cualitativo exploratorio descriptivo, con doce madres en un servicio de Unidad de Referencia Especializada. Fue recolectada en enero y febrero de 2018 mediante entrevista semiestruturada y posterior análisis de contenido en tres pasos. Resultado: Emergieron: 1) Superación del miedo de cuidar la ostomía; 2) Aprenda paso a paso cómo cambiar el equipo; 3) Superar la falta de orientación; y 4) Necesidad de contar con material educativo. El cuadernillo contaba con 19 hojas e imágenes a color, siendo dividido en siete partes, instruyendo el cambio, higiene y explicando adyuvantes y accesorios. Conclusión: Las acciones educativas que brindan las enfermeras en el nivel terciario aún son insuficientes. Se espera que la coproducción de la cartilla contribuya tanto a las madres como a los profesionales, visando la calidad de vida y la inserción del niño con ostomía.

DESCRIPTORIOS: Niño; Estomía; Ano Imperforado; Anomalías Congénitas; Relaciones Madre-Hijo.

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Sandra Regina Monteiro Ferreira

Nurse, Master by the Health, Environment and Society Graduate Program at the Federal University of Pará
ORCID: 0000-0003-3205-5818

Antonio Jorge Silva Correa Júnior

Nurse, PhD student in Sciences at the Fundamental Nursing program at EERP/USP
ORCID: 0000-0003-1665-1521



André Aparecido da Silva TelesNurse, PhD in Sciences from the Fundamental Nursing program at EERP/USP
ORCID: 0000-0002-0548-9592**Janderson Cleiton Aguiar**Nurse, PhD student in Sciences at the Fundamental Nursing program at EERP/USP,
ORCID: 0000-0002-6095-8689**Helena Megumi Sonobe**Nurse, PhD from the Fundamental Nursing program at EERP/USP
ORCID: 0000-0003-3722-0835**Mary Elizabeth de Santana**Nurse, PhD in Nursing from the School of Nursing of Ribeirão Preto, University of São Paulo
ORCID: 0000-0002-3629-8932**INTRODUCTION**

Children need urinary, gastrointestinal or respiratory stoma soon after birth or at any time in their life, with frequent causes being genetic diseases, trauma or congenital anomalies, some common causes are Anorectal Anomalies, congenital megacolon or Hirschsprung's disease, Crohn's disease, necrotizing enterocolitis, ulcerative colitis, and familial adenomatous polyposis.¹

It was estimated in a cohort of 400,000 births a prevalence of anorectal anomalies at birth of 5.21 per 10,000, and a frequency of joint congenital anomalies and anorectal anomalies of one in every two children, characterizing them as chronic deficiencies with great impact.²⁻⁴ They call for surgical corrections and adequate follow-up, being indispensable the provision of Nursing guidelines in the acquisition of new skills and competences, guiding and performing care, providing support and leading them to adaptation.⁵

The nurse is the link between knowledge/information and practices. However, due to the little specific information passed on to mothers about peristomal skin care and correct handling with the collection equipment, the execution of procedures generates feelings of fear and insecurity.⁶⁻⁷ It is emphasized that the skin of children, unlike adults, tends to suffer more damage from exposure to

effluents.⁸

Knowledge must be passed on with accessible language, preventing doubts that harm the quality of life, which health education through light technologies makes possible.⁹ Specialized inter-professional care in Brazil is carried out based on the macro policy of Ordinance No. 400, of November 16, 2009, on the guidelines applied regarding the care of people with ostomy in the Unified Health System (SUS). Thus, Care for Ostomized People II is responsible for assistance and social self-care actions.¹⁰

Demand and care go beyond clinical variables such as peristomal skin, prescribing adjuvants and protective equipment; administering, controlling stock and storage; guiding primary care; guiding support groups; carrying out and updating the register; forwarding in case of interurrences; and guiding social rehabilitation.¹⁰

After hospital discharge, the event of great interest to the family nucleus and people with ostomy is rehabilitation, which will be achieved through self-care and minimization of social, educational and assistance barriers.¹¹ Light technologies with illustrations can be used to reduce such barriers present in health education for the lay population, they end up being reference materials when in doubt and even resources for home training.¹²

Some materials are successful examples by bringing elucidation about peris-

tomal complications and their prevention, types of equipment, ways to make exchanges, doubts and channels that are a source of help.¹² It is argued that co-production models provide opportunities for organizations to assume as values the health education of their user demand, engage the served population around answers to doubts, improve through health education the special needs of people with low levels of literacy, and seek to remedy inadequate levels of apprehension of information related to care.¹³

Another aspect, pertinent to the proposal for co-productions, is to provide users with quick access to health-related information. To this end, professionals internationally and nationally design and distribute written, audio or visual materials that are easy to understand for home care providers, always explaining who to turn to in risk situations.¹³

Therefore, due to the need to expand the knowledge of caregivers regarding the subject, since it is a subject little debated, the objective is to describe the challenges faced by mothers in the care of their children with a stoma, proposing an educational booklet.

METHOD

Qualitative descriptive study¹⁴ aiming to propose light technology activated in relationships. The theoretical support recommends that the produc-

tion of knowledge is conceived together with the participant, rejecting neutrality, corroborating/questioning a collective construction in the groups, arising from assistance meetings in the intercession of professionals-users¹⁵ with a view to creating care innovations. The location was a Reference Service in Care for the Person with Ostomy, in the capital of the North region of Brazil, which provides daily appointments in the morning. The team is multidisciplinary and in the case of the nurse, the assistance has an office. It is the only service of its kind distributing equipment, accessories and adjvants in the Brazilian state in question.

Sampling was intentional¹⁶ of “guide users” who, in this case, had a path intersected by difficulties. Included were: mothers over¹⁸ years of age who could read and write; residents in the capital or in other municipalities in the interior of the state; exclusively responsible for the hygienic care of children with an intestinal ostomy from 0 to 12 years of age and who have already been seen in a nursing consultation at least twice in the service. Those who did not consent due to personal reasons or lack of time were excluded.

Negotiation took place after the consultation, reporting the research objectives, then 12 mothers were selected. The collection took place in the first half of 2018 with a single semi-structured interview with the four questions: 1) What are the difficulties in caring for your child with an ostomy? 2) How do you take care of your child's ostomy and peristomal skin? 3) What guidelines did you receive from the nurse regarding care at hospital discharge? The co-production question was: 4) Do you consider important educational material for you and your child? What issues do you consider important in helping with hygienic care? The duration ranged from 20 minutes to 40 minutes, at the end, it was informed that after analyzing the data and completing the research, a booklet would be made available.

All interviews were audio-recorded and the confidentiality of Mothers (M) was maintained with alphanumeric codes M1, M2, M3 to M12 in the sequence of interviews. The testimonies were

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transcribed in full in Microsoft Word files and then organized into a single matrix file, saturation occurred after the redundancies in new testimonies were smoothed out. The analysis and valida-

tion was carried out by qualitative researchers without the use of software, as follows: a) full transcription; b) exploration with floating and detained reading; c) treatment of results on maternal care with interpretation¹⁷ with derivation of the data themselves to form categories. Items were checked following the Consolidated Criteria for Reporting Qualitative Research (COREQ).¹⁸

Then, a booklet proposition was developed. The identified challenges were compiled by experts (two doctoral nurses, a master and the main researcher). Even if the identified challenges are for mothers of children with intestinal stomas, due to the equally scarce epidemiological profile and having similar health/self-care needs, the booklet also encompasses care with urostomies. It was planned as follows: listening to the participants and generating challenges to be addressed, survey of regulations and the proposition of the booklet “Nursing Care for Children with Intestinal and Urinary Stomies”.

The booklet was registered at the National Library of the Ministry of Culture (registration number 807.489 and book number 1570). All interviewees signed the Free and Informed Consent Term, which was approved by the Ethics Committee, under opinion n° 2.470.105.

RESULTS

Of the twelve mothers, two were from the capital and the others from the interior of the state, and the children's age ranged from eight months to eight years, with congenital disease being the main diagnosis. The most frequent type was the colostomy, regarding the gender of the children: six were male and six were female, and the ostomy time ranged from one month of life to two years. As for age range: ranged between 18 and 46 years. As for the level of education, two (17%) completed high school, one (8.0%) did not complete high school, five (42%) completed all of elementary school and four (33%) did not complete

this level of education.

First challenge: Overcoming the fear of ostomy care

Mothers feel powerless and fearful, so the procedure with the mother is necessary:

At first I looked at it and didn't even know what I was going to do, I put it on and it didn't fit right, so I left, then when I saw him, he was already all dirty, then we were desperate, not only me, me, my mother also helped me, we started to cry and didn't know what to do. (M7)

My only fear was of hurting her, of her colostomy straining, crying, for me, it seems like it would burst, her gut would come out, then it would bleed when she cried and the worst would happen. (M1)

When I go to change him, I'm afraid, when he's jumping, I'm afraid of something happening, sometimes it even bleeds, the difficulty is that he doesn't stop, when I go to change him, he doesn't lie down, it's very difficult for me to change him. (M5)

I was afraid of hurting him, afraid of opening "that", the skin was so sensitive, then sometimes it would bleed around... Bleeding him, I was afraid of all that, my biggest difficulty was cutting the bags. (M3 and M11 synthesis)

It seems like that, that they were disgusted, they didn't want to make the switch. (M1)

Second challenge: Learn the step-by-step process of changing equipment

Knowledge is deepened after knowing the service:

I very carefully remove the first piece, then I carefully remove the second one from there, I clean everything with a tissue until I remove all that layer of dirt, then it goes to the shower, so I wash it with soap, dry it with a suitable cloth and clean the place, lay it on the bed, I dry everything, apply the spray and dry it, apply the paste, cut the plate to the size of the stoma and place it very carefully too, always from bottom to top. (M11)

I bathe him, apply liquid soap all over his body, then I take just a little bit in my hand and apply it to the ostomy, then I dry it with that tissue you give me, when everything is dry, I apply Cavilon [skin protection spray] and pass the powder and put the bag. (M5)

Do I take it off with gauze? And the liquid soap... then I dry it with gauze... and take the ruler I have? I measure there, from there I put it in the bag, I mark it and cut it with scissors normally. (M4)

I clean it, apply the powder, barrier cream, then I remove all the excess and paste it together with the paste. (M8)

It is oriented towards hygiene and observation of the equipment, choosing what fits the body contour and paying attention to the correct cut of the adhesive base, so that there is no accumulation of effluents, the observance of the mothers' education is fundamental.

Third challenge: Overcoming the lack of guidance

The report of lack of information is quite blunt, or of episodic explanation at hospital discharge.

They didn't guide me there at all,

my son spent a year wearing a diaper because no one guided me, not even about the service. I just went from the hospital with the bags I had at the hospital, I only knew that I cut the bag and glued it, there wasn't even one other thing, I didn't know, I didn't know that they dispensed here too. (M5 and M8 synthesis)

I received guidance from the company nurse, she explained it to me, she brought me a kit, plus a manual, a booklet... Then she taught me properly, then she told me to put it on, if I could put it on, then I did it, but she was teaching me. It helps a lot, but at home it's the business. (M4 and M11 synthesis)

There was the girl from, from... I don't remember now, who works with this, she was the one who taught me everything, how to do it and change it. A representative... They said that I had to learn because I was going to do it at home, so in this case they taught me how to put it on, so they showed me, but at home I went to do it anyway. (M2 and M10 synthesis)

After cleaning and rinsing, dry the skin well, as excessive moisture interferes with adhesion and causes maceration: If the bag comes off during the shower, I have to wait for it to dry, many times I even stay there for about 5 minutes before putting it on, it takes longer, because the skin gets wet and does not adhere properly, and it takes longer. (M8)

The above situation is quite common in the Amazon region, where the hot and humid climate favors detachment of the adhesive bases of the child's collection equipment.

Fourth challenge: The need to have educational material

More relevant guiding topics were suggested and clarifications were centered on the booklet (Figure 1):

I think a booklet, I think putting figures representing the exchange, the most important thing is the exchange because if you don't have adequate hygiene. I think that in a booklet, the most important thing is to have the illustrative figures and the letters at the bottom explaining how to do the procedure. (M11)

How do you put the bag? How to use the products? The step by step of the exchange, how to do it, how not to do it, there's a lot of material that we don't know. It must be detailed, what it is for and not to hurt. (M3, M10 and M12 synthesis)

That's all, practice, because in theory everything is easier, but in practice you really have to know how to handle it... (M2)

With 19 sheets and color images and 21x15 centimeters, it was offered after collection as free return, and with joint reading. The summary showing the seven parts and the registration documentation are shown in topics (Figure 2). There is the step by step of the exchange, how to proceed with hygiene and also the explanation of adjuncts and accessories (Figure 3).

DISCUSSION

There is a lack of information since hospitalization, what should be the opportunity to start adapting becomes a difficult moment and of little help. It was confirmed that the family does not receive guidance satisfactorily, empowering it, nor are they encouraged. Informing them that the ostomy does not

Figure 1 – Booklet cover.



SOURCE: Authors, 2018

Figure 2 – Summary, necessary documents and Law n° 12738 (service address blurred).

SUMMARY	
01. Talking about stomas	05
02. Types of stomas	05
03. Types of collection equipment (collection bags)	07
04. Adjuncts and accessories	08
05. Step by step of changing the collector equipment	11
06. Taking care of the most frequent complications	12
07. Care tips for children with ostomies	16
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Documentation required to register for the service:

- 1- Copy of the child's medical report;
- 2- Copy of birth certificate;
- 3- Copy of ID;
- 4- Copy of CPF;
- 5- Copy of the SUS card;
- 6- Copy of proof of residence;
- 7- Person in charge must present a copy of the RG

WARNING:

The law no. 12738, of November 30, 2012, makes it mandatory for health plans to dispense collection equipment, accessories and adjuncts.

NURSING CARE FOR CHILDREN WITH INTESTINAL AND URINARY STOMAS

SOURCE: Authors, 2018

hurt and will be handled gently allows them to gain confidence, reducing their fear of changes.

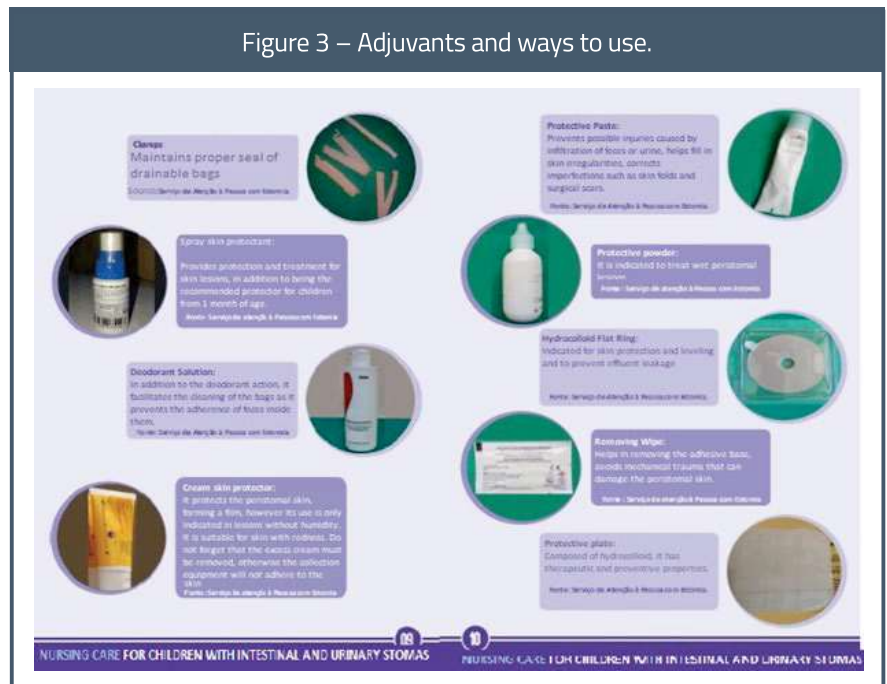
Simple activities are encouraged, depending on each case and the age of the child, allowing reflection on their insertion in society, with an emphasis on guiding the importance of the school space so that there are no differences due to the use of an accessory. In the perioperative visit and hospital discharge, they need information to arrive at home with coping strategies that minimize denial, fear and anguish.⁶⁹

Thus, regardless of the cause of the stoma, planning to prevent immediate and late complications is crucial in the context of a realistic discharge plan.¹⁹ It is of great relevance to the responsibility of nursing to ensure correct information that lasts.⁵

The nurse provides answers to questions, teaching how to handle the equipment and what the child's routine will be like, always bringing the beneficial aspects of care.²⁰ It should be noted that procedural technical knowledge is not enough, reception, qualified listening, humanization and information about rights are essential, such as the free provision of equipment.²¹

Fear, helplessness and uncertainty are the result of the lack of information arising from deficiencies in the training of the professional team²⁰ which requires constant improvement, especially from nurses, considering that they need to know all available products; be clear about its indications, advantages and disadvantages, requiring a comprehensive assessment of the physical, emotional and social dimensions.²² To assist them, professionals must have technical skills, sharing knowledge about maintaining the integrity of the peristomal skin, exchanges and material resources.²³

From the first exchanges, teaching-learning is stimulated, gradually preparing them, since many guidelines are not absorbed due to concern with the diagnosis and other demands. Thus, effective communication is essential in



SOURCE: Authors, 2018

the hospital institution to know which are the places of specialized assistance in quality of life and social insertion.

It is suggested that such production of knowledge is scarce in Brazil, where the focus is on the care action inherent to the family nucleus in scenarios such as outpatient clinics and at home, highlighting theoretical foundations and assistance.¹⁹ The need for informative material was confirmed, noting the lack of guidance in highly complex services and the challenges related to lack of knowledge. Explaining Law No. 12,738 of November 30, 2012 provides awareness of the legal obligation on the part of the State.²⁴

In the international literature, initiatives such as the production of a toolkit for pediatric ostomy, such as a guide, developed in collaboration with the health service and parents, it contributed to self-instruction, with the generation of a list for the postoperative adjustment, the co-production engenders a “bottom-up” execution.²⁵ As well as an educational resource like the Indian video, which clarified care with the prevention

of complications and infections, such resources for these parents enhance the acceptance of the condition or at least give a feeling of support.²⁶ The social and educational insertion with such materials will be another concern considering the physical and cognitive limitations, to help parents and teachers.²⁷

As a limitation for being accompanied by the child, there was distraction and loss of continuity of reasoning during testimonies, the collection at home would probably also favor the emergence of new challenges, it is also emphasized that the booklet needs psychometric validation. As for the contributions to the specialized practice, it is verified that the care of the child with malformation and/or trauma by the mothers is challenging since it is a scarce clientele from the epidemiological point of view, giving rise to their teaching to be initiated in the academic formation. Family members and professionals are expected to deepen their knowledge in their role as educators and need to plan hospital discharge.

CONCLUSION

It was found that the challenges are related to the lack of information at the tertiary level and the emotional and instrumental support essential for them to feel supported and overcome the barriers of having a child with a malformation. We emphasize the provision of guidelines on care for maintaining the

integrity of the skin and preventing possible infections if the recommendations regarding emptying the bag, as well as the removal and fixation of the equipment, are not followed. It was reported that hospital institutions do not provide collection equipment and protective adjuncts; moreover, professionals are unaware of the importance of light technologies aimed at children with a stoma.

Consequently, this set of shortages and challenges compromises rehabilitation. The research described that mothers feel helpless and with a lack of information, there is an inadequacy in the nurse's actions because care should be a priority, but it ends up becoming an inefficient action in which the expected communicative process does not materialize.

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