




# THE MOTHER'S UNDERSTANDING ABOUT CARING FOR STOMIZED CHILDREN

## COMPREENSÃO DA MÃE A RESPEITO DO CUIDAR DE CRIANÇAS ESTOMIZADAS

## COMPRENSIÓN DE LA MADRE SOBRE LOS CUIDADOS DEL NIÑO OSTOMIZADO

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**Funding:** No funding.

**Submitted on:** 2018/06/25

**Approved on:** 2019/07/10

### ABSTRACT

**Objective:** to understand the care provided by the health professionals to stomized children. **Methods:** a descriptive-exploratory study with design based on the interpretative qualitative research conducted in a public hospital in Brasília. The population consisted of nine mothers of stomized children. The research was performed between December 2015 and February 2016. Data from the field diary and from the semi-structured interview script were used and the analysis of the speeches was performed through content analysis, thematic modality. **Results:** in the maternal speeches reports prevailed of difficulty in the ostomy handling, because it was difficult to understand the guidelines provided by the health professionals, with unanimity in stating that they learned more from the practice of other mothers than from the professionals. They also reinforced the lack of preparation of these professionals to deal with the care of these children. **Final considerations and implications for the Nursing practice:** by understanding care, it was possible to deduce and support the need to establish priorities for this care. The diverse evidence found might strengthen the care provided by the health professionals working with the families and the stomized children, not only in routine care, but also in educational actions to prepare them to deal with the situation.

**Keywords:** Child, Hospitalized; Surgical Stomas; Professional-Family Relations; Nursing Care; Qualitative Research; Family.

### RESUMO

**Objetivo:** compreender o cuidado realizado pelos profissionais de saúde na assistência à criança estomizada. **Métodos:** estudo descritivo-exploratório com delineamento na investigação qualitativa interpretativa realizado em um hospital público de Brasília. População constituída por nove mães de crianças estomizadas. Realizado no período entre dezembro de 2015 e fevereiro de 2016. Utilizados dados do diário de campo e do roteiro de entrevista semiestruturado e realizada análise das narrativas por meio da análise de conteúdo, modalidade temática. **Resultados:** nas narrativas maternas prevaleceram relatos de dificuldade no manejo da estomia, por dificuldade no entendimento das orientações fornecidas pelos profissionais de saúde, sendo unânime em narrar que aprenderam mais com a prática de outras mães do que com os profissionais. Reforçaram também a falta de preparo desses profissionais em lidar na assistência dessas crianças. **Considerações finais e implicações para a prática de Enfermagem:** ao compreender o cuidado, foi possível concluir e apoiar a necessidade de estabelecer prioridades para esse cuidado. As evidências encontradas podem fortalecer o cuidado prestado pelos profissionais de saúde que atuam com as famílias e as crianças com estomias, não apenas nos cuidados de rotina, como também nas ações educativas para serem preparadas a lidarem com a situação.

**Palavras-chave:** Criança Hospitalizada; Estomas Cirúrgicos; Relações Profissional-Família; Cuidados de Enfermagem; Pesquisa Qualitativa; Família.

### RESUMEN

**Objetivo:** comprender la atención de los profesionales de la salud en el cuidado del niño ostomizado. **Métodos:** estudio exploratorio descriptivo con un diseño de investigación interpretativa cualitativa realizado en un hospital público de Brasília

### How to cite this article:

Silva JM, Melo MC, Kamada I. The mother's understanding about caring for stomized children. REME – Rev Min Enferm. 2019[cited \_\_\_\_];23:e-1223. Available from: \_\_\_\_\_. DOI: 10.5935/1415-2762.20190071

entre diciembre de 2015 y febrero de 2016. Población compuesta por nueve madres de niños ostomizados. Se utilizaron datos del diario de campo y del guión de la entrevista semiestructurada; el análisis de las narraciones se realizó mediante el análisis de contenido, modalidad temática. **Resultados:** en las declaraciones maternas prevalecieron los relatos sobre la dificultad en el manejo de la ostomía, debido a la dificultad para comprender las pautas proporcionadas por los profesionales de la salud, siendo unánimes al afirmar que aprendieron más con la práctica de otras madres que de los profesionales. También insistieron en la falta de preparación de los profesionales para tratar de estos niños. **Consideraciones finales e implicaciones para la práctica de enfermería:** al comprender la atención brindada, se ha podido concluir que es necesario establecer prioridades para mejorar dicha atención. La evidencia encontrada puede fortalecer la atención brindada por los profesionales de la salud que trabajan con familias y niños con ostomías, no solo en la atención de rutina, sino también en acciones educativas que los capacite para enfrentar la situación.

**Palabras clave:** Niño Hospitalizado; Estomas Quirúrgicos; Relaciones Profesional-Familia; Atención de Enfermería; Investigación Cualitativa; Familia.

## INTRODUCTION

The definition of the concept of ostomy consists of any opening made in the body with the intention of making a communication with the external environment. The term ostomy or stoma comes from the Greek *stoma*, which means mouth or opening, and can be used for food, elimination or breathing. It aims to decompress, drain, relieve anastomotic tensions, and to restore the functions of the affected organ, as well as to intervene in any other adverse local or systemic conditions.<sup>1</sup> It is a situation that can affect individuals of all ages and for various causes, and its performance should be seen as a therapeutic approach to the diseases, often firstly to be done to solve a problem. When performed in children, the most frequent causes are congenital anomalies and traumas that occur during development, which are mostly temporary stomata and performed in the neonatal period.<sup>1</sup>

Stomized children have specific and unique needs in each phase of their growth and development, with biological, emotional, social and cultural differences that lead them to an individualized care approach.<sup>2</sup> The family members need to be oriented about these care measures from the time of hospitalization, and there is a need to accompany them after discharge.<sup>3-7</sup> Most of the time, however, what happens is a quick training on the main techniques, regardless of the child and family needs. Thus, to take care of these children and meet their real needs, the health team and, especially, Nursing must seek strategies to apprehend the caring demands.

The follow-up of these children and their families by the health professionals is fundamental, as it is understood that the stomized child's care requires from the family the acquisition of

new skills and abilities that are not part of their daily lives. They need to rethink their structure and organizational form, and for this they need the support of the professionals involved.<sup>2</sup> This includes teaching specific ostomy care such as handling the devices and accessories, protecting the peristome skin, preventing hospital admissions, reducing family stress, and identifying the available resources in the community.<sup>3</sup>

This study was justified by the need to invest in research studies related to the intervention of the family and of the health professional in the care of the stomized child. After all, the arrival of a child with the ostomy individuality may bring up several feelings, such as anxiety and fear. Professional support can be crucial in gaining the ability and competence to act safely in this situation.

Therefore, this study sought to answer the following guiding question: what is the family members' understanding as regards the care received by their stomized children during the hospitalization? In order to answer this question, this research aimed to understand the care provided by the health professionals in the care of stomized children, from the perspective of the family members.

## METHODS

### ETHICAL ASPECTS

In all stages of the research, it was sought to comply with the national and international standards of ethics in research involving human beings, a project approved by the Research Ethics Committee of the *Secretaria de Estado de Saúde do Distrito Federal*, under protocol No. 1,257,739 and CAAE No. 38208614.6.0000.5553.

### TYPE OF STUDY

This is a descriptive and exploratory study, and the design based on the interpretative qualitative research constituted the research reference.<sup>8,9</sup> This method comes from the social sciences, but has great applicability in the health sciences, because it involves the understanding of human health and, thus, produces understanding in the contexts in which the health practice develops itself, and then produces knowledge for clinical practice support. For this purpose, we opted for the approach that favored the interpretation given by the authors in the analysis of the participants' speeches.

### RESEARCH LOCATION AND PERIOD

The study was conducted from December 2015 to February 2016. The setting chosen was the clinic and surgery

pediatric units of a public hospital in *Brasília*, Federal District. This is a medium-sized hospital whose purpose is to provide assistance, teaching and research, and where, since 2002, the multidisciplinary outpatient care clinic for stomized children has been structured and centralized. A nurse, a nutritionist, a social worker and a doctor provide the service. This hospital is linked to the Health Department of the Federal District and belongs to the Coordination of the Central Health Regional.

## STUDY POPULATION AND DEFINITION OF THE PARTICIPANTS

The definition of the participants was intentional and met the following inclusion criteria: parents, family members and/or guardians who claim being the main caregivers of the stomized child admitted to the hospital during the research; and had no cognitive limitation. The following were excluded: family members of children in serious condition. In this study, the child's primary caregiver is understood as someone belonging to the family. This family member may be directly responsible for the child in their daily care, that is, the primary caregiver, or someone who assists or replaces them, thus being the secondary caregiver.

## THE DATA COLLECT PROCESS

The interviews were conducted with a semi-structured script. This script was designed specifically for this study. The questions were elaborated after reviewing the literature, in an attempt to capture the speeches that fitted the scope of the objectives. Clear and accessible language was used for this. The script was composed of the characterization of the participants, with information on the hospitalized children's parents, relatives and/or guardians' sociodemographic data and the children's clinical and sociodemographic data, followed by the interview with the following questions: what was taught to you about caring for your child's stoma? Can you take care of your child's stoma? With these questions, it was possible to build a dialog with the children's parents, family and/or guardians, understanding the changes, potentialities, weaknesses and learning in caring for the stoma. During the interviews a field diary was used with the thoughts and feelings in which, the significant data of the researcher involved in the execution of the study were noted, aiming to understanding the speeches of the participants.

Each interview was conducted by the main researcher, face to face with the interviewee, in a place reserved for such purpose, with the only presence of the interviewee and the main researcher. Each one had an average duration of between

30 and 40 minutes. A digital recorder was used to record the speeches, which were then heard and transcribed in full and, at the end, the transcription was compared with the recordings, to reinforce accuracy. Complementary information of the filed diary notes was included in between round brackets. To guarantee the anonymity of the participants, the letter "M" was used to identify each speech, chosen because it is the initial letter of the word "mother", followed by the chronological sequence of the interviews.

## TREATMENT OF THE INFORMATION: CONTENT ANALYSIS

After conducting the field research, each interview was read, seeking familiarization with the speeches and the understanding experienced by the participants regarding the care provided by the health professional. Then each speech was read and reread several times, seeking intuition and synthesis. This process was made in order to thoroughly examine what was stated so as to elucidate the context as a whole, thus presenting the experiences of the phenomenon lived by the participants.<sup>9</sup> In order to reinforce the validity of data interpretation, the speeches were examined by another two researchers with knowledge and experience in conducting research studies with a qualitative approach.

The successive readings of the interviews served to analyze and elaborate the study thematic matrix, which was built in a structured way, analyzing the messages expressed in the verbalizations of the speeches and of the themes identified in the interview script and in the specialized literature that focuses on the subject.

The thematic content analysis technique was used for the treatment of the speeches.<sup>10</sup> Content analysis means a set of communication analysis techniques aimed at obtaining, through objective and systematic procedures for describing the content of messages, indicators that allow for the inference of knowledge regarding the conditions of production/reception of these messages. The modality chosen was the theme, which unfolds in three phases: pre-analysis, material exploration and treatment of the obtained results, and interpretation. The speeches allowed to support the inferences made in the discussion and to interpret them according to the national and international scientific production, as well as to the public policies regarding the care for the stomized child.

To maintain rigor in the study, the list of consolidated criteria for the *Reporting Qualitative Research* (COREQ) as a support tool was used. This consists of 32 verification items in relation to the research team, the research project and the data analysis in relation to the qualitative research methods.<sup>11</sup>

## RESULTS

### CHARACTERIZATION OF THE PARTICIPANTS

Nine mothers participated in the study. The age group ranged from 18 to 43 years old. Regarding schooling, three had completed high school, two had completed college education; and four, only elementary school. Regarding marital status, only three reported not having a spouse, the other were married or in a stable union. The number of children ranged from one to seven. Regarding occupation/profession, more than half reported being unemployed. Only two mothers declared themselves employed, but they are out of the service to take care of their child: a pedagogue and a Nursing technician. As for the number of children, they had one to seven. Only one mentioned not having or following any religion; four of them were Catholic and four evangelical. Only two live in the Federal District, the others in another Brazilian state: *Minas Gerais* and *Goiás* (Table 1).

According to the children's characteristics, their age ranged from four months to 13 years old, seven being boys and two girls. Five of the nine children had gastrostomies and the other four had intestinal ostomies. In this study, it was possible to find the main causes for the stoma reported by the family

members: three children born with an imperforate anus, three children due to the consequences of neuropathy, one with esophageal atresia, one with Niemann-Pick Type C disease and one with volvulus intestinal disease (Table 2).

### INTERPRETATIVE ANALYSIS OF THE DATA

In performing the interpretative analysis procedure, it was sought to understand the mothers about the care for their children's ostomy. More broadly from the speeches, we verified that in the mothers' narratives, reports prevailed of learning difficulties in the ostomy management due to the lack of guidance from health professionals; the mothers were unanimous in stating that they learned more from the practice of other mothers' than from the specialized professionals, evidencing the professionals' lack of preparation and knowledge to deal with children with ostomy.

The analysis of the speeches, by thematic area, develops from five categories: maternal intimacy with the child's stoma, maternal understanding in the care of the child's stoma, maternal strategy for the care of the child's stoma and maternal description of the complications of the child's stoma. The analysis by thematic area is below.

Table 1 - Characterization of the mothers of stomized children participating in the study

	Age	Schooling	Marital status	Occupation/ Profession	Number of children	Religion	Place of residence
1	43 years old	Higher education	Married	Pedagogue	3 children	Catholic	<i>Distrito Federal</i>
2	18 years old	Elementary school	Single	Unemployed	1 child	Evangelical	<i>Minas Gerais</i>
3	35 years old	High school	Married	Housewife	4 children	Catholic	<i>Minas Gerais</i>
4	36 years old	High school	Married	Unemployed	3 children	Evangelical	<i>Goiás</i>
5	29 years old	High school	Married	Nursing Tech	3 children	Evangelical	<i>Goiás</i>
6	37 years old	Elementary school	Divorced	Housewife	5 children	Catholic	<i>Minas Gerais</i>
7	38 years old	Elementary school	Divorced	Unemployed	7 children	No religion	<i>Goiás</i>
8	38 years old	Elementary school	Stable union	Housewife	5 children	Catholic	<i>Goiás</i>
9	31 years old	Higher education	Stable union	Unemployed	3 children	Evangelical	<i>Distrito Federal</i>

Table 2 - Characterization of the children with ostomies participating in the study

	Age	Gender	Ostomy	General illness
1	5 months old	Male	Colostomy	Multiple congenital malformations – imperforate anus
2	6 months old	Male	Colostomy	Multiple congenital malformations – imperforate anus
3	6 years old	Female	Gastrostomy	Niemann-Pick Type C Disease
4	10 months old	Female	Gastrostomy	Neuropathy - Cerebral Palsy
5	6 months old	Male	Gastrostomy	Esophageal atresia
6	5 years old	Male	Gastrostomy	Neuropathy - Cerebral Palsy
7	13 years old	Male	Colostomy	Multiple congenital malformations - imperforate anus
8	6 years old	Male	Gastrostomy	Neuropathy - Cerebral Palsy
9	4 months old	Male	Ileostomy	Intestinal volvulus

## MATERNAL INTIMACY WITH THE CHILD'S STOMA

Intimacy was defined in this study as resourcefulness or mastery in the handling of something. The intention of this theme is to identify how the experience of the mothers was when dealing with their child's stoma, what the challenges were and how they mastered this care. It was divided into only one category, called general report, and in four indicators: beginning, challenges, learning and experience.

The beginning indicator was shared with all the mothers. Some more communicative mothers gave very detailed reports and others, with just a sentence or a word, were able to convey their understanding, and presented in their speeches feelings of inability and fear to deal with this novelty of their children, the stoma. Some pointed out that they received superficial guidance and others none. See the following examples.

*[...] Even in the ICU, when I asked to see, because I was curious, right? So, right there the head nurse already taught me (M1).*

*[...] they started teaching me like that because of... because his skin was chafing a lot (M2).*

*[...] At first we didn't have much experience, right? [...] (M3).*

*[...] at first, it was very difficult because I didn't know anything (M8).*

*[...] the doctor gave me guidance shortly after the surgery (M9).*

In addition to the difficulties faced by them, the challenges indicator, also shared with all mothers, brings about the lack of guidance, the fact that some children require extra care with the ostomy, such as the occurrence of contact dermatitis or granuloma. Four record units were described, as follows:

*[...] the first moment I saw, I had a feeling of faintness [...] in the first bath, I panicked (M1).*

*[...] he had allergy to the bag, so he couldn't use it (M2).*

*[...] the gastrostomy always leaked and she had granuloma (M3).*

*[...] they didn't give me any orientation, they just said that they were going to do it for her not to eat through the mouth (M4).*

The learning indicator briefly describes how the mothers and families learning was in the care of the ostomy. They try to translate what this moment was like, when despair often arose, and it was necessary to seek other sources of knowledge and support from other experienced mothers. Thus, five record units were described.

*[...] they arrived here in the room and they taught already, they even made a little cream (M1).*

*[...] they taught me how to do the little cream, taught me how to put it [...] (M2)*

*[...] as time went by, my husband and I were taking our own, it's [...] good, we were learning to take care of her (M3).*

*[...] after he left the ICU, when I got here, the nurse taught me (M6).*

*[...] the nurses from the HUB taught me how to clean it right (M7).*

The experience indicator shows how mothers managed to overcome the initial phase when they were very afraid and insecure. At the time of the research, they knew how to deal with the ostomy, and to master the care and so were praised by the hospital professionals. Five record units were described:

*[...] I take a diaper, one that doesn't lose much cotton, then I cut it and I make a little hole according to the ostomy (M1).*

*[...] one day a little mother interned, because here one learns from the other, then she taught me a gel NaCl [...] but then I discovered that the best of all is soap and water (M3).*

*[...] you have to measure the bag right, clean around, so not to generate infection, right? (M7).*

*[...] his gastro is one of the best here, I'm well praised for them here for taking care of him (M8).*

## MATERNAL UNDERSTANDING IN THE CARE FOR THE CHILD'S STOMA

In this study, understanding is the comprehension of the mothers in the care of their children, if they perceive themselves as active agents in this care and feel insecurity or fear. It is



divided only into one category, called security, and only one indicator, yes. This indicator was unanimous for all mothers in which their answers, as units of record, were all positive, stating that they feel safe when exercising the care of their children's ostomies and that they do not feel any fear, they have total autonomy. Four record units were separated, as follows.

[...] *I have it, I know everything* (M2).

[...] *I have it, I'm not afraid of anything* (M6).

[...] *Easy, I'm not afraid* (M7).

[...] *I have plenty of confidence* (M9).

## MATERNAL STRATEGY FOR THE CARE OF THE CHILD'S STOMA

In this study, strategy is understood as the personal way that each of these mothers has to take care of their children, the particular way to perform hygiene and skin peristomy protection. The intention was to know their method and, if necessary, to help them. This theme was divided into only one step-by-step category and two indicators emerged: hygiene and protection. The hygiene indicator brings about the tactic used by each one to perform the hygiene of their children's ostomies, some use only water and gauze, but most use soap and water. We did not identify any way in which the form of hygiene would harm the child. Six record units were selected to exemplify, see below.

[...] *I sanitize with water, with soap. I only wet the gauze in water; first I remove the excess without water, then the gauze goes with the water and sanitizes, then I use a clean gauze and gradually remove it* (M1).

[...] *I always walk with a bottle of soapy water and another bottle with water, so when I change it, I use some soap and water, and then with the water later* (M2).

[...] *In the morning if I see it is dirty, I take a distilled water, throw it there, shoot it dry, and put a dry gauze; at the bath time, I throw some soapy water, rinse and dry it well* (M3).

[...] *I took a gauze, wet it with soap and water and wipe around* (M7).

[...] *I clean only with a gauze and water* (M8).

[...] *I clean the probe with alcohol, where the secretion comes out, then when I bathe it I wash it with soap [...] and the bag I am always changing, every hour, right?* (M9).

The protection indicator was also shared with all the mothers, but in this item each had a special way of protecting their child's skin and ostomy. Some used only some kind of oil; others used another type of home or industrialized protector. Six record units were selected:

[...] *I take a cream then I mix it with sunflower oil, then mix it with cornstarch and the cream, then make a paste and put it around. Then there is that powder that I put too* (M1).

[...] *I always walk with his little cream already done, right? After cleaning, I put his cream on top, then close with the diaper* (M2).

[...] *never removing the gauze without throwing water, it can hurt her skin... after drying well, I put a little dexa and a gauze and leave it, always keeping it dry and clean* (M3).

[...] *I use sunflower oil* (M4).

[...] *if it is necessary, I use the Dersane oil* (M8).

[...] *after washing it I put estomareli around, because sometimes it leaks a little bit, not to hurt his skin [...]* (M9).

## MATERNAL DESCRIPTION OF THE COMPLICATIONS OF THE CHILD'S STOMA

In this theme, the intention was to observe the description that the mothers give when their children's ostomies have a problem or complication. It has been observed that they do not have any scientific basis for what they bring about as problems, only reports of what has already happened to them. For example, if we formulated any complication hypothesis that never happened to them, they might not be able to classify it as a problem. This once again makes sure that their knowledge is based on their experience with their children and on the exchange with their peers, little of what they know has been passed on by a professional. This theme was divided into only one category, observed characteristics, and four different indicators: bleeding, edema, discharge, and erythema.

[...] *yes, when little white balls appear on his side or when it was bleeding* (M1).

*[...] her skin was getting very swollen, very ugly [...] is visible when it is needing more care (M3).*

*[...] I know, starts to have a secretion, the little secretion goes down (M4).*

*[...] a yellowish discharge starts coming out (M5).*

*[...] it becomes reddish and around it also becomes reddish (M7).*

## DISCUSSION

The data obtained reinforce that a child's hospitalization brings much discomfort to the family dynamics, arising negative feelings such as anger, despair and especially guilt.<sup>12</sup> These feelings are amplified when the child needs surgery, as in the case of a stoma, and especially because these surgeries are usually done in a hurry, they are emergencies and usually with a few days of life or even on the same day of birth.<sup>13</sup> All of these factors cause a lot of stress for the family.

This study confirms that, at hospitalization, most of the time, the mother is the main caregiver and responsible for the link between the family and the hospital setting.<sup>12</sup> The woman's role as a caregiver is seen as natural, as it is socially inserted in the mother's role. Her presence implies the maintenance of affection, offering emotional support and direct care to the ostomy.<sup>14</sup> This support is reflected in the following aspects: ostomy and peristomy skin hygiene, change, emptying and hygiene of the collecting equipment, observation and treatment of the signs of ostomy abnormality and also the disposal of the collecting equipment.

The greater the dependency of the child and, consequently, the more time spent on the care measures, the worse the caregiver's quality of life will be, especially when he or she has other responsibilities, such as other children or employment. Thus, depending on the social structure, she may have people in her support network, such as neighbors, spouse, child or other family member. Sharing this care for the child will directly impact on the stress response that this woman may have – depression, anxiety, fear, anger – and on coping with these responses.<sup>12,15</sup>

Therefore, the care provided by the health professionals should target the child-mother dyad and not just the hospitalized child. Trust and bonding among health professionals-child-mother will occur the earlier the care and attention to the dyad occurs. This bond will contribute to coping with the situation experienced by the mother and even to the child's healthy growth.<sup>2</sup>

After the ostomy surgery, it is very common for the mothers to have difficulty and even fear to take care of their children

alone. After all, something is very different; the physiological site for bowel movement or gastric feeding is no longer the same. And they recounted anxiety in insecurity, unable to hold and care for their children, such as performing hygiene around the stoma. In addition, the visibility of the ostomy in the abdominal region is something that impresses at first and not all feel comfortable to see or have contact with it, some even report feeling bad, with episodes of fainting in this first contact.<sup>12</sup>

Another moment narrated by the mothers is the moment to know the child's ostomy, learn how to handle, clean, exchange bags and know all the necessary devices. This is a period of great anxiety as the mother must acquire new skills and master them. For this matter, qualified professionals are necessary to provide the information, teach the techniques and solve all doubts; ensuring the parents are aware of the procedures performed; and provide more security and peace of mind for its realization.<sup>15</sup> The professional must respect each mother's adaptation phase, inserting them gradually in the care of the child.

However, this teaching and learning process is complex and stressful for them, especially when they are distressed and worried. The nurse is the professional responsible for ensuring that the parents get the correct information, understand it and use it properly. The study, however, presented results that corroborate the assertion made in this research: that most of these mothers do not receive guidance, and when they do; it is very superficial or incomplete, which makes them look for other sources of knowledge, such as information exchange with other mothers.<sup>15</sup> During hospitalization, when orientation is not performed correctly, hospital discharge is hampered due to fear and insecurity regarding the need for specific care with the ostomy and its devices. Therefore, the lack of specialized and qualified professionals reflects in the care for this dyad.<sup>2</sup>

The health professional, especially the nurse, must have educational skills in guiding the mothers to care for the child with ostomy and their devices. They should devote time to dialog, allowing empathy and mutual trust, facilitating understanding in the care process and preparing them for the performance of care delivery skills.<sup>2,15,16</sup> The nurses need to receive frequent guidance updates to inform about management and decision-making updates on the treatments used in the clinical practice.<sup>17</sup>

Given the above, we present some limiting points of this study: impossibility of generalization - it is observed that some mothers experience the care for the child with ostomy according to their family dynamics and knowledge; the scenario - the study was conducted in a restricted location, a single hospital, which has specific norms and routines, reducing the ability to generalize the findings. Despite these limitations, the results may cause changes in the relationship of the health professionals in the care of children with ostomies and their mothers.

## FINAL CONSIDERATIONS

With this study, it was possible to achieve the proposed objective as it became possible to understand the care provided by the health professionals in the attention of the stomized child, from the perspective of the family members. This care has situations that involve various aspects: technical, emotional and social. This demands preparation and assertive behaviors in the guidelines of health education passed on to the family members, transforming these fearful family members into confident and competent family members for care.

Most of the time, the use of stoma in children is temporary; however, it requires skill and competence in care, either in the specific area, such as the region to protect the skin near the stoma, as in the situation of nutritional maintenance and social needs of the child. Thus, it is understood that the evidence found proposes to provide data that allow not only reflections to improve the performance of the professionals, but also to adapt collaborative actions to improve the care provided, not being restricted to routine care for the maintenance and protection of the stoma, but also to educational actions to prepare the family members to deal with the situation. Thus, it is necessary that further research studies be carried out, with a similar methodological design, conducted in other health units, and thus portray the essence of care directed to children with ostomy and their families.

## ACKNOWLEDGMENT

To all the children and family members who live with the ostomy.

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