Revista
Brasileira
de Enfermagem
REBEn

ORIGINAL ARTICLE

Stomized children care practices: narratives of relatives

Práticas no cuidado à criança estomizada: narrativas de familiares
Prácticas en el cuidado de un niño estomizado: narrativas de parientes

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How to cite this article:
Melo MC, Vilas-Boas BNF, Martins BL, Vasconcellos AWA, Kamada I. Stomized children care practices: narratives of relatives. Rev Bras Enferm. 2020;73(2):e20180370.
doi: http://dx.doi.org/10.1590/0034-7167-2018-0370

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Submission: 05-29-2018 **Approval:** 10-07-2018

ABSTRACT

Objectives: to understand the practices adopted by relatives regarding ostomized children care. **Methods:** qualitative approach, conducted with 11 relatives of ostomized children. Methodological framework was used as narrative technique; NVivo® software for data categorization and information analysis; content analysis technique. **Results:** participants revealed unpreparedness in dealing with children, lack of knowledge about handling materials and equipment inherent to ostomy and challenges faced in the daily life of children in school. They are unanimous in telling they feel encouraged and strengthened by receiving support from nurses in child care. They suggested the development of strategies to guide ostomized children care, such as educational material use. **Conclusions:** to understand family members' experience made it possible to support training and qualification of nursing professionals, and to establish priorities in care. Evidence found may contribute to reflections that aid health promotion and prevention of complications in ostomized children care.
Descriptors: Health Education; Professional-Family Relations; Nursing Care; Qualitative Research; Software.

RESUMO

Objetivos: compreender as práticas adotadas pelos familiares no cuidado à criança com estomia. **Métodos:** abordagem qualitativa, conduzida com 11 familiares de crianças estomizadas. Utilizou-se referencial metodológico como técnica narrativa; *software* NVivo® para categorização dos dados e análise das informações; técnica de análise de conteúdo. **Resultados:** participantes revelaram despreparo para lidar com crianças, desconhecimento do manuseio de materiais e equipamentos inerentes à estomia e desafios enfrentados no dia a dia da criança na escola. Unânimes em narrar que se sentem encorajados e fortalecidos ao receberem apoio dos enfermeiros nos cuidados à crianca. Sugeriram o desenvolvimento de estratégias na orientação de cuidados à criança estomizada, como a utilização de material educativo. **Conclusões:** compreender a vivência dos familiares possibilitou apoiar formação e capacitação de profissionais de enfermagem, e estabelecer prioridades no cuidado. As evidências encontradas podem contribuir para reflexões que auxilia promoção da saúde e prevenção de complicações na atenção à criança estomizada.
Descritores: Saúde da Criança; Estomia; Integralidade em Saúde; Família; Enfermagem Pediátrica.

RESUMEN

Objetivos: comprender las prácticas adoptadas por los miembros de la familia en el cuidado de niños con estomía. **Métodos:** enfoque cualitativo, realizado con 11 parientes de niños ostomizados. La referencia metodológica se utilizó como técnica narrativa; Software NVivo® para categorización de datos y análisis de información; técnica de análisis de contenido. **Resultados:** los participantes revelaron falta de preparación para tratar con niños, falta de conocimiento sobre el manejo de materiales y equipos inherentes a la estomía y los desafíos que enfrentan en la vida diaria de los niños en la escuela. Unánime al decir que se sienten alentados y fortalecidos al recibir el apoyo de enfermeras en el cuidado infantil. Sugirieron el desarrollo de estrategias para guiar el cuidado infantil estomacal, como el uso de material educativo. **Conclusiones:** la comprensión de la experiencia de los miembros de la familia permitió apoyar la capacitación y la calificación de los profesionales de enfermería, y establecer prioridades en la atención. La evidencia encontrada puede contribuir a reflexiones que ayudan a la promoción de la salud y la prevención de complicaciones en el cuidado de niños ostomizados.
Descriptores*:* Salud del Niño; Estomía; Integralidad en Salud; Familia; Enfermería Pediátrica.

INTRODUCTION

Ostomy performance has a relevant impact on stomatized children and their family's lives, both in physical, emotional, social, and spiritual realms. When this problematization involves ostomies in children, the situation is no different. Relatives of ostomized children have to acquire skills that were not part of their daily lives, which requires multidisciplinary monitoring(1). It is also necessary to strengthen the family so that it can find its way to participate in daily care and develop its potential(1-3). Nurses are health professionals who are able to offer care that meets the needs of the individual and family.

The word "ostomy" or "stoma" means mouth or opening. It consists of artificial communication from internal organs to the external environment for elimination, breathing or nutrition(4). Interventions with ostomy involve care, such as maintaining peristome skin integrity, with careful hygiene; correctly change the collecting device; perform dressings; prevent dermatitis; check ostomy operating conditions; and predict complications (necrosis, infection, bleeding, trauma, invagination, and evisceration)(2,5-6). Nurses have a fundamental role in guiding ostomized children, relatives and caregivers on health care, to promote active participation in daily life, as well as to encourage and strengthen them in the face of the required changes.

This study highlights the need for investments in research related to family intervention in ostomized children care. It aims to instrumentalize relatives and health professionals' performance, especially nurses, besides broadening the body of theoretical knowledge in nursing based on scientific evidence. The question that guided the study was: how are care practices for relatives in ostomized children care established?

OBJECTIVES

This study aims to understand the practices adopted by relatives regarding ostomized children care.

METHODS

Ethical aspects

This study was approved by the Research Ethics Committee of the Federal district's Health Sciences Teaching and Research Foundation (*Fundação de Ensino e Pesquisa em Ciências da Saúde*). Opinion was issued on April 13, 2015, and had CAEE (*Certificado de Apresentação para Apreciação Ética* - Certificate of Presentation for Ethical Consideration). Development met national and international standards of ethics in research involving human beings. All participants were informed about the purpose of the study, as well as anonymity, confidentiality, access to results and the freedom to not answer questions that might cause embarrassment. All signed the Free and Informed Consent Term, prior to the beginning of data collection, according to guideline and regulatory standards involving human beings criteria - Resolution 466/2012 of the Brazilian National Health Board (*Conselho Nacional de Saúde*) for research with human beings, with privacy and individuality guarantee.

Type and period of study

To understand practices adopted by relatives regarding ostomized children care, this study follows a qualitative approach(7) and uses narratives as a methodological framework(8). This is a study conducted between May 2015 and February 2016.

Methodological procedures

Initially, the health service coordinator was requested and made available a list with names and contact details of ostomized children under follow-up, and from this list, families were located. An invitation was delivered, through nurse group, to each relative who follows their child monthly, a total of 40 children. At the time of delivery, the research purpose was presented as well as people who would conduct it. In order to reinforce invitation, confirmation was carried out by telephone, one day before the scheduled activity.

Study setting

The research was conducted in a hospital linked to the Federal District Department of Health, which belongs to the Southern Regional Health Coordination.

Data source

Participant selection for conversation round was intentional and followed the inclusion criteria: having ostomized children in the family; aged 0-12 years incomplete; perform outpatient follow-up at hospital service of the State Department of Health of the Federal District belonging to the Southern Regional Health Coordination; be resident in the city or regions adjacent to the DF; and be responsible for the child, directly or indirectly, being primary or secondary caregiver. Relatives of critically ill children admitted to a health facility were excluded.

"Child" was a person between 0 and 12 years old. This denomination is in accordance with Article 2 of the Brazilian Child and Adolescent Statute (ECA - *Estatuto da Criança e do Adolescente*)(9). The proposal to use ECA is due to the fact that there are other denominations of the term "child" in literature. As an example, the World Health Organization (WHO) establishes the use of the term "child" for people from 0 to 10 years of age. "Relative caregiver" relates someone from family or someone alike without health education who has been gaining experience (this is the definition adopted by the Brazilian Ministry of Health and this study). This relative may be directly responsible for the child in their daily care, that is, primary caregiver or someone who assists or replaces him, being secondary caregiver(10).

In this study, it was performed only from a conversation round. Invitation to participate in the conversation was delivered to 40 relatives of children enrolled in the program, but only 11 relatives attended it. During conversation round development, there was little variance in relatives' narratives, resulting in data saturation. There was no need for other moments with the same participants.

Collection and organization of data

Two resources were used for data collection: for participants' characterization, socioeconomic and demographic questionnaire was applied; to obtain the reports, conversation rounds(11) were performed using semi-structured. By narrating their daily life, participants not only conveyed information, but also allowed us to capture their view, define their experience and deepen their investigations, and thus retrieve the most relevant aspects of the experience. To ensure anonymity, participants were designated with the letter F and a sequential number from 1 to 11.

On the scheduled day, November 12, 2015, participants were greeted and embraced in a hospital unit room reserved for meetings. Chairs were organized in a circle, promoting eye contact and encouraging interaction among participants. Soon after, the questionnaire was distributed to collect socioeconomic, demographic, and clinical data. Participants who could not or could not write were assisted by one of the supporters.

Conversation rounds were organized by two researchers who have experience with this methodological strategy, and carried out with the support of three undergraduate nursing students in the School of Health Sciences' Scientific Initiation Program (*Programa de Iniciação Científica da Escola Superior em Ciências da Saúde*), a DF's public institution. For this support, it was necessary to conduct student driving meetings for the activity. Two meetings were held, and the following themes were chosen: about embracement, relative approach, guiding question conduction, participant group relaxation, positioning at the moment of filming, field diary relevance for this activity, among other points.

A semi-structured script was prepared consisting of the following questions: What is it like to care for ostomized children? Talk about the beginning and the daily life. How were you prepared for this care? How could your experience help another person in the same situation? Questions were thrown to the group and each participant narrated their experience. During this process, other questions were formulated in order to explore verbalizations and deepen reports' understanding. The session lasted about an hour.

Conversation rounds were a technique chosen to favor interaction among participants and thus data collection. This technique suggests that the group is not large, but may have commonalities - in this case, all were relative caregivers of a stoma. A small group facilitates theme exploration, discussion deepening and reflection exercise.

Statements were recorded and filmed, being transcribed shortly thereafter. After transcription, additional information from the field diary was included in parentheses. Then, consecutive readings were made with time frameworks of the text content and also structuring of the information collected. Qualitative Solutions Research NVivo® 10 was chosen for data categorization(12).

NVivo® is a qualitative analysis software that works with data from different collection tools - interview transcripts, focus groups, field notes and reports, among others. Data are in document format, where interviews are stored. The program allows to encode in the text the so-called "nodes". Nodes are spaces where categorization is located and where terms or word cloud are visualized, being formed by the frequency of citations present in each category.

For this study, peculiarities of ostomized children care were used as pre-categories. Coding was performed by two researchers separately. Subsequently, a crossover was carried out, thus seeking greater process reliability. All lines of text have been numbered to make the process easier.

Data analysis

As categorization was performed with software support, information analysis was carried out using the content analysis technique (thematic categorical type proposed by Bardin)(13). Pre-analysis, material exploration or coding and treatment of results - inference and interpretation were followed. The material was grouped, read, reread and reorganized by two researchers. From the reports, six Nodes (categories) and 21 Subnodes (subcategories) were coded, which allowed us to substantiate the inferences created in discussion, and interpret them according to national and international scientific production as well as public policies related to the theme.

To maintain study rigor, the list of Consolidated Criteria for Qualitative Research Reports (COREQ) was used as a supporting tool. This consisted of 32 verification items regarding research team, research project, and data analysis(14).

RESULTS

Eleven relatives of 10 ostomized children were interviewed (nine mothers, one aunt and one father accompanying his wife). All were between 20 and 40 years old. In terms of education, six people had complete elementary school, four completed high school and one completed higher education. Regarding relative income, six received up to one minimum wage from government aid, and four received more than three minimum wages. One person did not report income.

Of the children, seven were under 2 years old and three were over 7 years old. All were schoolchildren, living in the surrounding region. Two of the ostomies were definitive and eight temporary: eight children intestinal ostomy (seven colostomies and one ileostomy), one urostomy and one gastrostomy. Hirschsprung's disease was the predominant motivation of ostomies. Only one child had autonomy for self-care. Regarding the main caregiver, three were cared for by the mother and the father, one had the aunt as secondary caregiver, and the other only by the mother.

In the speeches of relatives, ignorance and unpreparedness to deal with ostomized children prevail. Relatives were unanimous in reporting that, despite the difficulties, they get support from health professionals, especially the nursing staff. In addition, they narrated the relevance of exchanging information among peers, and gave the idea of receiving information from health professionals or through an educational booklet.

The episodes narrated develop from five themes: *family experience in ostomized children care; guidance and follow-up to ostomized children care; relatives' perception with school-age ostomized children; implications for ostomized children care;* and *facing the situation regarding ostomized children care*.

Family experience in ostomized children care

"Experience" was defined as the way each person lives or behaves. This theme aims to understand the family's daily life living with the ostomized children. The understanding of this theme was made possible by grouping the nodes "difficulty" and "initial problem". The inference that stands out from narartions are difficulties faced by relatives in this care.

For relatives, "difficulty" is related to the obstacle to the experience of ostomy care, expressed as the subnodes "fear", "daily life", "frustration", "experience", "specialized care" and "adaptation to the stoma". Difficulties were shared by all relatives. Problems and concerns were narrated, reinforcing the relevance of relatives being close to ostomy and people from its support network. The pair of nurses who serve this clientele at the hospital stands out:

> [...] *At first it was very difficult, we do not know how to handle the tube* [gastrostomy], *but over time you learn, everything is easier* [...]. *Today he is 9 years old. We left a hospital on Tuesday* [...], *and then he stayed at home, so I came here.* (F2)

> […] *we have to work, there are no conditions, I earn little, I can't afford a nursing professional, we pay a nanny, an ordinary person, but it's hard, because a lot of people don't want this kind of work* […]. (F9)

"Initial problem" is related to the relatives' experience with the diagnosis or the problem that led to ostomy. It is expressed by the following Subnodes: "initial moment report", "follow-up", "initial neglect", "ignorance", and "fortress". Relatives narrated the problem from the beginning, the situation experienced with the new, complications that arose and the itinerary for care taken by families:

> [...] *he had surgery but found out at 7 years old that he has megacolon* [Hirschsprung's disease], *I don't understand how he didn't find out before, I was shook!* (F2)

> [...] *When I got here, I saw many children with problems, I met many mothers who had problems with their children, that's where I got more aware of the situation. Then he had the surgery, stayed in the ICU for a few days, but it was quick* [...]. (F6)

Guidance and follow-up to ostomized children care

As ostomy is a surgical procedure and needs guidance and follow-up from preparation, going through preparation in pre, trans and postoperative periods and home care, this theme was organized in the node "first exchange".

Relatives identified, in this theme, the main difficulties presented in ostomy care, in the first days, in hospital or at home. From this Node, they highlighted the subnodes "lack of adequate material", "lack of guidance", "inadequate guidance" and "difficulty in adapting". The idea that stands out from reports is the difficult conditions faced by relatives in the first contact with ostomy:

> [...] *By the time she left the hospital, she had already left with her bag, and first received bags for a month. I was sent to* [another] *hospital and had to get there, they only gave ten bags for a month. Then it was a struggle to get it, I got angry!* (F4)

> *Actually, my son doesn't use a bag because it's too low* [colostomy]. *I was informed by doctors* [pediatric surgeons] *about megacolon* [Hirschsprung's disease]. *They said how they have to do it, how it worked* [...]. *They are already used to it, it sounds like a simple thing, but I got scared!* (F10)

Relatives' perception with school-age ostomized children

Here we tried to understand relatives' perception in relation to ostomized student care. As already narrated, of the ten ostomized children in this study, three were of school age, and the situation of ostomy aggregated this.

Perception was defined as the ability of relatives to observe ostomized student's dynamics. This theme was organized according to the node "school". From this node, "difficulty", "adaptation", and "support" were built. The idea that stands out from narrations are ostomy daily reports in school and conditions faced:

> *In fact, the first day he went to school with the bag, it popped and leaked all the stool, it was hard! The colleagues kept looking at my son strangely* [...], *looking at him with another look.* (F3)

> *At school there is the teacher and the monitor, I explained, I showed everything how you do it. I showed that in the case* [child] *has everything. Then they* [teacher and monitor] *adapted well!* (F4)

Implications for ostomized children care

"Implications" in this study are related to what the relative needs to know to provide ostomized children care. The theme was constituted by the node "information". The idea that stands out from narrations is communication relevance, knowledge exchange on ostomy with peers and health professionals. For relatives, "information" is about the exchange of insight or ideas that each relative received or discovered, whether by talking to professionals in the field, or by reading books, booklets, or websites. From this node were derived "information" and "tips":

> […] [It is] *also interesting to receive a booklet with the information* […], *it is very important to put in this booklet that there are many people who have prejudice.* (F5)

> *It's interesting to show also the complications that can have, because if you have bleeding, the person needs to know what to do* [...]. (F10)

> […] *There are people who use paper, put the powder after the ointment dries, this ointment is the same used for baking. The solution I found was to put on a daily protector* [instead of diaper] *because it warms the area less.* (F11)

Facing the situation regarding ostomized children care

This last theme reflected encouragement, support, and hope directed to the other who goes through the same situation. The theme is represented in "message" and "difficult" and "perseverance". The idea that stands out from narrations is encouragement for relatives to manage ostomy in daily life. It strengthens each other and creates integration among peers:

> *I have two sentences, it's hard, but it's normal* [...]. (F3)

> [...] *At first comes despair, but everyone learns, just want and try. Nowadays there's a lot of resources, a lot of people wanting to help, so there are a lot of stomatherapists, nurses, so it's not the end of the world, there's a lot of people to help, it's a phase that goes by* [...]. (F5)

> [...] *I think God knows what He does! I thought I would not have the strength to deal with his problem, we will learn. Have strength, courage! It's a phase in his life.* (F8)

DISCUSSION

The data obtained suggest that caring for relatives with children with health problems - in this case, the presence of ostomy - is not a static process. It is a continually changing one, especially in relative dynamics to suit the constant child care, hospitalizations and uncertainty about the future. All these aspects are experienced by relatives who, therefore, risk being affected in their relationships, being the mother figure, in most cases, the main caregiver.

Ostomy is a result of a congenital defect and may occur in the digestive, urinary/respiratory system or abdominal wall. Traffic reconstruction depends on underlying disease and surgical interventions. In relative understanding, although it is a problem solution, carrying out ostomy also becomes the cause of multiple disorders in the child's and family's daily life. It implies changes in the physiological process and lifestyle, as well as greater demands on caregivers for time and resources(15).

Studies confirm that nurse experts in ostomy care are differential in care. It is up to the nurse not only to deal with devices, but also create subsidies to guide health education and provide independence in intra and extra-hospital care(5-6,16).

Malformations or deficiencies leading to ostomy are necessarily prenatal. Malformation may occur before conception, affecting the production of the affected egg, or during pregnancy's first quarter, affecting embryo development. It may also appear at more advanced stages of pregnancy, injuring the well-developed fetus(17). Early diagnosis enables improvement in birth conditions and care for children and, consequently, increased survival.

The predominant disease, in this study, for ostomy need was Hirschsprung's Disease or Congenital Intestinal Agganglionosis. This disease is an anomaly of the enteric nervous system, characterized by severe constipation in newborns associated with colon hypertrophy due to changes in viscera intrinsic innervation. In many children, disease signs and symptoms do not show up in the neonatal period, but they manifest later. Thus, due to the characteristics similar to those of chronic constipation, diagnosis becomes lengthy(16). Long-term follow-up is required. Relatives should be carefully welcomed, oriented and calm in their expectations and daily care.

In "guidance and follow-up to ostomized children care", it was found that being a caregiver for a child with congenital malformation or chronic disease is not an easy task, acquiring significant importance for the family, as he effectively wants become responsible for care. Thus, strategies for coping with ostomy-related problems are developed, especially in care practice.

Several studies present the need for attention of the multidisciplinary team, especially with the presence of nurses. They point out as primary approaches recovery and integration of the individual in the relative and social environment. Knowledge about anatomophysiological aspects of clinical and surgical treatment is not sufficient to support a more effective proposal for comprehensive care. Other factors that affect the affective relationship between child and his relatives, relative and social discrimination of the child, and difficulty of accepting and caring for the disabled child should be known(1,15-16,18)

As ostomy is carried out, family and children go through a long adaptive process. Relative support is therefore an important mechanism in the face of the difficulties faced in daily life. Nurse training to care for the child's ostomy should be progressive, so that mother and/or relative are able to perform them until hospital discharge(19-20).

In order to conduct guidance, reduce family anxieties and assist the ostomized children, health professionals must have technical and humanized training. It is an essential requirement for a trusting relationship with families. Professionals should, among other things, provide information about care, impart specific knowledge (such as maintaining peristome skin integrity), advise on hygiene and change of the collection device, and also inform about the material available at outpatient clinics(5,16). This will help to reduce anguish, fear, and anxiety due to lack of awareness of the situation.

After reflecting on these aspects of family and child experience, it is necessary to highlight that, in "relatives' perception with school-age ostomized children", narrations presented relatives willing to rescue from ostomized children' daily life, limitations imposed by life. Resigning oneself to being away from school produces negative repercussions on psychological and social development, since it is at school that children develop cognitive and motor skills, establish the first social ties, and understand the need for interaction between family, teachers, and peers. So it is important to encourage her to attend school, even in the face of mishaps.

In this sense, the school must enable learning that enables children to build their own knowledge. The situation must be planned to receive these children. Therefore, teachers are prepared to deal with any limitations and procedures that may be required; adjusting the physical space of the school, with regard to accessibility, structure and hygiene of toilets, ensuring adequate space for performing the procedures; and preparing colleagues to receive the colleague and his limitation. Individualized care planning for ostomized students is necessary, aiming at their inclusion, not only integration(21-22).

Problems related to ostomized people care are known throughout the country, as well as lack of care policy that integrates health and social assistance. This is contrary to the precepts of isonomy expressed in article 5, as well as articles 196 and 198 of the Federal Constitution of 1988(23). In Brazil, Ordinance 400(24), deliberated by the Health Care Office, establishes the general guidelines for health care services of ostomized people. This Ordinance values ostomy care, but still requires vigilance from state and local agencies. Thus, in "implications for ostomized children care", relatives reinforced the need to obtain information on the supply of appropriate products; the correct use of the devices; the possible complications and complications; and how to follow the evolutionary process of the underlying disease(5,18).

Advice on stoma care should be added to information to detect complications and observe changes: color, size, shape, protrusion, moisture and mucosal integrity, peristoma hyperemia, stenosis. There is still need for guidance in pediatric surgery units, which favors safety in home care. It is necessary that health institutions invest in professional training in the technical, human and material areas, so that all receive specialized care during diagnosis, treatment, guidance and follow-up. Guidance should be in accordance with the individual's sociocultural understanding or relative. Studies with a qualitative approach present reports of mothers feeling safe and receiving information, as devices require skill to handle them(1-4,18).

Given the obstacles that interfere in the relative and the child's daily life, it becomes necessary to adjust to reality. Given this, "facing the situation regarding ostomized children care" reveals encouraging information, as relatives face an overload of activities and demands that can lead to physical, emotional stress and stress(21). In general, the accumulation of activities falls on the mother, who often needs to leave work outside the home or reduce the workload to take care of the child's physical and emotional care, just when the family most needs extra income(4,21).

The need to develop means that facilitate the continued presence of one or more caregivers causes changes in the relative lifestyle and rescues their potential. The relative environment could therefore be safe and quiet as it will serve as a basis for ensuring the necessary adaptations. Support in care aims at a rapid recovery and rehabilitation of the child, bringing benefits to the ostomized and preventing complications.

Study limitations

The study presented as a limitation not being representative of a broader reality, that is, performed in only one ostomy child care service. Therefore, it is impossible to generalize, making it necessary to be replicated in other places of care for ostomized children, in order to seek understanding of the experience of other participants. Despite this limitation, the study achieved its objective, as it presented the understanding of relatives regarding ostomized children care.

Contributions to nursing

This study infers the need for health professionals, especially nurses, to maintain a relationship of trust with families, in order to ensure the benefits and quality of care for ostomized children. Therefore, there would be group and intergroup relationships resulting from the relative, school and social coexistence of child and relatives.

Ostomized children and their families should be prepared to develop their skills and potential. This preparation involves the pre, trans and postoperative moment in stoma preparation. When well planned, they favor the individual's and family's autonomy. Pediatric nurses need to act, as this reduces anxiety and increases self-confidence in the daily stoma care in hospital and home environments.

As school-age children, the need for institutional and interinstitutional support by the teacher regarding ostomized children care is necessary to change the curriculum of teacher education and specialization. This should occur for the strategies used are broadened and appropriate to ostomy. It favors an active role in promoting children's health. Ostomized children inclusion in school units is provided with actions not only on teacher training, but also on physical environment adequacy and multidisciplinary care possibility (involving the school nurse in student care and teacher support).

School can be another space for nurses' activity. Their presence in school units is supported not only in curative care to be performed, but also in health education preventive actions by reducing the barriers to ostomized children school inclusion.

Another contribution that this study favors is elaboration proposal of an educational booklet, as proposed by participants. It would facilitate information conduction to relatives and children, as well as teachers. Didactic materials streamline health education activities as long as texts are constructed with simple language, easy to read and understand, besides being consistent with the target audience and followed by illustrations.

CONCLUSION

This study evidenced the understanding of the relatives' experience in the daily ostomized children care, adding knowledge and elements that facilitate and support social and school dynamics of this child. Understanding how relatives perceive ostomized children care practices, coupled with coping with difficulties, allowed relatives to develop positive and strengthening strategies. Significant aspects emerged from both literature review and relative report. Due to the relevance and timeliness of the theme, understanding of these aspects can help and strengthen care by nurses who work with families and ostomized children.

ACKNOWLEDGMENT

A special thanks to the relatives who agreed to participate in this study and their children who are more than special. And to the nurses Taciana Ramalho and Ana Flávia Lima Araújo who brilliantly conduct ostomized child care service at the Federal District's Maternal Infant Hospital of Brasilia (*Hospital Materno Infantil de Brasília*).

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