



PARTICIPATION OF THE FAMILY IN THE CARE FOR STOMIZED PEOPLE: PERCEPTIONS OF NURSING PROFESSIONALS

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ABSTRACT

Objective: To know the perception of nursing professionals regarding the participation of the family in the care of people with intestinal elimination stoma during hospitalization. **Method:** Qualitative, descriptive study, whose data were collected through the use of guided interviews, with 21 nursing professionals from a general surgery unit in a public hospital in southern Brazil, and submitted to the spiral analysis technique. **Results:** Data analysis allowed the organization of two themes: "The family as part and participant of nursing care" and "The family as a link that can weaken and compromise care", evidencing the perception of nursing professionals. Family participation is identified as relevant, as it forms an active and effective support network for maintaining stoma care, but also as a link that can weaken and compromise care, often impacting acceptance and adaptation of patients facing their new reality of life. **Final considerations:** The difference in the way nursing professionals perceive the family's participation as a co-participant in care and guidance tends to influence the care provided.

Keywords: Family. Ostomy. Enterostomal therapy. Nursing care. Nurse practitioners.

INTRODUÇÃO

The term "ostomy" refers to the surgical construction of a stoma, that is, an orifice with the purpose of externalizing an organ through the body, being named according to the body segment of origin, and may be temporary or permanent. Among the different types of stoma, there are intestinal elimination, which come from the exteriorization of the ileum or colon through the abdominal wall, with the objective of evacuating fecal effluents⁽¹⁾.

The patient needs time to (re)signify his life from the creation of the stoma, with adaptation and acceptance being a complex process in the face of the biological and physical changes resulting from the surgery, often culminating in psychological morbidity and social isolation⁽²⁾. In this context, the support of the family is essential, including during the hospitalization period, as the active and collaborative presence

of the family provides security and comfort⁽³⁾.

However, it should be noted that the family also suffers with the repercussions of the illness and hospitalization associated with the presence of the stoma, as it is the family that lives with the individual daily, perceives the difficulties and the suffering, and help with care demands, in particular, when back home. Thus, the family is the main caregiver in the home environment, which results in mobilization of the patient to assist in care actions with the stoma and collection bag, as well as in daily life activities⁽³⁾.

When experiencing the changes resulting from the illness and the making of the stoma, the family performs an internal movement that aims to restore balance and restructure the functionality of the family unit, resulting in reorganization and adaptation to the new reality. From this perspective, having a sick member comprises a circumstance that involves the entire

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family context, characterized as a collective experience⁽⁴⁾.

The person with a stoma and his family need specific nursing care that demands theoretical-scientific knowledge capable of promoting adequate practices that qualify the assistance offered⁽⁵⁾. Therefore, care implies transcending the patient-professional binomial, with a view to involving the family as part and participant of a shared therapeutic process, aiming to make it active in promoting the health and well-being of the family member⁽⁶⁾.

Thus, it is essential that nursing is prepared to welcome the family, considering the sociocultural context to which it belongs and with which it interacts, offering continuous support, guidance and information that enable it to develop knowledge and skills to provide safe and effective care⁽⁶⁾. In view of this, understanding how nursing professionals perceive the family in the hospital environment allows for knowing the nuances that permeate the professional-patient-family relationship, in order to weave intervention strategies that make it possible to integrate the family in care.

Although studies with families of people with intestinal elimination stoma are identified in the national and international literature, they tend to address the repercussions of having a person with a stoma on family dynamics, as well as the family's knowledge and adaptation to care, in particular, regarding the process of caring for children with stoma^(3,7). Thus, it is still relevant to expand the understanding of this phenomenon from the perspective of nursing professionals, since it is urgent to identify the relevance of this support and care network as a significant factor for the adaptation and rehabilitation of the person with a stoma, being pertinent to develop an inclusive and sensitized practice to also welcome the family in the care.

In view of the above, the objective was to know the perception of nursing professionals regarding the participation of the family in the care of people with intestinal elimination stoma during hospitalization.

METHOD

In order to meet the proposed objective, a qualitative, descriptive research was carried out,

which was presented according to the recommendations of the Consolidated Criteria for Reporting Qualitative Research (COREQ). This type of study makes it possible to apprehend the particularities of the behavior of individuals or a group, allowing to understand the interaction that exists in relationships, as well as describing the characteristics of a particular population, phenomenon or experience, providing an in-depth detail⁽⁸⁾.

The setting was the General Surgery Unit (GSU) of a public hospital in southern Brazil, where patients are cared for in the pre- and postoperative periods for the surgical fabrication of intestinal elimination stomas. The GSU nursing team consisted of 54 professionals and, of these, 17 were nurses and 37 were nursing technicians. The sample was not initially defined and followed the logic of the relationship in terms of reaching the objectives and answering the research question.

Study participants comprised 21 professionals, eight nurses and 13 nursing technicians, from different work shifts. The following inclusion criteria were defined: nursing professionals who worked in the direct care of the person with a stoma and who worked in the sector for at least three months, a period that allows them to adapt to the routines of the GSU. As an exclusion criterion: nursing professionals on vacation or on leave of any kind. It should be noted that there was a refusal to participate in the study.

For data collection, initially, the researcher approached the investigative field, aiming to know the workflow and organization of the GSU. After the acclimatization period, the selection of participants was carried out, intentionally, through the nursing report, to identify patients with intestinal stoma, and the personnel distribution scale, which made it possible to verify the professional responsible for care. Thus, professionals who met the inclusion criteria were invited to participate, being clarified about the research objectives. Upon acceptance, the Informed Consent Term was signed.

Data were collected from March to July 2018, through a guided interview, carried out in the health education room available at the unit, as it is a pleasant environment, which allowed

face-to-face interaction between interviewer and interviewee, favoring the dialogue and privacy, being free from interruptions. The guided interview is a data collection technique that makes it possible to explore the subjective aspects, guided by a script, bringing to light the perceptions of the study participants about the family's participation in the care of people with stoma⁽⁸⁾.

It consists of carrying out open and closed questions, in order to contemplate the objectives of the study, being a conversation established with the purpose of deepening communication⁽⁸⁾. In order to facilitate the conduct of the interview, the following guiding question was started: "How do you, based on your work experiences, perceive the family's participation in the care of the person with intestinal elimination stoma?"

The interviews were previously scheduled, conducted by the same interviewer and carried out only once, with a mean duration of 40 minutes, having been audio-recorded and then transcribed in full for further analysis. The content of the interviews was not subject to a validation process by the participants. The return of the results to the professionals of the GSU was carried out through the availability of the research report, and the main results were discussed.

The collected data were analyzed according to the spiral technique of data analysis, which makes it possible to understand the phenomenon, from circular and interrelated analytical movements, being developed in three stages: data organization; reading and reminder; description, classification and interpretation in codes and themes⁽⁸⁾.

The analysis process began with the organization of the data in the first turn of the spiral, when it was possible to organize and compile the evidence in files (text units) on the computer to design the database, facilitating the exploration of the material. Thus, the textual units organized were related to the transcription of the interviews⁽⁸⁾.

The second stage of the analysis allowed advancing the analytical process, through the exploration and repetitive reading of text units, making it possible to scrutinize the details related to the analyzed data and facilitate the interpretation of information. In this turn of the

spiral, reminders were also created with keywords, short phrases and central concepts to guide the subsequent stage and move forward in a circular way⁽⁸⁾.

Then, it evolved into the description, classification and interpretation of data in codes and themes, thus constituting the third stage of the spiral. Coding allows the separation of the text into broad groups of information, the themes, which add several codes to strengthen a common idea⁽⁸⁾. Thus, it was possible to organize 11 codes, according to the similarity of meanings, which supported the formation of two themes that constitute the corpus of interpretative analysis of the study. The interpretation made it possible to understand the data, abstracting beyond the codes and themes, being carried out from the theoretical appropriation of the theme and based on the scientific literature.

This study complied with the ethical precepts of Resolution number 466/2012, of the National Health Council, and was approved by the Ethics Committee under Opinion number 2,507,460. The anonymity of the participants was protected, and they were identified by alphanumeric codes: (N1, N2, N3...) for nurses; and (NT1, NT2, NT3...) for the nursing technicians, successively.

RESULTS AND DISCUSSIONS

Study participants were eight nurses and 13 nursing technicians, who worked in different work shifts, 17 female and four male, aged between 26 and 57 years. Regarding the time of professional training, a variation from three to 35 years was identified and, for the time of work at the GSU, a period of less than one year of service to 20 years of work in the sector was found. Of the eight nurses participating in the study, five had a *lato sensu* graduate degree, however, none was a specialist in stomatherapy.

After the interpretative analysis of the data, it was possible to organize two themes: "The family as part and participant of nursing care" and "The family as a link that can weaken and compromise care", which evidence the perception of nursing professionals in caring for people with a stoma and their families.

The family as part and participant of nursing care

The professionals participating in the study recognized that they should not ignore the family during their work process, but include them, in order to actively interact in nursing care, with a view to generating well-being for the family unit, valuing their presence and commitment with the hospitalized person.

We do not pay attention only to the patient, but to the family as well. Sometimes the patient does not feel prepared and the family member is the one who is holding everything together, so we guide them both. The support that this patient has is the family. It's no use ignoring the family in care, because later, at home, the ones who will be helping and encouraging the patient, who sometimes lives alone, is the family itself. So, you have to include the family. (N2)

We care about offering support. We know that they are always much more sensitive when they are in a hospital, for whatever reason, both the patient and the family. So, it is important to give attention and support to both, so that they can understand and assist in the best possible way in the care. I think that when family members are well oriented, they provide the patient with security. (NT2)

We also consider the family very fundamental, because, sometimes, the patient will only be able to handle that (referring to the stoma) when they are at home, without having other patients around, without sharing the same environment. (N1)

It is identified that the insertion of the family in the care was perceived as fundamental, including encouraging the development of its skills, considering that family members may become caregivers until the patient reestablishes his autonomy and independence, since, during the post-treatment period, operative, generally, the patient is not prepared or able to perform self-care. Thus, the active and collaborative presence of the family ensures continuity of care when returning the patient return his home.

In this sense, the effective participation of the family in the different phases of the adaptive process makes the person with a stoma able to overcome the challenges and difficulties related to the physical changes perceived in his body, as he feels welcomed and respected, adapting more

easily to the new life condition⁽⁹⁾. In addition, it helps to alleviate moments of physical and emotional fragility, interacting with the person with a stoma and motivating him in the search for his autonomy^(9,10).

However, when there are limitations regarding the educational guidelines and information provided to the family and the patient with a stoma during the perioperative period, the learning process for caring for oneself is weakened and compromised. Thus, the family uses the resources available in its context of life and interpersonal relationships, which do not always include professionals, in order to meet the demands that arise, with a view to developing its skills and competences for care⁽¹¹⁾.

Nevertheless, professionals recognized that the initial support available to patients to face the changes that come with the stoma comes from their family members, and they perceived that they more easily assimilate the guidelines for care provided, being multipliers of knowledge on return home.

The family members are usually more attentive to care and guidance, and I believe that, with the patient at home, they replicate the care. (N1)

Whenever we give guidance to the patient, we try to have the family members by his side, because, in most cases, they are the ones who will do the care at home. Patients who are bedridden like this, it is usually the family who does it. (N4)

I include the family members as if they were a reminder, persons who will help to remember the details, who will help to clarify doubts, who will provide psychological support. (N3)

Still, they recognized that family members are ready to support the person with a stoma, being presence and encouragement in the psychological and emotional demands. The family members are included in the nursing work process and, for this, it is useful to involve them in all dimensions of care, and it is important that professionals are receptive to their demands, in order to promote a supportive attitude. Nursing work with families makes it possible to equip them for the care of their family, ensuring continuity in the return home⁽¹²⁾.

Strengthening the relevance of family

inclusion in care, a study that implemented and assessed the repercussions of an educational video with families of people with colostomy due to cancer identified that the use of technology subsidized the development of some skills related to colostomy handling and collecting equipment. Consequently, the family expanded its understanding of care, being an instrument that complements nursing guidelines and strengthens the emotional and relational aspects of families⁽¹¹⁾.

Even so, it is important to consider that the stoma is not something natural in the daily life of families, for which they also express insecurity and fear, often feeling incapable of performing care, requiring the presence and support of the nursing professional, in order to encourage them to face the situation.

Support of family members will always be needed, but in the sense of carrying out care. So, always at the time of the exchange, advise them to be present and make them understand that it is not an ugly thing or a bad thing. First, make them see it in another way, as a more normal thing. Starting to look first, then showing how to do it, making them understand what is happening and preparing them to take care of it. (N7)

Colostomy is not a natural thing for them. So, the most important thing is to ease the fear, it is to demystify their inability to deal with it. Providing them like this, I wouldn't even say tools, but skills to deal with the situation through conversations and guidance. (NT8)

When there is a family member who will have contact with this patient at home, I start talking and also providing guidance on how to care. And I tell the family not to look with terror and fear because the patient has a small bag of feces hanging in front of his belly. (NT13)

I think the fear, the insecurity of the new is what causes a lot of resistance. It's different for them, it's new. I don't know what will happen with them at home. (NT7)

It is identified that the nursing team, by gradually approaching/including the family in care practices, offers emotional support and provides a dialogic space for family members to verbalize their anxieties and demystify their fears. The family feels the implications of the disease and is faced with a new world, permeated by conflicting feelings, with the

presence, support and care of the nursing team being important^(13,10).

In addition, by offering information and guidance, professionals help the family members to overcome a possible distorted view of the stoma and the collection bag, allowing them to gradually assimilate the situation experienced, with the aim of training them for care. The consolidation of interpersonal relationships in the hospital environment can favor communication and interaction between the family and the nursing team, as well as have a positive impact on actions aimed at family care, as a group of people who also need attention⁽¹⁴⁾.

The data elucidate the importance of the nursing team getting closer to the family so that there is co-participation in care, and it is necessary for professionals to dedicate time and attention to understanding the behaviors and attitudes of families towards the health/disease process. Thus, understanding the multiple aspects that permeate the family experience in the face of illness makes it possible to broaden the view of nursing beyond the traditional models related to the care process, aiming to break the paradigms related to the presence of the family in care⁽¹³⁾.

Thus, it can be seen that the professionals, for the most part, recognized the importance of the family members in the rehabilitation process of the person with a stoma, since it is from them that emotional support and the necessary care come to restore balance and well-being.

The family as a link that can weaken and compromise care

The hospitalization of a family member causes changes in family dynamics, which can lead to destabilization and imbalance, even if temporary, being accompanied by conflicts and abdication of oneself to be present and take care of the other. Family members who accompany patients with stoma during the hospitalization period have their life routines changed, being exposed to physical and emotional fatigue, and may express their concerns and fears in the difficulty of participating in care.

In this perspective, professionals often identify that the family is afraid, difficult and even repulsed to participate in nursing care, not

feeling comfortable cleaning the stoma, changing the collection bag and handling the fecal effluents of their family member.

Some family members do not feel comfortable changing and sanitizing the bag. I realize they don't want to. I think they are disgusted with dealing with the family member cleaning, removing the feces, but I try to make them understand that it will stay there and he will have to go home. (NT1)

There are families who don't even want to touch it there (referring to the stoma), God forbid, they call the nursing team. (N8)

We try to include the family, sometimes the patient is a little disowned in the first days, but then you sit down and talk to the family, you explain little by little. Because, including the family, it becomes easier for them. Together they can. (NT11)

In addition to the issues of opposing care for feelings of repugnance to the effluents, this reaction of the family may be linked to insecurity due to the lack of knowledge and skills to care, which can establish a relationship of dependence with the nursing professionals, delaying the development of autonomy and emancipation.

However, even in the face of the objection expressed, professionals sought to encourage care, informing and guiding about the existence of the stoma, intending to involve the family in therapeutic nursing actions, since, upon hospital discharge, they will have to assume this responsibility. It is important to highlight that family support is essential for care and rehabilitation, since, being present, it directly influences acceptance and adaptation to the stoma, as well as facilitating the ability to face current or potential problems⁽¹⁵⁾.

The professionals perceived that there is a dichotomy related to the family's participation in care activities, sometimes having an active and co-participatory insertion, sometimes showing themselves to be reluctant and even resistant to handling the stoma and the collection equipment, transferring the responsibilities regarding the process of take care of different family members.

Some collaborate, but most don't want to. One passes to the other. I see a lot of resistance from some family members in wanting to learn and manipulate the ostomy to provide care. (NT7)

There is that family that is very active, in this case, that the patient does not want to move and who ends up moving, often, is the family member, it is the companion who is there. Just as there are family members who are the opposite. (N8)

In order to promote trust, security and acceptance, it is important that nursing promotes integrative therapeutic actions, capable of involving the family members in care demands, in an attempt to help their adjustment to the health/disease process. Thus, professionals must identify family members as beings who also need care, since they also feel the impact of the disease, being vulnerable to the various unexpected demands that come with the stoma⁽¹³⁾.

When the family is not equipped and prepared to provide care when returning home, they feel overwhelmed, needing to seek strategies to ensure continuity of care. Thus, the collective mobilization of family members, associated with the reorganization of family dynamics, aims to ensure the performance of basic and essential care⁽¹⁶⁾.

The lack of educational guidelines in the pre and postoperative period increases the level of anxiety, compromising the development of skills for self-care and care⁽¹⁷⁾. However, when the family receives support, attention and guidance from nursing professionals, they start to feel encouraged and strengthened to carry out care actions⁽¹³⁾.

Nevertheless, the professionals also stated that the bond and proximity between the patient and the family caregiver interfere with their co-participation in nursing care actions.

I think it goes far beyond not having a very close relationship with the patient; the person is here caring for lack of option. It depends a lot on the family member who is here and his behavior towards the patient. If he really cares about the patient or is he here just because it didn't have someone else in his place and he was sent to take care of the patient. I think that's what interferes. (NT8)

The family member's behavior towards the care established for the patient may be a consequence of the established relationship of affection and well-being, which can strengthen or weaken family support. Thus, professionals often find resistance to consolidate the family's

participation in care demands, which can be an element that weakens the rehabilitation of the person with a stoma.

A study that aimed to understand the influence of the social network in the care of people with stoma for colorectal neoplasia and to describe the type of support offered identified that the primary social network, composed especially of children, spouses, siblings and friends, is essential and influential for care. It also showed that social network offers emotional and material support and care, generating tranquility to face the adverse situations arising from the making of the stoma⁽¹⁸⁾.

The professionals identified greater difficulty in inserting the family into care, especially during the night shift, with resistance in accepting the nursing guidelines and information.

At night, family members want to sleep and do not want to know about these things and guidance. They are not very interested; they do not want to know much about patient care, they just want to sleep. (E6)

The nursing guidelines in the general surgery unit have their routine directed to daytime activities, being reinforced in subsequent shifts, intending to promote teaching-learning for care and self-care in an integrated, gradual and continuous way. However, during the night, professionals found it difficult to involve family members in care, referring that they showed little interest in relation to the treatment of patients with stoma.

The little insertion of the family as a co-participant in care becomes a link that weakens care, both for the patient with a stoma and for the family unit itself, which may compromise the emancipation of subjects and their independence in the care activities provided by nursing. From this perspective, the absence of family support can constitute an element that delays the process of acceptance and adaptation of these people to their new reality of life, as identified in a study that sought to examine the relationship between family functioning, perceived social support and adaptation to the stoma⁽¹⁵⁾.

As a limitation of the study, the fact that it was carried out solely in the context of the GSU is presented, which reflects the perception of a

specific group of professionals regarding the participation of the family in the care of people with stoma, restricting the possibilities of generalization to others scenarios. However, the results validate the evidence of studies on the subject, indicating the relevance of including the family in the daily work of nursing professionals, being sensitized to access and understand family experiences, through professional training.

FINAL CONSIDERATIONS

Nursing professionals perceived a difference related to the participation of families in care, with some identified as part of and participating in care and guidance, and others as a link that can weaken and compromise the care process. Thus, the active presence of the family can be a significant factor, offering support, or, being passive and resistant to nursing stimuli, it can be an element that compromises the acceptance and adaptation to the new reality of life of the patient with a stoma.

Thus, establishing a relationship of trust and commitment with the family members, including them in care actions for the person with a stoma, makes it possible to develop a shared care plan, in which there is co-responsibility and co-participation of both parties. Thus, understanding family relationships and their perspective in the face of illness and the presence of the stoma is a challenge for nursing, requiring sensitivity and caution, as it includes subjective aspects that represent the uniqueness of each family's life.

Based on the reflections arising from the results of this study, the aim was to contribute to the planning and implementation of teaching, management, assistance and outreach actions aimed at the insertion of the family as a nursing care unit, beyond its ability to be present in the instrumental demands related to the stoma and the collection bag, but as vulnerable subjects, who have multiple needs that need to be met. With this, professionals contribute to the development of an integral, holistic and humanized care, which aims to support the family experience, through a shared and singular therapeutic approach, which meets the specificities of each family.

A PARTICIPAÇÃO DA FAMÍLIA NO CUIDADO À PESSOA COM ESTOMA: PERCEPÇÕES DE PROFISSIONAIS DE ENFERMAGEM

RESUMO

Objetivo: Conhecer a percepção dos profissionais de enfermagem quanto à participação da família no cuidado às pessoas com estoma intestinal de eliminação no transcorrer da hospitalização. **Método:** Estudo qualitativo, descritivo, cujos dados foram coletados mediante uso da entrevista guiada, com 21 profissionais de enfermagem de uma unidade de cirurgia geral em um hospital público do Sul do Brasil, e submetidos à técnica de espiral de análise. **Resultados:** A análise dos dados permitiu a organização de dois temas: "A família como parte e partícipe do cuidado de enfermagem" e "A família como elo que pode fragilizar e comprometer o cuidado", evidenciando a percepção dos profissionais de enfermagem. A participação da família é identificada como relevante, pois conforma uma rede de apoio ativa e efetiva para a manutenção dos cuidados com o estoma, mas também, como um elo que pode fragilizar e comprometer o cuidado, repercutindo, muitas vezes, na aceitação e adaptação dos pacientes frente à sua nova realidade de vida. **Considerações finais:** A diferença presente no modo como os profissionais de enfermagem percebem a participação da família como copartícipe do cuidado e das orientações tende a influenciar no cuidado prestado.

Palavras-chave: Família. Estomia. Estomaterapia. Cuidados de enfermagem. Profissionais de enfermagem.

LA PARTICIPACIÓN DE LA FAMILIA EN EL CUIDADO A LA PERSONA CON ESTOMA: PERCEPCIONES DE PROFESIONALES DE ENFERMERÍA

RESUMEN

Objetivo: conocer la percepción de los profesionales de enfermería en cuanto a la participación de la familia en el cuidado a personas con estoma intestinal de eliminación en el transcurrir de la hospitalización. **Método:** estudio cualitativo, descriptivo, cuyos datos fueron recogidos a través de entrevista dirigida, con 21 profesionales de enfermería de una unidad de cirugía general en un hospital público del Sur de Brasil, y sometidos a la metodología de espiral de análisis. **Resultados:** el análisis de los datos permitió la organización de dos temas: "La familia como parte y partícipe del cuidado de enfermería" y "La familia como eslabón que puede fragilizar y comprometer el cuidado", evidenciando la percepción de los profesionales de enfermería. La participación de la familia es identificada como relevante, pues conforma una red de apoyo activa y efectiva para el mantenimiento de los cuidados con el estoma, pero también, como un eslabón que puede fragilizar y comprometer el cuidado, repercutiendo, muchas veces, en la aceptación y adaptación de los pacientes frente a su nueva realidad de vida. **Consideraciones finales:** la diferencia presente en el modo como los profesionales de enfermería perciben la participación de la familia como copartícipe del cuidado y de las orientaciones tiende a influir en el cuidado prestado.

Palabras clave: Familia. Ostomía. Estomaterapia. Atención de Enfermería. Profesionales de Enfermería.

REFERENCES

1. Smeltzer SC, Bare BG. Brunner & Suddarth: tratado de enfermagem médico-cirúrgica. 14ª ed. Rio de Janeiro: Guanabara Koogan; 2020.
2. Gómez GP, Mejía BC, González SH. Tener una colostomía: transformación de la corporalidad. Cult Cuid. 2017; 21(48): 23-32. DOI: 10.14198/cuid.2017.48.03.
3. Dalmolin A, Girardon-Perlini NMO, Simon BS, Coppetti LC, Machado L. Família convivendo com uma pessoa com estomia intestinal: un análisis documental. Cult Cuid. 2019; 23(53): 219-229. DOI: 10.14198/cuid.2019.53.21.
4. Wright LM, Leahey M. Enfermeiras e Famílias: guia para avaliação e intervenção na família. 5ª ed. São Paulo: Roca; 2012.
5. Santos CRS, Corrêa ACS, Silva D. Conhecimento de enfermeiras do programa de estratégia saúde da família sobre estomias intestinais e urinárias. Estima (online). 2017; 15(3): 161-168. DOI: 10.5327/Z1806-3144201700030007.
6. Vieira RFC, Santo FHE, Lima FFS. Vivência familiar da criança hospitalizada com câncer. Rev Enferm Cent-Oeste Min. 2020; 10: e3546. DOI: <http://doi.org/10.19175/recom.v10i0.3546>
7. Silva TP, Silva IR, Silva LJ, Ferreira MJC, Moreira MC, Pinto CB. Criança com estoma nos estudos de Pós-Graduação Stricto Sensu em Enfermagem: destacando aspectos epistemológicos. Rev Enferm UERJ. 2020; 28: e48514. DOI: 10.12957/reuerj.2020.48514.
8. Creswell JW. Investigação qualitativa e projeto de pesquisa. 3ª ed. Porto Alegre: Penso; 2014.
9. Barbosa G, Paschoalin HC, Greco RM, Dias SM. Vivências de pessoas com estomia no mundo do trabalho. Estima (online). 2017; 16(e0218). DOI: 10.30886/estima.v16.372_PT.
10. Zaccarin CFL, Borges AA, Dupas G. The family's experience of children and adolescents with gastrointestinal stomas. Cienc Cuid Saude. 2018; 17(2). DOI: 10.4025/cienccuidsaude.v17i2.41278
11. Stragliotto DO, Girardon-Perlini NMO, Rosa BVC, Dalmolin A, Nietzsche EA, Somavilla IM, et al. Implementação e avaliação de um vídeo educativo para famílias e pessoas com colostomia. Estima (online). 2017; 14(4):191-199. DOI: 10.5327/Z1806-3144201700040002.
12. Simon BS, Budó MLD, Schimith MD, Leal TC, Silva MM, Wunsch S, et al. Atenção profissional às famílias de pessoas com estomia de eliminação: a dualidade vivenciada. Estima (online). 2018; 16(e1918):1-9. DOI: 10.30886/estima.v16.457_PT.
13. 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: 10.1590/0034-7167-2018-0370

10.1590/0034-7167-2018-0370

14. Azevêdo AVS, Júnior ACL, Crepaldi MA. Interação equipe de enfermagem, família, e criança hospitalizada: revisão integrativa. *Cien Saude Colet*. 2017; 22(11): 3653-3666. DOI: 10.1590/1413-812320172211.26362015.

15. Baykara ZG, Demir S, Karadag A. Family functioning, perceived social support, and adaptation to a stoma: a descriptive, cross-sectional survey. *Wound Manag Prev*. 2020; 66 (1): 30-38. PMID: 32459659.

16. Dias BC, Marcon SS, Reis P, Lino IGT, Okido ACC, Ichisato SMT, Neves ET. Dinâmica familiar e rede social de famílias de crianças com necessidades especiais de cuidados

complexos/contínuos. *Rev Gaúcha Enferm*. 2020; 41 (e20190178). DOI: 10.1590/1983-1447.2020.20190178

17. Harris MS, Kelly K, Parise C. Does Preoperative Ostomy Education Decrease Anxiety in the New Ostomy Patient? A Quantitative Comparison Cohort Study. *J Wound Ostomy Continence Nurs*. 2020; 47(2): 137-139. DOI: 10.1097 / WON.0000000000000623

18. Nascentes CC, Moreira MC, Oliveira NVD, Palasson RR, Ghelman LG, Souza MHN. Rede social no cuidado à pessoa estomizada por câncer colorretal. *Rev enferm UFPE on line*. 2019; 13 (e239569). DOI:10.5205/1981-8963.2019.239569

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