

Challenges to self-care for people with intestinal elimination stomas: a qualitative study

Lucas Borges de Oliveira¹ 
 Juliana Balbinot Reis Girondi¹ 
 Letícia de Oliveira Grespi¹ 
 Daniela Soldera¹ 
 Thaluana Selvero de Souza¹ 
 Camila Caroline Szpin² 
 Robson Giovani Paes² 

¹Universidade Federal de Santa Catarina (UFSC), Florianópolis, Santa Catarina, Brasil.

²Universidade Federal do Paraná (UFPR), Curitiba, Paraná, Brasil.

Corresponding author:
 Letícia de Oliveira Grespi
 E-mail: grespileticia@gmail.com

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ABSTRACT

Objective: to identify the challenges to self-care for people with intestinal stomas.

Methods: descriptive research with a qualitative approach based on Grounded Theory that involved people registered with a stoma association in southern Brazil. The interview, conducted through a working group and guided by a semi-structured script, took place online in September 2023. Issues related to living with a stoma, challenges/difficulties, complications, and information necessary for self-care were explored. The recordings were transcribed using Reshape software. The recordings were transcribed using Reshape software. Bardin's content analysis, a thematic analysis modality, was then performed. **Results:** from the analysis of the statements of the eight participants in the operational group, three categories emerged: 1) Living with a stoma; 2) The process of stoma care; and 3) Support network and accessibility as necessary conditions for the adaptation of a person with a stoma.

Conclusion: individuals with intestinal stomas face difficulties and challenges in developing essential self-care actions to promote their health. This scenario highlights weaknesses in nursing and healthcare team performance in promoting self-care in this group, reinforcing the need for nursing guidance throughout the care process, from admission to patient adaptation to the new condition.

Descriptors: Ostomy; Self Care; Colostomy; Ileostomy; Qualitative Research.

INTRODUCTION

In Brazil, in 2021, there were approximately 400,000 people with intestinal stomas resulting from congenital malformations, tumors, abdominal trauma, inflammatory bowel diseases, among other conditions⁽¹⁾. This condition impacts people's daily lives, as it necessitates adapting to the use of collection devices to manage bowel incontinence^(2,3).

The adaptive process involves physical and psychological dimensions that can influence self-care. In the early stages of stoma construction, people experienced difficulties with self-image, insecurity, fear of effluent leakage, flatulence, and concern about bothering those around them^(2,3).

Moreover, these individuals experience needs for changes in dietary habits, peristomal skin care, and access to adapted toilets⁽⁴⁾. It is essential that nurses pay special attention to these individuals, understanding the feelings they express, thus fostering a better understanding and perception of their quality of life, which are both self-care process antecedents and outcomes⁽⁵⁾.

In this regard, it is necessary to understand the main challenges inherent in the self-care of a person with a stoma so that nurses can plan a support and guidance system, as foreseen in Orem's theory⁽⁶⁾, aimed at promoting health⁽⁷⁾ and independence of ostomized patients in their rehabilitation process. Furthermore, it contributes to quality care, reducing the initial anxieties caused by the new health condition.

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Orem's Self-Care Theory⁽⁶⁾ highlights the importance of individual autonomy in caring for one's own health, which is essential for people with stomas. The theory guides professionals to identify self-care requirements, self-care capacity, self-care agency, and to promote interventions that strengthen self-care and adaptation to the new condition⁽⁶⁾.

Understanding the difficulties these individuals face throughout the adaptation process is essential for providing guidance that promotes self-care and for developing strategies to promote health⁽⁷⁾.

Therefore, this research aimed to identify the challenges to self-care for people with intestinal elimination stomas.

METHODS

This is a descriptive study with a qualitative approach based on Grounded Theory⁽⁸⁾. The report followed the COnsolidated criteria for REporting Qualitative research (COREQ) guidelines⁽⁹⁾. It was developed in an association of ostomized people located in southern Brazil, which has been operating since 1989. In this entity, the monthly service, in mid-2023, was 150 people with intestinal and urinary stomas.

Recruitment was carried out through prior, individual meetings with people registered with the service, to whom the research project was explained. One of the researchers regularly attended at the Stoma Association, where he was vice-president. During his time at the institution, he participated in nursing consultations to invite users to join in the support group, strengthening ties with the community, and promoting participation in the research project.

In the course of the data collection period, low patient demand was observed at the stoma association. Many users obtained their stoma collection devices directly from primary care units, resorting to the association only in cases of stoma-related complications. It is important to highlight that the association is not formally part of the municipality's healthcare service network and should therefore not be considered an official distribution center for stoma collection devices.

Individuals with intestinal stoma for at least three months, over 18 years of age, who were followed by a stoma association were included. Individuals with cognitive impairment.

Participant selection was based on convenience, and the criterion for ending data collection in the operational group was theoretical saturation⁽¹⁰⁾.

For those who expressed interest, an invitation was sent by email to participate in the operational group, along with an Informed Consent. Of the 15 people with stomas present at the meeting, all were invited again in person by the same researcher, who explained the research's objective and the importance of self-care for intestinal elimination stomas. However, only eight agreed to participate in the operational group.

The operational group was conducted via the Teams platform in September 2023, lasting one hour and 40 minutes. The group was led by the same researcher, who also invited participants. The Operational Group technique is a group work method aimed

at promoting learning among participants, in group, through critical reading of their realities, an investigative attitude, and opening up questions that lead to new inquiries⁽¹¹⁾.

Data collection was guided by a structured script with the following questions: what is it like to live with an intestinal stoma? If you were to make a video with guidelines on stoma care, what would those guidelines be? What were the greatest challenges regarding stoma care? Have you had or do you have any complications? The meeting ended when data saturation was reached, from the moment interviewees' experiences and answers began to repeat themselves.

Careful listening and text transcription were organized with the aid of Reshape software (version 3.0.1, 2024, Hotmart Company, Brazil), followed by a text skimming of speeches, during which coinciding narratives were grouped without software.

The interviews' transcripts were returned to participants, allowing them to read, review their statements, and, if they wished, reformulate or supplement any information. This precaution aimed to ensure the accuracy of the reports and respect for the voice of each participant in the research process.

Material analysis was developed according to the stages proposed by Bardin⁽¹²⁾ for thematic analysis. The process began with "pre-analysis", which involved the organization and preparation of all the empirical material. Subsequently, "content exploration" and subsequent "treatment of results" were carried out. The last stage was "interpretation", which made the data meaningful and consistent, allowing the construction of "empirical categories" that brought to light the fundamental elements of the investigated phenomenon.

It was deemed unnecessary to form a second working group or hold another meeting with the group, given the theoretical saturation of the data already achieved in the first group. According to the methodological framework adopted, saturation occurs when the collection of new data does not yield substantively new information in relation to the emerging analytical categories^(9,10).

The anonymity of the people involved in the research was guaranteed, the letter "P" followed by an ordinal number was used to identify them, according to the order of the narratives. The ethical precepts of Resolution n. 466 of 2012 of the Brazilian National Health Council were respected, and the study received authorization from the Research and Ethics Committee through the Certificate of Presentation of Ethical Appraisal (In Portuguese, Certificado de Apresentação para Apreciação Ética - CAAE) 69679323.0.0000.0121 from a public university located in southern Brazil.

RESULTS

Participant characterization

Eight people with intestinal stomas, aged between 20 and 83 years, participated in the study. Of these, seven were female. Four had stomas due to inflammatory bowel disease, two due to colorectal cancer, one due to congenital Hirschsprung's disease, and one

due to intraoperative perforation after hysterectomy. Five participants were white and three were black. Two were married and six were single.

From data analysis, three categories emerged: 1) Living with a stoma; 2) The process of stoma care; and 3) Support network and accessibility as necessary conditions for the adaptation of a person with a stoma.

Living with a stoma

In this category, the narratives identified mechanisms of acceptance and adaptation in the face of the difficulties of living with a stoma. The feelings involved during this process were sadness, fear, and concern regarding how others perceived them. At the same time, a sense of improved quality of life after the procedure is evident. After contact with other people with the same condition, the perception of the stoma changes. In this process, there are life cycle-related events, such as pregnancy, which adds an element to the process of living with a stoma, as shown in the following statements.

"[...] at first I didn't accept it, it was very difficult for me, sometimes it still is very difficult, because I have dermatitis [...]" (P1)

"[...] it's been a shock so far... and now I'm going through all this. I never imagined I'd be going through this [bowel cancer], so I'm not getting used to it, but I'm adapting to the new routine [...]" (P6)

"[...] for me, it was difficult at first, because of the issue of acceptance. I thought that if I went out on the streets, people would be staring [...]" (P4)

"[...] it's a little difficult, but you get used to it after a while, right [...]" (P7)

"[...] for me, it was quality of life, because I suffered a lot with my illness [Crohn's disease], with several hospitalizations [...] but after the ileostomy surgery I improved a lot, the symptoms, you know [...]" (P2)

"[...] In the beginning, I only had a little sadness, for a week. But, when I met a 5 or 6 year old boy with the same problem as me... Then, I was never sad again, never again, I only sought joy [...]" (P8)

"[...] the size of my stoma didn't change much. I used a double-support plate and then I used a single-support plate because my belly grew. I had to change many plates... but it didn't change much... there was a little prolapse... but it was fine, of course it was scary. My doctor was shocked because it wasn't planned... the pregnancy was very calm [...]" (P4)

The process of stoma care

When asked about the main information they should receive from healthcare professionals to develop their self-care, people highlighted hygiene and cleanliness, clothing, environments (such as going to the beach), nutrition, physical activities, sexual life, and how to avoid skin complications, in addition to the prevention of bowel elimination problems, such as fecal impaction.

The comments reveal special care that must be taken in stoma and peristomal skin hygiene and cleaning to avoid complications, as well as concern about the type of clothing indicated so as not to reveal the presence of the pouch or compromise its fixation.

"[...] the main thing, you know? Clean with soap and water, don't use anything too perfumed. The more... the harder, unscented soap because of the skin, so as not to irritate it [...]" (P3)

"[...] avoid perfumed products. Always use neutral soaps to wash. I always advise using coconut soap, coconut soap. I use it for everything [...]" (P2)

"[...] I think it's about the bath itself, the beach thing, as the girls mentioned [...]" (P4)

"[...] the point is that you don't have to stop wearing clothes you used to wear. The bag won't stop you from wearing a tight dress, tight pants [...]" (P3)

Another concern discussed was diet, mentioned by all participants. Regarding this aspect, the importance of recognizing which foods are constipating or laxative for better adaptation and regularity of bowel movements was highlighted. Another interviewees' concern was with foods that produce gas, expressing a fear of having an unpleasant odor around other people, in addition to concerns about physical exercise, as shown in the following statements.

"[...] regarding food, there are some foods that leave a really smelly smell (in the stoma). Fish-type gas smells really bad [...]" (P3)

"[...] and about food too. Avoid foods that cause constipation. Sometimes it can cause such a severe obstruction that it can create those stones (fecaloma) and can perforate. Like, avoid eating too much popcorn. It's not about stopping; it's about not eating excessively [...]" (P2)

"[...] since there are foods that... there are foods that give off a very strong smell, so the person has an idea. If they eat that, they can have a stronger smell [...]" (P4)

"[...] the doctor said I have to eat every two hours, drink plenty of fluids, and exercise has helped my bowel function... if someone is going to do any exercise, they should use a belt to avoid prolapse and hernia [...]" (P2)

Since most participants were sexually active, difficulties were identified regarding hygiene during sexual intercourse, both in relation to collection equipment and in discussions about their new condition, which should be the subject of professional guidance, as reported below.

"[...] the issue of sexuality, I think it's a taboo... a lot of people are afraid to have relationships, the issue of talking about it... I met my husband six years ago and I was very afraid to tell him I had a stoma [...]" (P4)

"[...] I always empty the bag and check if it's properly attached, and if it's not, like, there's a possibility of it coming loose [...]" (P3)

"[...] concerning the act itself... kind of positions that are very close, it's not always the case, not that I don't do it, but I'm careful, you know, but I find that part very easy... I've heard people say that during the act you have to hide the bag. I don't, it's just me and the bag, and that's it [...]" (P3)

Support network and accessibility as necessary conditions for the adaptation of a person with a stoma

In this category, the support network, after the creation of a stoma in patients' lives, discusses this condition with the aim of improving quality of life and minimizing the effects of a procedure that generates biopsychosocial impacts.

The support network includes friends, family, or other people who already have a stoma, and through this emotional support, many patients have been able to go through this situation in a safer and more peaceful manner, as the following reports show.

"[...] I asked them (my friends) a lot of questions. We "talked" about... we exchanged a lot of stories about what it was like to have a stoma, and that gave me comfort, a lot of security and peace of mind to face my surgery [...]" (P5)

"[...] my husband always helped me a lot in this part. He always calmed me down. We'd go home, take a shower, and he was always calm [...]" (P1)

"[...] it wasn't so difficult for me to adapt, because I already lived with P4 (sister), and since I was hospitalized a lot, having the colostomy surgery meant having a better quality of life. I couldn't study or work, and after the surgery, I wasn't hospitalized anymore... I can do so much now [...]" (P3)

Other interviewees have already demonstrated that they are adapted to their new condition. One of them highlighted that the problem was not having a stoma, but rather the accessibility to places that facilitate stoma care in its various social contexts, according to the following statements.

"[...] living with a stoma, I don't have any problems, in fact I like to talk about it, because by talking about it, we raise awareness [...]. In my daily life, I don't have a problem with the stoma, but I do have a problem with the barriers, obstacles in the places I attend to that don't provide accessibility... it's a matter of bathrooms. There are no suitable bathrooms there (at the university where I study). There are no bathrooms in the shopping mall. What bothers me the most is going to a bathroom that says it's for people with disabilities, but it's only designed for wheelchair users [...]" (P5)

DISCUSSION

The creation of a stoma initially presents difficulties in acceptance, both due to the threat to self-esteem and the prospect of changes in daily life and challenges, such as learning how to handle the collection device and clean the stoma. However, some factors that contributed to the adaptation and acceptance of the new lifestyle were mentioned by the research participants, which can contribute to nurses' care plans. These factors will be discussed according to the categories presented in the results, namely: Living with a stoma; The stoma care process; Support network and accessibility as necessary conditions for the adaptation of a person with a stoma.

Living with a stoma

The quality of life of people with stomas is influenced by several factors, such as acceptance, adaptation to changes, self-esteem, self-image, stoma complications, and adaptation to the use of collection devices. To promote this quality of life and increase the level of satisfaction, a qualified multidisciplinary team is necessary to assist in the rehabilitation of a person with a stoma, making them feel healthier⁽¹³⁾.

In this study, some strategies, such as contact with other people living with stomas and a feeling of improved quality of life after stoma creation, were mentioned by participants, which contributed to acceptance and adaptation in the face of stoma-related adversities.

In the process of creating a stoma, during the hospital stay and in the post-operative period, family support is important to mitigate suffering during convalescence⁽¹⁴⁾. Many participants reported feelings of sadness, fear, and concern after stoma creation. In these circumstances, a stoma negatively impacts ostomized people's quality of life, mainly due to fear, embarrassment, and concern regarding intestinal physiology, which can interfere with their status and social life^(15,16). Patients with stomas must be educated and guided about their new condition, as this can reduce anxiety, stress, and fear. Knowing stoma care, possible complications, and bodily adaptation contributes positively to self-care, quality of life, and acceptance of the new reality, as well as to preventing future complications⁽¹⁵⁾. For this to happen, educational and support actions are needed from nursing and healthcare professionals.

Concerning self-esteem, participants' statements revealed changes in their perception of self-acceptance as patients with a stoma after interacting with others with the same condition. Self-esteem and body image are the issues that most impact the lives of

people with stomas, causing negative feelings about their bodies⁽¹⁷⁾. They may experience a lack of confidence in others' ability (physicians, nurses, friends, family) to contribute to their recovery⁽¹⁷⁾. These feelings are sometimes divergent, as people with stomas simultaneously report the importance of a social support network in coping with this new condition⁽¹⁷⁾.

Although individuals with stomas experience conflicting feelings due to their new health condition, it is important to emphasize the crucial role of their support network. This network should include diverse individuals (professionals, friends, family, etc.), as shared experiences and interactions foster the exchange of information and knowledge, contributing to the learning process related to living with a stoma. Hence, the social network becomes a health promoter, since stable and active relationships protect individuals from illness, facilitate access to healthcare services, and promote a faster healing process. Therefore, family support is essential, as a family member typically has closer contact with patients with a stoma, allowing for greater openness to dialogue, encouraging social interaction, and facilitating the resumption of previously performed activities⁽¹⁴⁾.

The process of stoma care

Creating a stoma requires different perspectives in order to offer the best option for patients. In this context, enterostomal therapy nurses' clinical assessment is fundamental, as they have the capacity and skill to adequately plan the surgical demarcation, aiming to avoid complications by choosing the most appropriate location for better adaptation of the collection device⁽¹⁸⁾. Furthermore, this specialist plays a fundamental role in promoting health education, making themselves available to clarify doubts about stoma creation, necessary care, and other questions raised in the first nursing consultation⁽¹⁹⁾.

Understanding the difficulties faced by people living with stomas facilitates the planning of appropriate nursing interventions through educational strategies that address the identified needs, in order to help them cope with the new challenges of having a stoma, whether permanent or temporary. Furthermore, having family members as allies in this process of change contributes to the development of knowledge, skills, and the internalization of self-care in individuals' daily life⁽²⁰⁾. Therefore, the importance of using accessible techniques and resources for health education focused on self-care, prevention, and recovery from complications stands out, providing safe care for patients with a stoma⁽²¹⁾.

Another topic addressed by participants in this study refers to the use of comfortable clothing that promotes self-confidence. Thus, the choice of fabrics with natural fibers and a looser fit to avoid highlighting, constricting, or suffocating the stoma and collection device is recommended. Furthermore, the use of patterned or dark colors is recommended as they reflect less light, as well as an extra band at waist level worn under the clothing—conditions that increase self-confidence in case of leaks⁽²²⁾. When choosing inclusive clothing, one must consider individuals' social aspirations for self-realization, efficiency, effectiveness, wearability, flexibility, and comfort, while also taking into account different environments^(23,24).

To maintain a healthy lifestyle, it is essential to practice physical activity without excessive effort, maintain an adequate diet, and regulate sleep/rest without losing attention to the collection device fixation⁽²⁵⁾. This also requires appropriate clothing.

In relation to sexuality, most participants reported having an active sex life, although this may be seen as taboo. For men, a stoma has negative repercussions on sexuality, whether related to grief over the amputated "invisible" limb, or to the loss of self-confidence and control over bowel movements, which, in their view, affects their masculinity^(26,27).

Reports from spouses of partners with stomas reveal different situations ranging from no change in sexuality to radical changes that may include complete abandonment of the practice, making it necessary to seek internal and/or external tools to restructure the couple's identity. In this context, it is important that healthcare professionals, especially nurses, offer knowledge and promote support to encourage couples to maintain an active and alternative sexuality⁽²⁸⁾. Therefore, it is worth highlighting the importance of making informed decisions regarding the implementation of care practices for maintaining healthy sexuality⁽²⁷⁾.

In general, in men with stomas, the presence of the stoma causes erectile dysfunction, while in women, it leads to low self-esteem due to altered body image, generating fears and anxieties such as collection device detachment during intercourse, refusal of sexual relations, and shame in exposing their body⁽²⁰⁾.

Another aspect raised concerns about compromised skin integrity due to the recurrence of peristomal dermatitis. Peristomal dermatitis was also the main post-stoma creation complication in the postoperative period following rectal tumor resection, with an incidence of 40.74%, negatively impacting patients' quality of life⁽¹⁸⁾. Given these situations, it is necessary to raise awareness among the multidisciplinary team assisting patients indicated for intestinal resection with stoma creation, especially the medical team, about the importance of performing preoperative marking of the ideal site, in order to reduce postoperative complications and promote self-care maintenance^(18,19).

Difficulties related to stoma hygiene and cleaning and collection equipment handling, especially in the first few days after surgery, were also reported in a previous study⁽²⁰⁾ in which the authors consider that this can be resolved through knowledge and the acquisition of specific skills needed for each patient.

Pre- and post-operative guidelines should address issues related to stoma construction and care, such as changing the collection device, peristomal skin hygiene, changing and acquiring collection equipment, preventing complications, and adjuvant products used for stoma care⁽²⁹⁾.

Support network and accessibility as necessary conditions for the adaptation of a person with a stoma

Most participants in this study reported doubts about the appropriate diet to prevent side effects from consuming foods not recommended for people with stomas. These doubts can be quickly clarified during a nursing consultation, at which time nurses can

identify the concerns of a person with a stoma and promptly plan care, including health education about foods that should be avoided and those recommended, in order to prevent the occurrence of distension, abdominal pain, and discomfort⁽¹⁹⁾. A nursing treatment plan is individual and dynamic and should be constantly assessed in relation to goal achievement.

In general, the diet should be unrestricted, varied, and divided into smaller portions, respecting personal preferences. Patients need to observe the bowel's response to food intake, noting any points of doubt or undesirable reactions, so that, upon returning for consultations, they can describe their experience in detail, expanding the discussion with healthcare professionals about the impact of certain foods on daily life to facilitate future adjustments⁽¹⁹⁾. These guidelines should focus on strategies and care aimed at minimizing complications, such as diarrhea, which lead to frequent changes of the collection device, development of peristomal skin dermatitis associated with contact with effluents, and improper handling of the collection device, such as incorrect cutting in relation to the stoma size⁽²⁰⁾.

In addition to nursing care, nutritional counseling is important to prevent malnutrition and vitamin and mineral deficiencies, ensuring a diet that meets nutritional needs. This monitoring, aimed at establishing proper bowel function and preventing malnutrition and vitamin deficiencies, should be individualized⁽³⁰⁾.

Healthcare professionals must transcend the biological aspect, valuing the socio-affective aspects and the therapeutic relationships between professionals and patients. In this sense, enterostomal therapy nurses need to master various technologies (soft, semi-hard, and hard) to promote self-care and health education⁽³¹⁾.

Health education should be one of the strategies included in nurses' care plan in the care process, with a view to promoting the development of skills for achieving self-care and patient independence⁽³²⁾.

Another aspect addressed in the questions from participants in this study relates to the rights of patients with a stoma, which points to the fragility of dissemination of this information. The specific rights of patients with a stoma are explicitly stated in Ministerial Decree n. 400 of November 16, 2009⁽³³⁾. This document addresses the Brazilian National Guidelines for Healthcare for People with Stomas. It recommends targeted actions through interdisciplinary interventions, as well as fully addressing their needs, from prescription and provision to proper fitting of stoma collection devices and protective and safety accessories^(33,34).

Care for this patient profile encompasses procedural, psycho-emotional, and sociocultural aspects, as well as advocacy, to promote rehabilitation, improve quality of life, and guarantee their rights as citizens⁽³⁵⁾.

Accessibility for people with disabilities requires building new ways of survival, defining new desirable standards, and ensuring that public policies structure a society that enables the democratic coexistence of all citizens across different social contexts⁽³⁵⁾.

People with intestinal stomas face several challenges in the self-care process, including changes in body image, feelings of shame and rejection, as well as emotional and social difficulties. Lack of knowledge and skills for stoma management, especially af-

ter hospital discharge, compromises patient autonomy, often leading to dependence on caregivers. Fear of leaks, odors, and others' reactions can lead to social isolation and negatively affect quality of life. Furthermore, limited access to specialized services and insufficient psychological support hinder adaptation to this new life condition, making continuous, multidisciplinary follow-up essential to promote self-care and social reintegration^(13,36,37).

This study proves relevant in supporting care for people with intestinal stomas and their families, focusing on promoting self-care. Through attentive listening to participants, it was possible to identify emotional, social, and practical needs that directly impact these individuals' quality of life, highlighting the need for interdisciplinary and humanized approaches in healthcare follow-up. Furthermore, the results contribute to strengthening educational and support strategies, both institutionally and in the community, to empower patients with a stoma in managing their daily care.

Despite its contributions, it is necessary to consider that one of the study's limitations was the difficulty in having more older patients participate, due to their lack of familiarity with the use of digital platforms. Another limitation to consider is the majority participation of women, which may have influenced the diversity of perceptions and experiences shared in the operational group.

CONCLUSION

This study allowed us to understand the challenges related to self-care for people living with intestinal stoma. These individuals perceive the need for mechanisms to facilitate acceptance and adaptation to the difficulties of living with a stoma. Initial feelings regarding the creation of a stoma are marked by sadness, fear, and concern. However, throughout the adaptation process, these feelings can be transformed into perceptions of improved quality of life after the procedure and contact with others in the same condition.

Furthermore, information provided by healthcare professionals is essential for promoting self-care, particularly regarding collection equipment hygiene, peristomal skin care, nutrition, clothing, exercise, sexuality, and access to appropriate locations for effluent disposal. A social support network and accessibility facilitate the adaptation process, leading to a safer and more peaceful life.

The importance of strengthening the active participation of enterostomal therapy nurses in the multidisciplinary team is highlighted, to minimize complications caused by the inappropriate choice of stoma site, considering the different aspects of self-care, in order to prevent complications such as inadequate collection device fixation and the occurrence of contact dermatitis.

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Authors' contributions - CRediT

LBO: conceptualization; data curation; formal analysis; investigation; methodology; project management; resources; supervision; visualization; writing – original draft and writing - revision & editing.

JBRC: conceptualization; data curation; formal analysis; investigation; methodology; project management; resources; supervision; visualization; writing – original draft and writing - revision & editing.

LOG: visualization; writing – original draft and writing - revision & editing.

DS: visualization; writing – original draft and writing - revision & editing.

TSS: visualization; writing – original draft and writing - revision & editing.

CCS: visualization; writing – original draft and writing - revision & editing.

RGP: visualization; writing – original draft and writing - revision & editing.

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