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Promotion of bowel elimination ostomy self-care: A qualitative study based on the nurses' and patients' perspectives

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ABSTRACT

Background & Aim: The construction of an ostomy has a physical, psychological, and social impact, requiring the need to adapt. The way this event is experienced is influenced by several factors, namely ostomy self-care competence, the aspect most referred to in the literature. Nurses' specific and systematic intervention positively influences the person's adaptation to the ostomy. This study aimed to describe the perception of nurses and people with ostomies about promoting ostomy self-care.
Methods & Materials: A qualitative descriptive study was conducted. Semi-structured interviews were conducted with ten nurses specializing in stoma therapy and twelve people with bowel elimination ostomy. Content analysis was performed according to Bardin with categorical analysis.
Results: Two themes emerged from the interviews: the promotion of awareness, with three categories and four sub-categories, and the promotion of ostomy self-care, with five categories and twenty-four sub-categories.
In promoting awareness, the participants mentioned key contents that could be included in the nurse's approach: assessing awareness, content for promoting awareness, and awareness indicators.
Within the scope of promoting self-care, categories emerged, such as the intervention standardization, the contents, the methodologies, and the resources to promote self-care.
Conclusion: This study adds to evidence about promoting awareness of bowel elimination ostomy and self-care competence after the procedure. These results can be useful for nurses, allowing them to reflect on clinical practice and helping to improve the planning of their intervention in promoting stoma self-care.

Introduction

Colorectal cancer is the third most frequent type of cancer worldwide, with about 1.9 million new cases per year, and its incidence is likely to grow by 60% by 2040 (1). The most common treatment for colorectal cancer is surgery, and in 10 % of the cases, it results in the construction of a permanent ostomy (2). The construction of a stoma has physical and psychological repercussions for the person, representing a potential threat to all aspects of their lives, not only in having to learn to manage stoma care but also in incorporating them into their daily lives (3).

Considering the various factors associated with the acceptance process and its impact on quality of life, a systematic and complete approach to care by a nurse, from

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the preoperative phase to the follow-up after hospital discharge, has a significant impact on the development of self-care competence in the adaptation process and quality of life (4, 5).

The nurse assumes a central role in promoting self-care. To ensure the best results in this area, you must provide the right information to the right person at the right time to reduce the concerns expressed by the person undergoing the construction of a bowel elimination stoma. The nurse is responsible for recognizing and responding to each person's educational needs (6).

Given the importance of nurses in the continuity of care and the relevance of their intervention since the preoperative period, when we refer to the person with a bowel elimination ostomy in this study, we also include the person proposed for ostomy construction.

It is important to develop a theoretical understanding of the process of competence development for ostomy self-care based on existing evidence and theories, like the transition theory of Meleis (7), and complement with primary studies that help to understand the context in which the intervention will be implemented, namely in inpatient hospital contexts, in ostomy consultation or the community context.

Transition theory provides a conceptual basis for understanding a person's experience undergoing the construction of a stoma, which requires new skills, feelings, goals, behaviors, and functions. It is, therefore, a transition to life with a stoma (8).

Thus, it is important to know the perception of those involved in the change process, the nurses, and the person who will need to develop the competence for ostomy self-care to optimize the nurse's intervention in this population group (9).

Currently, the evidence is scarce regarding the experience lived by the person with an ostomy from the moment they receive the diagnosis until the fluid integration of the new condition. The studies identified were conducted to determine the satisfaction with care received, psychosocial problems and emotions of the individuals, their adaptation to the stoma, their quality of life, and spiritual attitude (10–12)

Knowing the perspective of nurses and patients is relevant to optimizing the nurse's intervention, promoting better results in developing self-care competence, adaptation, and quality of life. The aim of this research is: To describe the perspective of nurses and the people with a bowel elimination ostomy about self-care to bowel elimination ostomy.

Methods

Design

This is a qualitative descriptive study using semi-structured interviews.

The guidelines of the consolidated criteria for reporting qualitative research (COREQ) were followed (13).

Participants

Participant selection was carried out in three hospitals in Portugal: two in the north of the country and one in the center, as well as through the Portuguese Stomatherapy Care Nurses Association (APECE). The sampling process was intentional, looking for a maximum variation to increase the diversity of participants to gain broad characteristics, contexts, and perspectives of findings (14). Thus, the selection of nurses has related to diversified sociodemographic and training characteristics who worked in hospitals that included different care models for people with an ostomy and serving different populations from urban, rural, or island contexts. The selection of people with an ostomy has related to the type of ostomy and their duration, age, the cause of the construction of the stoma, and level of education.

The eligibility criteria for people with an ostomy to participate in the study were: people over 18 years of age, followed up in a stoma therapy care nursing consultation, with the potential for autonomy for ostomy self-care.

For the selection of nurses, the criterion was to have enhanced advanced competence in stoma therapy, recognized by the Ordem dos Enfermeiros de Portugal (Nursing Order of Portugal) (15).

Potential participants recruited from the institutions mentioned above were contacted personally by the first author and invited to participate in the study. The purpose of the study was explained to them. Participants recruited through APECE were approached by the first author using the telephone number provided by the association. All of the potential participants approached agreed to take part in the study.

Participant recruitment proceeded until the interviews did not generate any new information or only repeated information was obtained, which occurred in the eighth interview with the nurses. With the patient's group, no new information was identified from the tenth interview.

In accordance with participant convenience, the interviews were carried out in institutions with prior approval. They were conducted in person in a room close to where the stoma therapy consultation was carried out after the routine consultation. The nurses were interviewed during their working hours.

Participants recruited through APECE were interviewed via telephone or video call per the participant's preference.

A family caregiver was present in only one interview with a patient; all of the other interviews were carried out with only the first author and the participant present.

Some participating nurses knew the interviewer from the work institution and others from congress or conferences and formation contexts.

Data collection

Semi-structured interviews were conducted to understand the participants' perspectives on the person with a bowel elimination stoma on promoting ostomy self-care. The interviews were carried out by the first author, a Master's in nursing, and a stoma therapy nurse trained in qualitative methods. Data collection took place between November 2020 and January 2022. Each interview with nurses lasted 50-70 min and 18-45 min with patients. During the interviews with the patients, whenever the author identified a need for care, they were provided with guidance afterward.

The interviews were audio-recorded and fully transcribed in Portuguese. Taking notes during the interviews was unnecessary as no situations or behaviors relevant to the study's purpose were identified. The identification information of the participants was not included in the transcribed data to maintain the participants' identities undisclosed. Instead, letters and numbers were used as identifiers for the participants.

A script divided into two parts was used to conduct the interviews. The first part focused on the sociodemographic characterization of the participant, and the second part focused on the objectives of the interview, seeking to identify relevant issues to promote ostomy self-care. Table 1 exposes the main questions of the participant's interviews.

Pilot interviews were conducted with two scripts, one for the interview with the patients and the other for the interview with the nurses, and no need to reformulate them was identified.

Ethical considerations

The study complied with the standards of the Declaration of Helsinki (16). Approval was obtained from the ethics committees of the three health institutions involved in the study and from the Catholic University of

Portugal (nº 168) for data collection using APECE and patients recruited from other institutions.

A written consent form was obtained from all participants before starting the interview, which informed them of the study's aims, the implications of their participation, the data collection procedure, and the audio recording of the interviews. The possibility of canceling involvement at any time without personal prejudice was also addressed, and they were guaranteed confidentiality by removing all personal information from the data. In cases where the interview was not in person, informed consent was sent by e-mail, or the document was read and the audio recorded. All participants gave their consent to be interviewed and for the respective audio to be recorded.

Table 1. Script of the semi-structured interview with the participating

Main questions to the nurses
• Talk about the nurse role-play in the promotion of ostomy self-care • Talk about the preoperative nursing consultation for the person with bowel elimination ostomy • Talk about the promotion of bowel elimination ostomy self-care during hospitalization • Talk about the nursing follow-up after hospital discharge • What would change or improve in the promotion of self-care in the different contexts that the person with an ostomy goes through?
Main questions to the people with bowel elimination ostomy
• Talk about what it's been like to take care of your ostomy • When did you feel ready to start learning to take care of your ostomy? • Talk about the information you considered most important to receive in each of the stages you went through to take care of the stoma. • Talk about the preoperative nursing consultation • Talk about the teaching for stoma care during your hospital stay. • Talk about the teaching for stoma care at the ostomy nursing consultation after hospital discharge. • Talk about returning home after hospital discharge. • Talk about the methods and strategies used by nurses to teach you how to care for your stoma. • What would change or improve in the teaching take care of the stoma in the different contexts that you go through?

Data analysis

A content analysis was performed according to Bardin (17) using the categorical analysis technique. The NVivo software version 1.3 was used for data management.

In the first phase, the transcribed interviews were meticulously read, and the content of the interviews was selected for analysis. They were coded in a second phase. Categorization followed, which involved organizing and classifying selected texts and key points of the interviews transcribed into context units to form codes. Finally, the interpretation process was concluded, which involved the inferential process that represented the explanation of the codes of categories and sub-categories that emerged. Two experienced researchers coded and validated the categories, reaching a consensus with the remaining authors.

Results

Participants

Ten nurses and twelve ostomy patients were interviewed. Table 2 summarizes the characteristics of the participants.

Table 2. Characteristics of the participant

Nurses: Demographic and professional characterization (n=10)	**N (%)**	**Mean**	**Range; SD**
Age	-	46.4	34-57; 7.5
Gender			
Female	9 (90)	-	
Male	1 (10)	-	
Qualifications			
Stomatherapist nurse	10 (100)	-	
Years as a nurse	-	24.4	12-35; 7.3
Years as a nurse in ostomy care	-	19	10-31; 6.4
Context of ostomy care			
Stomatherapy nursing consultation	2 20)	-	
Stomatherapy nursing consultation and surgery hospitalization department	8 (80)	-	
Patients: Sociodemographic and clinical characterization (n=12)	**N (%)**	**Mean**	**Range; SD**
Age	-	55	33-83; 13.5
Gender			
Female	5 (42)	-	
Male	7 (58)	-	
Education			
1st cycle	8% (1)	-	
2nd cycle	50% (6)	-	
3rd cycle	33% (4)	-	
Higher education	8% (1)	-	
Type of surgery			
Urgent	8% (1)	-	
Scheduled	92% (11)	-	
Hospitalization days	-	13	5-30; 7.5
Months after discharge	-	6	0.3-18; 4.6
Type of ostomy			
Colostomy	67% (8)	-	
Ileostomy	33% (4)	-	
Type of ostomy in terms of time			
Temporary	42% (5)	-	
Definitive	58% (7)	-	
Diagnosis associated with stoma construction			
Neoplasm rectal	75% (9)	-	
Colon neoplasm	17% (2)	-	
Other	8% (1)	-	
Presence of a family caregiver			
Yes	33% (4)	-	
No	67% (8)	-	
Preoperative nursing consultation			
Yes	75% (9)	-	
No	25% (3)	-	

Themes, categories, and sub-categories

From the systematic analysis of the participant's perspective on the promotion of ostomy self-care, two main themes are identified: the promotion of awareness, with three categories and four sub-categories, and the promotion of ostomy self-care, with five categories and twenty-four sub-categories.

In both categories, there were contributions from both subgroups of participants; however, in promoting

awareness, more sub-categories emerged from the interviews with nurses.

When sub-categories emerge from both subgroups, these are mentioned as "participants" to facilitate the interpretation of results. When the sub-category originates from only one of the subgroups of participants, reference is made to the specific subgroup.

Promoting awareness

Several aspects related to the awareness process were identified in the interviews, specifically the level of awareness, the relevant content in promoting awareness, and awareness indicators.

Table 3 contains the categories and sub-categories identified within the theme of raising awareness.

The nurses mentioned the importance of assessing awareness to determine the patient's level of knowledge, perception, and recognition of change, namely whether the person is aware of their situation and whether their perception of their new condition has changed.

One of the issues mentioned by both groups of participants as a promoter of awareness was the marking of the stoma site. Only nurses refer to this step as a fundamental issue with a positive impact on variables such as the incidence of complications, autonomy in self-care, and improved quality of life. However, as a first phase, it contributes to promoting awareness.

The observation of the stoma, the first observation of its presence in an image or photograph of the stoma, is something that later promotes the knowledge and recognition of the change itself. This issue was mentioned exclusively by nurses.

Participants see preoperative teaching about ostomy as an important step in the process of internalizing change.

The analysis and demonstration of the day-to-day changes of the proposed patient for the construction or already with a stoma, anticipating the experience and the changes or adjustments that may be necessary, namely in activities of daily living, at work, and in clothing, is an essential step towards recognizing the change and the implications it has on the person's everyday life, which is an issue mentioned exclusively by nurses.

The participants refer to a set of issues understood as indicators of awareness or the absence of awareness, emerging as a determinant to know where the recognition of change is.

Table 3. Categories and sub-categories of the promoting awareness theme

Category	Sub-category	Quotation
Assessing awareness	-	"The first issue is awareness… the first assessment starts with awareness… the person has a knowledge of the situation and the idea of is implication…" (Nurse 10)
Contents for promoting awareness	Marking the stoma site	"in the stoma site marking, we use an ostomy simulator … we will put it on abdomen... the patient will also be the reality, changing their perception of how it is to really had or not had an ostomy and the bag." (Nurse 1) "They made the stoma site marking for me to see where the stoma was going to stay, how comfortable it was…" (Patient 3)
	Observation of the stoma	"Looking at the photograph (of a stoma) so that something awakens..." (Nurse 5)
	Preoperative teaching about ostomy	"the day before or even a few days before, a person starts thinking and becoming aware of what they are going to do." (Nurse 4) "that learning, that class, let's put it this way, was beneficial… to internalize…this preparation even before the operation." (Patient 1)
	Day-to-day changes	"anticipate the experience of had colostomy ... what you will need to live with a stoma" (Nurse 10)
Awareness indicators	-	"…when the person tells us that everything is fine, they do not express their concern about the presence of a stoma; this is also worrisome. It is a sign that they are not internalizing their situation…" (Nurse 5)

Promotion of ostomy self-care

In the interviews, within the scope of the theme of promoting ostomy self-care, categories emerged that are directly related to promoting self-care, and others aimed at the assumptions that must be present or that influence this process. Table 4 shows the categories and sub-categories of the topic promoting self-care for bowel elimination ostomy.

Table 4. Categories and sub-categories of the theme promoting self-care in people with bowel elimination ostomy

Category	Sub-category
Standardization of interventions in promoting self-care	Minimizing discrepancy between professionals
	Systematizing educational methodology
Contents of nursing interventions	The surgery
	Monitoring and support
	Activities of daily living
	Stoma care and devices
	Selection of devices
	Prevention, detection, and management of complications
	Involving and empowering the family
	Encouraging autonomy in care
	Promoting interaction with peers
	Assessment of self-care competence
Methods and resources for interventions	Face-to-face
	Telephone contact
	E-mail
	Mannequin or simulator
	Video
	resource Internet resource
	Paper media, text, and images
	Design
	Material resources – mirror
Personalization of care	Adapting intervention to the patient
Continuity of care	Hospital stoma therapy consultation
	Community care

The nurses mentioned the importance of standardizing the nurse's intervention in promoting self-care, ensuring that all the information transmitted is consistent and rigorous among the different self-care promotors. This category includes the need to minimize discrepancies between professionals, achieved through training the team whenever it integrates new members.

"The problem is between us, professionals, sometimes we do not teach the same thing. Some say one thing, others say another, and then the person, or the caregiver, gets a little confused."(Nurse 4)

The participants also highlighted the need to systematize the educational methodology, which includes a systematic promotion of self-care to have complementarity between the intervention of the stoma therapist nurse and the general care nurse, thus optimizing the process of developing ostomy self-care competence. Ensuring the methodology responds to specific needs was also mentioned, adjusting the different methods to the person's characteristics and objectives and defining the intervention methodology with nurses who are not specialists in stoma therapy.

In the interviews, a category emerged focused on the content of interventions to promote ostomy self-care, which includes the different topics to be addressed. The participants mentioned the follow-up and support in care. This includes information about the follow-up that the person will have throughout the perioperative period and after

returning home, namely the planning of consultations, support available from the stoma therapy consultation, and community.

Participants also mentioned the need for adjustments in activities of daily living related to the construction of the ostomy, namely clothing, food, work, recreational activities, sexuality, and participating in sports activities. Stoma care was reported by participants and includes hygiene, plate cutting, removal, and application of devices. Directly related to this category is the selection of devices at different times.

Prevention, detection, and management of complications were reported by participants and included skin and stoma care, recognition of changes to normal skin or stomal characteristics, and recognition of situations that require a healthcare professional (prolapse, maceration, dehiscence). Skin protection, dehydration, and possible expected changes, such as blood loss, were also mentioned. Involving the family was pointed out by the participants and refers to the importance of integrating the family in developing competence in ostomy self-care as a support to be replaced only if necessary and in case of uncertainty after returning home.

The participants mention the need to encourage autonomy in care from an early stage of promoting self-care; there is always an incentive for autonomy. However, after returning home and as the person develops more mastery of their skills, the need to develop autonomy in managing stoma care is reinforced. The family caregiver's recognition of the patient's autonomy potential also proves very important.

Participants mentioned promoting interaction with peers as a strategy that can be useful to help the patient solve day-to-day problems and enhance the development of autonomy. The person has a positive impact when seeing another person with an ostomy who has assumed this new condition and has good quality of life. Only the nurses mentioned the need to assess the evolution of the self-care competence to understand the level of competence developed, what needs to be addressed or trained, and if the patient is assimilating the issues addressed.

Methods and resources for promoting self-care were a category that emerged from interviews with both groups. In this category, the methods to implement interventions that are face-to-face or by telephone emerged. E-mail is a non-face-to-face contact strategy mentioned by nurses for patients to ask questions or to request telephone or face-to-face contact. The resources identified to promote self-care are mannequins or stoma simulators. Video content available directly on the internet and viewed through a computer, tablet, or mobile phone is a resource used to show content aimed at stoma care and activities of daily living.

In addition to providing access to the videos, the internet was mentioned by the participants as a source of information as a strategy to develop easily accessible knowledge. Paper content with text and images is the most used strategy to provide information about stoma care, complications, activities of daily living, and nutrition. This resource is used as a brochure, book, or technical sheet.

"We have our guide that we built, and this guide is very visual…to demonstrate through anatomical and surgical diagrams…we have stoma molds…" (Nurse 6)

The use of drawings is a strategy mentioned by nurses that facilitates the teaching of what an ostomy is as well as its location, allowing the patient to understand more easily. Nurses mentioned that care should be adapted to each patient's characteristics and needs so that the category of personalization of care emerged, requiring an individual assessment of each situation to adjust the intervention to the patient.

Regarding continuity of care, primary health care, and hospital stoma therapy consultation was mentioned as a guarantee of safety on returning home and to promote self-care, reinforcing the need for professionals who can provide quality care to the person who has undergone the construction of a bowel elimination stoma, highlighting the need to transmit information to make the process continuous.

"I contact the family nurse to say that they will be discharged…the point at which they are in terms of and whether or not they need support is mentioned in the discharge letter."(Nurse 3)

Discussion

The entire process experienced by the person with a stoma is a transition triggered as soon as the event or change is foreseen, characterized by a period of instability (18).

Of the various categories and sub-categories that emerged from the interviews, there is an agreement in some categories and complementarity in others in the perspectives of nurses and patients

Promoting awareness

The transition to a life with a bowel elimination stoma is complex and accompanied by multiple, significant, lasting changes that include body changes, dissatisfaction with appearance, incontinence, odor, gas, and adjustments in clothing and food. A vulnerability phase marks this experience due to self-care-related challenges, and it is expected to end with a state of stability and adaptation to the new condition (7).

Awareness of the change or the situation that triggered the change is the essential condition, without which it is assumed that there is no transition (8).

The level of awareness is a changing process, and it is unlikely that there will be full awareness of the new condition at an early stage.(7).

Participants refer to a set of topics that aim to promote the perception of change in the person with a stoma. These issues alert to the changes yet to occur, such as marking the stoma site, preoperative teaching about ostomy, and day-to-day changes, which allow for anticipating the experience. These are referred to in the literature as significant and relevant to be started in the preoperative period (19) and are conditions that facilitate the awareness process (20).

However, only after they return home and their daily activities will this confrontation entirely occur. Behaviors that suggest intermediate points of the awareness process will be identified throughout the process. These behaviors indicate whether the awareness process has already started and is ongoing.

Promoting self-care

One of the main objectives in planning nursing care, not only after the presence of the stoma but at the precise moment when the person is proposed for its construction, is the promotion of self-care for the ostomy.

The daily care of the stoma is a challenge that the person has to learn to manage, and the availability of information seems to facilitate the acquisition of autonomy; however, not adapting the information to the person can induce stress and anxiety, as mentioned by the participants (21).

In promoting self-care, continuity of care, and the need to maintain consistency and harmony in the process, ensuring that the intervention is carried out as planned is essential to obtain the best results. Thus, the category of standardizing interventions to promote self-care emerged, a characteristic that is difficult to maintain due to a large number of individuals, from the various nurses in the hospital to the follow-up in the

community and the hospital consultation (22).

After defining the strategies to maintain the continuity and standardization of the interventions, it is crucial to define the contents to be addressed in promoting self-care. In the interviews, a set of contents were identified that were considered most pivotal to encouraging self-care.

The competence for self-care of the ostomy and peristomal skin, the competence to identify problems and complications, and seeking adequate physical and psychosocial solutions should be the priority areas for the nurse to intervene with the person undergoing the construction of a stoma (5, 7).

The participants mentioned involving and empowering the family within the scope of the contents to be integrated into promoting self-care. In effect, incorporating the family as emotional and physical support at a time of the loved one's fragility is associated with better adaptation and empowerment of the patient, easy the overcome of negative factors that the construction of an ostomy brings (23).

The family of the person undergoing the construction of a stoma assumes a role that ranges from making recommendations to the patient from the performance of self-care to being substituted in terms of care when the patient is unable to take care of him or herself (21), thereby justifying the need to involve and train the family to care for the stoma.

The nurses mentioned the need to assess self-care competence to promote self-care. In effect, a correct assessment of self-care competence before each nurse's intervention constitutes a data collection process that will allow the specific needs of the person to be identified, allowing for a more targeted and personalized intervention. This favors the transition process and the quality and continuity of care (24).

Regarding methods, telephone contact was a strategy mentioned by the participants as useful for monitoring and clarifying doubts. Indeed, telephone follow-up after hospital discharge effectively improves satisfaction with care, reduces colostomy complications, improves self-care competence, and increases the patient's self-confidence in dealing with the ostomy. Although it is performed at a distance, this type of monitoring has become a significant factor for better adaptation to the stoma (25).

Methods to improve the patients' educational process through information and communication technologies, such as computer-aided education models and videos, are rapidly evolving. Nurses play a central and privileged role in using these technologies to improve and optimize their interventions with patients (4).

Limitations

An attempt was made to include a large variability of participants with different characteristics to cover the greatest possible variety of experiences and perceptions; however, the results of this study are based exclusively on the participants' perceptions, exploring the uniqueness of the phenomenon in depth.

All data were collected in a European country with a specific sociocultural context, which may have influenced the results.

We consider the fact that the transcripts were not returned to the participants for validation a limitation.

Conclusion

This study adds evidence to the intervention of nurses in people with bowel elimination ostomy, specifically in promoting awareness of the new condition and ostomy self-care. These results corroborate previous findings and contribute to a more significant deepening and understanding of the process of developing stoma self-care competence.

On the one hand, knowing the factors that influence the development of self-care

competence helps to understand better and predict the transition process. On the other hand, they are relevant data for nurses' decision-making regarding the prescription of interventions and their suitability for the person proposed for the construction of a stoma.

Knowing the perspectives of nurses and clients on the promotion of self-care allowed us to understand to what extent they agree and can complement each other.

These results can be helpful for nurses, allowing them to reflect on clinical practice and helping to improve the planning of their intervention in promoting stoma self-care. Also, the results can be relevant for the construction of nursing intervention programs, contributing to the definition of contents, strategies, and teaching methods of stoma self-care, which enhance better outcomes.

Future researchers could explore the family's perspective on promoting self-care and the promotion of awareness in the person proposed for the construction of a stoma.

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Conflict of interest

The authors have declared no conflict of interest.

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