

## PERCEPTION OF OSTOMIZED PATIENTS AFTER SURGERY AND THE PROCESS OF A STOMA

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### ABSTRACT

The purpose of this study was to understand perceptions about stoma of ostomized patients after surgery. This descriptive study with a qualitative approach used three guiding questions and the testimonies of 13 ostomized patients cared for in a coloproctology outpatient clinical of a university hospital in the interior of São Paulo, Brazil were submitted to André's Prose Analysis. Four themes emerged: experienced feelings, difficulties experienced after the stoma, sexual life after stoma, and future expectations. Another ten topics were identified: anger, resignation, faith, difficulties faced to self-care, social re-insertion, apparel changes, sex with loss, support from family members, healing, and improved quality of life. The studied perceptions led to the conclusion that the teaching-learning process of self-care and stimulus for social re-insertion enabled by the nurse and team consists the central focus of care provided to ostomized patients.

**Keywords:** Emotions. Ostomy. Nursing.

**Keywords:** Infant. Health Resources. Quality. Access, and evaluation of health care.

### INTRODUCTION

An intestinal stoma refers to the temporary or permanent exposure of a portion of the intestines through an opening in the abdominal cavity, which depending on the segment exposed, has different names, such as colostomy or ileostomy. Even though these interventions increase life expectancy, they also lead to considerable changes in the lives of patients and of family members regarding the need to manage the limitations posed by a stoma<sup>(1)</sup>.

A stoma may limit one's quality of life due to the physical, psychological and psychosocial difficulties with which patients have to cope. The body changes due to a lack of sphincter function and the presence of a hole in the abdomen, which becomes the point of feces disposal. It may harm one's self-image, self-esteem and social life; patients

may isolate themselves, believing they are not accepted by society due to their condition. Body image is related to youth, beauty, vigor, integrity, and health and those not meeting these standards may experience a sense of rejection<sup>(2)</sup>.

Body-image-related feelings and attitudes compose a concept of body that is essential for adequate social life. The patient with a stoma becomes alienated in relation to his/her body from feeling different, less confident, and having less self-respect<sup>(3)</sup>.

The patient with a stoma often faces difficulties regarding sexuality, which may be psychological difficulties, or, most of the time, caused by changes in body image<sup>(2)</sup>.

Family support or support provided by significant and close people, as well as that provided by health services, is essential for patients to reintegrate into society and understand the changes in their bodies. Given the previous discussion, this study's question

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is: What is the experience of person with an intestinal stoma?

Appropriate care-planning and the support of a multidisciplinary team eases the adaptation of patients to physiological, psychological and social changes, significantly improving their quality of life<sup>(4)</sup>. Therefore, this study's aim was to understand the perceptions of patients with intestinal stomas after surgery.

## METHOD

This exploratory and descriptive study with a qualitative approach was conducted in October and November 2010, in the coloproctology clinic of a university hospital in the interior of the state of São Paulo, Brazil.

Sample selection in qualitative research is driven by the participation of people linked to the problem under investigation and representativeness, by the possibility of covering the entire object of study in its multiple dimensions<sup>(5)</sup>. This study included 13 patients with intestinal stomas cared for by the aforementioned coloproctology clinic at the time of data collection. The participants were selected according to data saturation. Inclusion criteria were being 18 years old or older, both genders, and having a permanent intestinal stoma. Exclusion criteria were being younger than 18 years of age and having a temporary intestinal stoma. After the participants were selected, they were individually approached and received clarification about the study and then provided their formal consent.

Data were obtained through a scheduled interview, conducted in a private room, lasting from 30 to 60 minutes. A scripted interview was used. It addressed sociodemographic characterizations and included two open questions: How did you receive the news that you were going to have surgery resulting in a stoma. What has changed in your life so far?

The study was approved by the hospital's Institutional Review Board in accordance with Resolution by the Brazilian Council of Health (466/2012, protocol No. 5753/2010). All the participants' reports were recorded and transcribed by the researcher. The reports are identified by names of flowers to ensure confidentiality.

André's Prose Analysis is "a form to investigate the meanings of qualitative data. It is a means to raise questions concerning the content of a given material. What does it say? What does it mean? What are its messages?" This analysis includes intentional and non-intentional, implicit and explicit, verbal and non-verbal, alternative and contradictory, messages.

Qualitative data present many advantages, such as allowing the complex and multidimensional nature of phenomena to be grasped in their natural manifestations<sup>(6)</sup>.

The topics and themes emerged from the examination of data and their contextualization in the study. These topics and themes were frequently revised, questioned, and reformulated as the analysis evolved, considering theoretical principles and the study's assumptions<sup>(7)</sup>. First, topics and themes should be distinguished: topic is a subject, while theme is an idea that evolves to a higher level of abstraction<sup>(5)</sup>.

André states that whether the themes and topics are generated concomitantly or whether the themes emerge from the aggregation of topics is not explicit. One should bear in mind that the process of categorizing qualitative data involves not only logical, objective and/or intellectual knowledge, but also the researcher's personal, subjective, or intuitive knowledge<sup>(6)</sup>.

## RESULTS AND DISCUSSION

Most of the 13 participants were men aged from 57 and 65 years old, had completed middle school, were retired and had a family income from one to two times the minimum wage; 60% of the ostomy patients were diagnosed with cancer. From the analysis and interpretation of the patients' reports 11 topics emerge, which were grouped into four themes, namely:

### **Feelings experienced by patients after stoma surgery**

The need for a stoma causes a rupture in the lives of patients and each individual has a unique response to it. Each individual questions their existence, especially when the patient experiences something negative in daily life and is unable to move on. At this point, the human

being shuts down emotionally and does not understand his/her existential condition, denying the truth. This process is accompanied by an initial resistance to bodily changes and the way feces are excreted.

Feelings of the desire to revolt, conformity and faith invade the individual, when one realizes s/he is an individual with a stoma, and thus requires interdisciplinary and integral care that is not restricted to the disease and technical care<sup>(7-8)</sup>.

The disease's diagnosis, such as cancer, and the need for a stoma, triggered many painful feelings and a sense of rebellion among patients, which led to being preoccupied and a sense of being different for having one's intestine diverted and for having the bag continually attached to the skin.

[...] a feeling of desire to revolt, sadness, and despair from knowing I'd have to use the bag. I wouldn't accept it, I wouldn't, I wouldn't. So I underwent surgeries to see whether I could change it back. (Belladonna)

[...] I was disturbed by all that was happening...I opted for a clinical treatment. I did not accept the bag and I think that anyone would have this type of reaction. (Fleur de lis)

[...] Before, I wanted very much to take this bag out, but the cardiologist would not authorize it. (Fuchsia)

These results coincide with those reported in the literature that mutilating surgeries, such as mastectomies, often necessary to treat breast cancer, result in changes in women's self-image, in the relationship they establish with their own bodies, their sexuality, and social relationships<sup>(9)</sup>.

Conformity was evident in the reports of patients, as they showed they did not have a choice in regard to the stoma. Even when informed prior to the surgery, they did not have time to stop and reflect on what they wished. Sometimes, there was a lack of interaction between the physician and patient that would enable them to discuss other alternatives.

[...] I had no option, I had to resign myself, I had to do it, right? (Chrysanthemum)

[...] I had to accept it because when you get sick, you have to receive treatment, don't you?

(Carnation) [...] Now I have to accept it, right? Now it's done and I have to accept it! There's no other way!(Amaryllis)

This lack of options in regard to the surgical treatment was also found in another study, which shows that even though the reports of patients reveal an extreme and severe situation with risks, imposing the surgery as a possibility of cure, many accepted the stoma due to a lack of options. This emphasizes that, despite the difficulty in dealing with the bag, they are alive, and are no longer sick, with pain or facing imminent death<sup>(10)</sup>. Spirituality, faith, and belief in God stood out in the interviewees' reports as a support helping them to face their disease and treatment. The following report shows that the patient's spiritual dimension should be considered by the health staff and in the planning of nursing care.

[...] Ah! I'm not afraid. I have no fear. Since the beginning I put it in God's hands. It's in the Lord's hands and in the physician's hands all the needs I had to get cured [...] It didn't matter what I was going through. I asked God to give me strength to overcome whatever I had to face. (Pansy)

Strategies to cope with the disease and death are directly linked to faith and religious beliefs, i.e., the ways patients express spirituality. One of the strategies used by elderly individuals with chronic conditions to face adversity lies in faith in God. Faith in God is a feeling rooted in the Brazilian culture and is as relevant as other coping strategies<sup>(11)</sup>.

### Difficulties experienced by ostomy patients

Living with a stoma leads patients to adopt many measures to readjust and try to adapt as best as possible to daily activities, including learning self-care actions, such as caring for the stoma and peristomal area and handling devices. The reports highlight difficulties in performing self-care, social reintegration and changing clothing. Difficulty in dealing with the device was reported by the patients because they did not receive sufficient orientation to perform this task by themselves. It led to a trial and error process until they found the right device, which resulted in skin problems such as dermatitis and detachment of the bag earlier than should have occurred.

[...] The greatest difficulty with the bag was in the beginning because we don't know how to deal with it, how to care for it [...] and another thing is shame, we have to let somebody else see it, you know? It's really complicated, I learned by myself [...] (Orchid)

[...] It doesn't stay glued. We travel, it falls off, poop spills on the road... (Rose)

[...] a difficulty, for instance, is first to learn how to change it, you know? (Chrysanthemum)

Studies show that dealing with stoma devices is important to ensuring skin integrity and preventing infection. For these measures to be properly performed, ostomy patients need to be taught by nursing professionals and become able to perform self-care<sup>(12-13)</sup>.

The difficulty of patients in resuming leisure, as well as social, activities was often perceived not as a problem of society accepting their conditions, but a difficulty arising from the patients themselves.

[...] Society does not accept it; it may even accept it, but deep down, there's something! (Fleur-de-Lis)

[...] Listen [...] the truth is only one thing: it's the bag, it [...] doesn't cause concern in some sense but it does cause concern in others. It's no reason for concern in terms of hygiene; it's not a problem, because it's practical. The problem is uneasiness when you're in social settings [...] the smell[...]. (Acacia)

When experiencing rehabilitation, patients with stomas feel completely different from other patients and their psychosocial needs concerning self-image and self-esteem are more strongly affected because they have no control over eliminations, their daily activities are limited, and they are deprived of leisure and work, among other activities<sup>(4,14)</sup>.

When patients acknowledge their condition immediately after surgery, they tend to declare the death of their civil lives, i.e., the end of an autonomous existence. The reason is that now they have an unnatural bowel movement in which feces are collected through a device that is considered, by many patients, shameful, alienating and repulsive. Eliminating feces this way goes beyond the biological sphere and reaches the social sphere of their existence in the world<sup>(8,14)</sup>.

Change in dressing style was also mentioned as a difficulty to overcome. Because of the stoma and the collector device, the patients have to change and adapt their clothing, using loose clothes or untucked shirts to hide the collector device.

[...] you have to hide the stoma. I used to wear suit and tie and I can't anymore because you have to tuck in the shirt, so I can't use it anymore (Acacia)

[...] You can't make yourself comfortable anymore, you put on a shirt and it shows (Daisy)

Changes that impact patients at an emotional and psychological level basically are changes in body image and consequences accruing from it. Body image is defined as how we feel and think about our body and its appearance. Feelings and attitudes related to body image form a concept of body that is essential to a more appropriate social life, but ostomy patients are concerned with keeping their stoma a secret. Some patients perceive that their friends withdraw, while others withdraw themselves for experiencing stigmatized in social relationships<sup>(3)</sup>.

### Sexual life after a stoma

Ostomy patients find it difficult to resume sexual activity because, among men, the surgery may result in erectile dysfunction, if the nerve and vessels responsible for erectile function are injured, as well as retrograde ejaculation, while decreased libido may be experienced by both genders. There is also a concern over the sexual partner accepting the condition and a concern in satisfying him/her, as well as low self-esteem<sup>(7)</sup>.

The interviewees' reports show that sexuality is an important aspect affected by the stoma. The patients reported that sexuality was affected after their surgery, in physiological terms, but also due to fear of not being accepted or of being rejected by a sexual partner.

[...] I haven't had a sexual life for many years now. (Fuchsia)

[...] Ah! Sexual life has changed. I had the surgery at the age of 65 years old and considered myself to be 40 years old; it was over after surgery. (Orchid)

[...] Now, I simply cannot have sex [...] how will

a woman accept such a thing knocking on her belly? (Acacia).

Most patients with intestinal stomas are not able to resume sexual life easily, or only resume it partially, due to problems with the device, shame, smell, or rejection on the part of the partner. One study reports that understanding and acceptance on the part of the sexual partner are essential for better sexual readjustment<sup>(15)</sup>.

[...] I'd say there is a withdrawal. I believe that both cases, for instance, contact of a man with a woman in a situation like this, I guess there is an obstacle. There is mutual blockage. (Fleur-de-Lis)

[...] Well, it was different before the disease, you know? Now, you're not the same person you were before, because there was chemotherapy, a lot of things, so we're not the same as before. (Camellia)

Fear, pain, and physical changes complicate sexual desire and a lack of dialogue impedes pleasure resuming a place in a couple's life. Sexual function is crucial to quality of life. A satisfactory sexual life significantly reflects on life in general and a lack of sexual practice leads to decreased self-esteem and triggers emotional tensions<sup>(16)</sup>.

### Future prospects

Patients became very emotional when they reported that the only thing they wished for the future was being cured. Those who were diagnosed with cancer were not free of recurrence and wished they could enjoy life in whatever way pleased them. Hence, patients with intestinal stomas emphasized their expectations of maintaining family support, achieving a cure and attaining a better quality of life.

All the patients reported the support of family, friends, professionals and other significant people to coping with the disease, as the following except shows:

[...] So, I tell you that my family is wonderful. (Fleur-de-Lis)

[...] My aunt said: we want you with a bag or without a bag. The important thing is that nothing will ever change because of it. (Belladonna)

[...] I had and still have the support of my family and friends. Thank God. (Fuchsia)

Family relationships, in the case of a chronic condition, can change drastically depending on the degree of stability and ties established among its members. How the family responds is also influenced by the way society deals with disease issues, a condition that moves away from normality. The most painful sort of rejection is that arising within the family, from which total support would be expected to cope with the disease and deal with the new condition in a less traumatic way<sup>(17)</sup>.

The support provided by family is a safe harbor for the patient and contributes to his/her self-esteem, self-confidence, physical recovery, and return to social activities. The role the family plays in the life of a patient with a stoma is as important as the preoperative preparation. Support provided by the family and partner is essential for the patient to develop positive attitudes in the face of his/her new situation, making the process of recovery easier and faster, as well as easing adaptation and return to daily living activities<sup>(15)</sup>.

Even patients with cancer, which still is a stigmatized disease, believe and expect that they will achieve a cure in order to move on with their lives.

[...] Ah, I hope I'll heal and move on with my life. (Fuchsia)

[...] I've always worked with cane sugar trucks, I expect to leave here and go back to work, do my job. (Chrysanthemum)

The emergence of cancer, still seen as proximity to death, leads patients to accept the stoma as a possibility to prolong life and forget death as something existential, facing it as a phase, the result of a healing process, not as a deficiency or disease<sup>(8)</sup>.

People with degenerative chronic diseases that have been diagnosed and treated require some other form of care in addition to the psychosocial management of physical, psychological, social and economic sequelae. The problems faced by cancer survivors are unique and multifaceted, including physical, emotional and social stress that emerge as a result of treatment side-effects, changes in life style, ruptures in the roles the patient played at home within the family, and fear of recurrence. Each person has unique needs based on the extension of their disease, treatment side-effects, and priorities related to the patient's health

condition, functional level, coping strategies, and support system, among other factors<sup>(18)</sup>.

For this study's patients, quality of life means achieving the maximum level of well-being and autonomy, in addition to resuming social life and daily living activities, while rehabilitation is essential to achieving these objectives.

[...] I'll keep on fighting. I'll stay here, helping ostomy patients and every day improve the condition of our lives, of patients with stomas, so that the world understands that a stoma is life, not death (Belladonna)

[...] I expect a better future for me. (Tulip)

[...] I expect a 360° turn in my life. (Pansy)

Quality of life in the face of a stoma's impact is closely linked to rehabilitation. The first step of this process is acceptance, always bearing in mind that the purpose of the surgery was to preserve life. From this point on, care with food and hygiene, social and family reintegration, resuming work and leisure, should be the objective of rehabilitation. Resuming a routine is extremely difficult, but the individual has to overcome difficulties so current life is fully enjoyed within his/her physiological limitations<sup>(19-20)</sup>.

Ostomy patients can enjoy good quality of life, though criteria for this should be in accordance with one's social and cultural characteristics. Even in the face of a stoma, patients can see the possibility of overcoming limitations.

Data collection was a limitation in this study because it was a one-time situation; i.e., we could not verify whether these perceptions remained over time. Future studies are needed to fill in the gaps and define strategies to improve treatment and the coping process. This study's results support the teaching/learning process of self-care and encourage social reintegration as performed by nurses and the multidisciplinary team among individuals with intestinal stomas.

## FINAL CONSIDERATIONS

This study enabled understanding the perceptions held by patients with intestinal stomas after their surgeries, such as feelings of rebellion, resignation, and faith, which were the coping mechanisms used.

The main difficulties reported by the patients included self-care, change of dressing style, sexuality and social reintegration, though they expected to resume daily activities and considered their difficulties to be phases of a process in which family support and faith in God were strategies to cope with their conditions while retaining quality of life.

Further research is essential to show particular aspects of patients with intestinal stomas and contribute to improved planning of individualized care and quality of life.

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## PERCEPÇÕES DOS ESTOMIZADOS INTESTINAIS APÓS A CIRURGIA E CONSTRUÇÃO DE UM ESTOMA

### RESUMO

Objetivo desta pesquisa foi compreender as percepções dos estomizados intestinais sobre o estoma após a cirurgia. Estudo descritivo de abordagem qualitativa que utilizou três questões norteadoras, sendo que as falas dos 13 pacientes estomizados intestinais, atendidos no ambulatório de coloproctologia de um hospital de ensino do interior do Estado de São Paulo, Brasil foram submetidas à análise de prosa de André. Da análise desses registros emergiram quatro temas: sentimentos vivenciados, dificuldades vivenciadas após estoma, vida sexual após estoma e expectativas futuras e dez tópicos: revolta, conformismo, fé, dificuldades no autocuidado, reinserção social, mudança no vestuário, sexo com prejuízos, apoio dos familiares, cura e melhor qualidade de vida. As percepções levantadas neste estudo permitiram concluir que, o processo ensino aprendizagem do autocuidado e estímulo para reinserção social, realizados pelo enfermeiro e sua equipe consiste no foco central da assistência aos pacientes estomizados.

**Palavras-chave:** Emoções. Estomia. Enfermagem.

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## PERCEPCIONES DE LOS OSTOMIZADOS INTESTINALES SOBRE ESTOMA DESPUÉS CIRUGÍA

### RESUMEN

La finalidad de esta investigación fue comprender las percepciones de los pacientes ostomizados intestinales al respecto del estoma después de la cirugía. Estudio descriptivo con enfoque cualitativo que utilizó tres preguntas orientadoras. Los discursos de los 13 pacientes ostomizados intestinales, atendidos en el ambulatorio de coloproctología de un hospital de enseñanza del interior del Estado de São Paulo, Brasil, fueron sometidos al

análisis de prosa de André. El análisis de esos registros reveló cuatro temas: sentimientos vividos; dificultades vividas tras el estoma; la vida sexual después del estoma; y expectativas futuras; además de diez temas: enfado, conformismo, fe, dificultades en el autocuidado, reinserción social, cambio en la vestimenta, sexo con perjuicios, apoyo de los familiares, cura y mejor calidad de vida. Las percepciones identificadas en este estudio permitieron concluir que el proceso de enseñanza aprendizaje del autocuidado y estímulo para la reinserción social, llevado a cabo por el enfermero y su equipo, es el foco central en la atención a los pacientes ostomizados.

**Palabras clave:** Emociones. Ostomía. Enfermería.

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