

## PERCEPTION OF PATIENTS LIVING WITH INTESTINAL STOMAS: REFLECTION IN THE LIGHT OF PHENOMENOLOGY

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### ABSTRACT

**Objective:** To reflect, in the light of phenomenology, on the perception of ostomates about their bodies. **Method:** This is a reflective study based on the philosophical theoretical basis of phenomenology, presenting findings in the literature and the author's view on the topic addressed. **Results:** The perception is not simply the thing visible to the eye. It has a meaning in relation to the subjective interpretation of the observer, with the body as the center of observation. Ostomates have an individual perception of the changes that the ostomy brings to their lives. In this sense, we associate the perceptions with Merleau's thoughts, in which the perception of the body and oneself is presented in a particular way from the perspective of the observer. **Conclusion:** This reflection enabled a better perception of ostomates. They show for each situation they experience a positive or negative emotion as a reflection of the relationship between body and mind. It enabled the understanding of the point of view of ostomates in the face of their experiences of change in the bodies.

**DESCRIPTORS:** Stomatherapy. Adaptation. Philosophy in Nursing. Patient-centered care. Shift change.

## PERCEPÇÃO DOS PACIENTES VIVENDO COM ESTOMIAS INTESTINAIS: REFLEXÃO À LUZ DA FENOMENOLOGIA

### RESUMO

**Objetivo:** Refletir, à luz da fenomenologia, sobre a percepção dos pacientes vivendo com estomias intestinais sobre seus corpos. **Método:** Trata-se de um estudo de reflexão fundamentado na base teórica filosófica da fenomenologia de Merleau-Ponty na literatura e a reflexão acerca da visão do autor sobre a temática abordada. **Resultados:** A percepção não é simplesmente a coisa visível ao olhar, mas apresenta um sentido em relação à interpretação subjetiva de quem observa, tendo o corpo como o centro da observação. Pessoas com estomias apresentam uma percepção individual das mudanças que a estomia pode trazer para suas vidas. Nesse aspecto, relacionamos as percepções com os pensamentos de Merleau, em que a percepção do corpo e do ser apresentam-se de forma particular diante da perspectiva do ser observador. **Conclusão:** Tal reflexão possibilitou melhor percepção dos pacientes vivendo com estomias intestinais. Eles apresentam, para cada situação que vivem, uma emoção positiva ou negativa como um reflexo da relação corpo e mente. Ela possibilitou uma melhor compreensão da visão das pessoas com estomias diante das experiências vivenciadas a partir da mudança corporal.

**DESCRIÇÕES:** Estomaterapia. Adaptação. Filosofia em Enfermagem. Assistência centrada no paciente. Mudança de função.

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# PERCEPCIÓN DE PACIENTES QUE VIVEN CON ESTOMAS INTESTINALES: REFLEXIÓN A LA LUZ DE LA FENOMENOLOGÍA

## RESUMEN

**Objetivo:** reflejar sobre la percepción de los pacientes que viven con estomas intestinales en el cuerpo, a la luz de la fenomenología. **Método:** se trata de un estudio reflexivo basado en la base teórica filosófica de la fenomenología, presentando hallazgos en la literatura y la visión del autor sobre el tema abordado. **Resultados:** La percepción no es simplemente la cosa visible al ojo, sino que tiene un significado en relación con la interpretación subjetiva del observador, con el cuerpo como centro de observación. Las personas con ostomía tienen una percepción individual de los cambios que la ostomía puede traer a sus vidas. En este aspecto relacionamos las percepciones con el pensamiento de Merleau, en el que la percepción del cuerpo y del ser se presentan de manera particular desde la perspectiva del ser observador. **Conclusión:** Esta reflexión posibilitó una mejor percepción de los estomizados, presentando, para cada situación que viven, una emoción positiva o negativa, como reflejo de la relación cuerpo y mente, posibilitó la comprensión de la visión de estomizado antes de las vivencias del cambio corporal a partir de la fenomenología del pensamiento de Merleau-Ponty.

**DESCRIPTORES:** Estomaterapia. Adaptación. Filosofía en Enfermería. Atención centrada en el paciente. Cambio de rol.

## INTRODUCTION

Ostomates are people who have had a surgical opening of hollow viscera or internal organs. After a surgical procedure, these openings communicate with the external environment, externalizing a particular internal organ and taking over the body's physiological functions to eliminate, secrete or nourish.<sup>1</sup>

Ostomies are defined based on the externalized body segments. When they occur in some portion of the intestine, they are described as intestinal stoma, being classified as ileostomy (externalized part of the intestine - ileum) or colostomy (the externalized portion is the colon). Both are carried out to eliminate feces, which can be definitive or provisional, depending on the context and clinical situation of the individual. Colostomy is the most common type of ostomy performed in surgical procedures. The creation of a stoma is a phenomenon that generates multiple psychosocial effects that directly influence the patient's postoperative living condition.<sup>2</sup>

The main indication for ostomies is colon and rectal cancer, with colorectal cancer being the second most prevalent type of cancer in the population. The National Cancer Institute (*Instituto Nacional de Câncer-INCA*) estimates, for each year from 2020 to 2022, approximately 41 thousand diagnoses, with a similar proportion between men and women.<sup>3</sup>

Living daily with a bag attached to the abdomen and adapting to the ostomy can result in patients, in addition to the need for understanding, regarding the loss of involuntary control of physiological eliminations, depressive symptoms, social isolation, loss of self-esteem, image deviation body, breakdown of marital relations, deprivation of human freedom, in addition to social discrimination. Therefore, many issues must be considered in the health care of these patients, such as the family, social, cultural and economic context and the level of education, to offer holistic assistance to these subjects.<sup>2,4</sup>

Adapting and learning self-care for people living with intestinal stoma is long and challenging to accept, not only for the person with a stoma but also for the family and circle of friendships, directly interfering in the patient's interpersonal relationships. During the adaptation period, caused by the change in your body image and physiological changes in a portion of the body, there is physical, emotional, psychological and even spiritual wear.<sup>5-6</sup>

Studies that address the perception of patients with intestinal stoma in the light of a theoretical framework that supports and allows reflection on this topic are rare. Most studies on the perception of patients with intestinal stoma deal with nutritional changes, lifestyle, health care received in care services, and the perception of companions concerning stoma care.

This study aims to expand the production of knowledge in nursing to understand the specificities of the perceptions of people living with ostomies. This understanding makes it possible to promote health and nursing actions that help overcome inequities and difficulties these people face. Furthermore, it contributes to formulating critical thinking with a philosophical basis with a potential impact on the quality of life and health of the population living with an intestinal stoma, regardless of the possibility of stoma reversal surgery.

## OBJECTIVE

In the light of phenomenology, reflect on the perception of patients living with intestinal ostomies about their bodies.

## METHODOLOGY

The present is a logical-reflective exposition based on scientific literature and critical analysis by the authors of studies found in the literature, addressing the perception of patients living with intestinal ostomies and adopting the theoretical perspective of phenomenology in the perception of Merleau-Ponty. For each situation experienced, positive or negative emotion is presented as a reflection of the body and mind relationship, proposing to understand the vision of patients with ostomies regarding their health conditions and experiences lived from the body change.

The theoretical perspective of phenomenology in Merleau-Ponty's perception was adopted. This perspective proposes the discovery of original meanings as a trajectory toward human understanding. Thus, it constitutes a radical human reflection on one's situation. In his proposal, preserving the subject and the object, rationality is brought to science, that is, finding the subjects' perceptions of the world and which possibilities can be confirmed or denied<sup>7</sup>. Given the objective already stated, in the first stage, the following guiding question was defined for this study: What are the perceptions of patients living with intestinal stomas?

Within a second stage, the study was anchored in readings of texts extracted from the following databases: LILACS, MEDLINE/PubMed (All Fields), and Web of Science, and subsequently reflected based on Merleau-Ponty's theoretical framework. Those that had full text available via Federated Academic Community (*Comunidade Acadêmica Federada-CAFe*) access on the Capes journal portal via the Federal University of Rio Grande do Norte login were selected, as long as they contained some aspect related to the patient's perception of the experience with intestinal stomas and the light of Merleau-Ponty's phenomenology. The aim is to portray, in the composition of this essay, connections between the logical-reflective exposition in two fundamental aspects: Merleau-Ponty's phenomenological perspective and perception in the light of Merleau-Ponty's phenomenology.

## RESULTS AND DISCUSSION

Perception is not simply visible to the eye but presents a meaning concerning the subjective interpretation of the observer, with the body as the center of observation. People with ostomies have an individual perception of the changes that the ostomy can bring to their lives through a personal sense of being affected. In this sense, we can make a relationship with Merleau-Ponty's thoughts, in which the perception of the body and being presents itself in a particular way from the perspective of the observing being.

### Merleau-Ponty's phenomenological perspective

The phenomenological method idealized by Edmund Husserl (1859-1938) is present in the philosophical thought of Merleau-Ponty (1908-1961) and is reflected in his studies on existence. The choice of the philosopher Merleau-Ponty to direct this discussion was because his principles point to the importance of Husserl's phenomenology, which maintains

the intention of moving away from idealistic and realistic criteria in the investigation of phenomena and explanation of experiences. Furthermore, Merleau-Ponty follows in Husserl's footsteps to primarily investigate perception.

In "Phenomenology of Perception", Merleau-Ponty addresses the insertion of man in the reality of existence and claims that phenomenology aims to return things to their concrete physiognomy, regardless of the context in which the subject finds himself. The object of study is seen from different angles and ways, presenting itself as what is shown to your consciousness, thus developing the perception of the phenomenon. In this way, perception is not simply visible to the eye. Still, it presents a meaning concerning the subjective interpretation of the observer, with the body as the center of observation.<sup>7</sup>

## Perception of people with ostomies in the light of phenomenology

People with a stoma have an individual perception of the changes that having a stoma can bring to their lives through a personal sense of being affected<sup>4</sup>. Rejection turns into acceptance when individuals perceive the stoma as a way to avoid future complications so that, even though they can undergo reversal surgery, they choose to keep the stoma since the new surgery does not provide guaranteed results. In this sense, a relationship can be made with Merleau-Ponty's thoughts, in which the perception of the body and being is presented in a particular way from the perspective of the observing being.

Merleau-Ponty informs that the intentionality present in Husserl's thoughts, which only exists from a mental perspective, also occurs from a bodily point of view. Thus, the body also represents an intentionality, a consciousness in the physical senses that articulates with the mind, giving meaning to the world. In other words, the body is considered a source of knowledge and intentionality, becoming an element that thinks, articulating with the mind and producing meanings and meaning to the world in which we are inserted.<sup>7</sup>

A study carried out in Brazil regarding the emotions and adaptive processes experienced by people with ostomies shows that their perceptions vary according to the different phases of the disease, the construction of the ostomy and the lack of knowledge of people with ostomies about their bodies. Some feelings are triggered due to the lack of understanding of the body adapting to the stoma. These are feelings such as revolt, denial, anguish, anxiety, feelings of incapacity, rejection, insecurity, shame, low self-esteem and, in some cases, depression, feelings arising from the modification of your body, and such perceptions can also similarly present themselves in their relatives.<sup>6</sup>

These characteristics can be well understood through Merleau-Ponty's phenomenology. He highlights that the body always provides awareness of something, bringing awareness to the senses and shows that our body, through its personal perceptions, gives meaning to the world and context in which we are inserted, making it impossible to separate it from the soul. This body is intelligent and expressive, capable of demonstrating its feelings regarding the individual's bodily condition and presenting a meaning to the other person observing. In the case of patients with ostomies, these feelings also affect their family members.<sup>7</sup>

In the first months after having a stoma and the consequent change in body image, patients commonly experience increased concerns and anxieties. This new condition generates conflicting feelings, leading to a decreased quality of life due to the difficulty in dealing with the new perception regarding the new diet, practices performed, interpersonal relationships, self-care and general changes in the new lifestyle. However, over time, this initial vision may change, as by adapting to their new body and new routine, people with a stoma find satisfaction and consequently an improvement in their quality of life.<sup>4,8</sup>

In the book "The Visible and the Invisible", Merleau-Ponty argues that our bodily senses are responsible for knowledge, and there is a relationship between our body and the mind. There is a connection whereby the body is not just a piece of meat but a bodily system where all the senses exchange their perceptions to understand the world. The idea of the body for philosophy is modified, being able to explain the perception of phenomena through the senses, such as touch, smell, taste, hearing and vision.<sup>9</sup>

When we analyze the situation of a patient with a stoma, we observe that the process of modifying and accepting self-image, in addition to generating a personal conflict of emotions, can cause a change in the way the person expresses their explanations for this phenomenon. The above is because the modified body forms an interrelationship with the mind and its systems, being able to construct the perception that this subject presents regarding the bodily condition they are experiencing.

The body is phenomenological and presents meanings for worldviews. It can make us perceive phenomena. It is intentional and always feels something. It is not only the mind that organizes the way we perceive something, but the mind and the body, with an interrelationship between these systems (mind and body), one being an extension of the other.<sup>7</sup> The change caused in the life of the patient with an intestinal stoma due to the abnormal functionality of their body causes changes in their mind, and there needs to be an adaptation to the current body image, as well as an adjustment to the functional aspects of the organism. The negative feelings arising from this condition generate low self-esteem and can promote social isolation.<sup>10</sup>

Merleau-Ponty's phenomenology can explain some perceptions of people with ostomies. The fact that patients feel shame may be related to a change in body image, in which the mind does not feel satisfied with the body and, for this reason, triggers feelings such as shame, fear and isolation. The mind and body relationship changes, in which the events and meanings of the body, still adapting to the stoma, present a new definition of actions experienced by these people, a meaning that modifies and alters concepts and experiences already pre-established in the connection of the body, senses and mind.

## CONCLUSION

The experiences and perceptions of human beings in the world cannot be understood in exact scientific terms, as they are presented in a broader way within the particularities of each subject. In this way, these issues can be observed based on the phenomenological approach, considering that it guides us in studying phenomena concerning the world and the being in its interactions with others.

In this way, the perception of patients living with intestinal stoma generally presents positive emotions for the situations they experience when people with intestinal stoma adapt and can exercise self-care without other problems or conflicts. Negative emotions are exposed when some perspectives are frustrated post-surgery, leading to feelings of sadness, fear and shame as a reflection of the body and mind relationship. These sets of emotions can be explained through Merleau-Ponty's thoughts in his speech on phenomenology. Therefore, it is pertinent that more studies in the health area use phenomenology as a theoretical and philosophical basis.

## AUTHORS CONTRIBUTION

**Conceptualization:** Nascimento RM, Araújo RO; **Methodology:** Nascimento RM, Bessa IF; **Investigation:** Nascimento RM, Bessa IF, Araújo RO and Costa IKF; **Writing – First version:** Nascimento RM, Bessa IF; **Writing – Review and Editing:** Bessa IF, Araújo RO and Costa IKF; **Supervision:** Costa IKF.

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Data will be available upon request.

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