

## Body consciousness of people with intestinal stomach: A phenomenological study

*Consciência corpórea de pessoas com estomia intestinal: estudo fenomenológico*  
*Consciencia corpórea de personas con estoma intestinal: estudio fenomenológico*

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### ABSTRACT

**Objective:** to describe the bodily awareness of people with stomies. **Method:** a descriptive study with a qualitative approach, carried out in the Ostomized Association of the State of Ceará, through semi-structured interviews with ten people with intestinal stomies, according to Merleau-Ponty's phenomenological thinking. **Results:** two categories of analysis emerged: The body that I have, in which the sensations of deficiency, imperfection and bad odor add to the feeling of strangeness towards one's own body, affecting the way of being in the world of each deponent; and The body that others perceive, in which the stoma is seen as an embarrassing and complex experience, since it hampers daily activities and conviviality with other people. **Final considerations:** The corporeal consciousness of Being-Stomped-in-the-world requires the movement to reconstruct the senses of the body from the body I have and from that which others perceive.

**Descriptors:** Consciousness; Body Image; Stomach; Surgical Stomas; Nursing.

### RESUMO

**Objetivo:** descrever a consciência corpórea de pessoas com estomia. **Método:** estudo descritivo com abordagem qualitativa, realizado na Associação dos Ostomizados do Estado do Ceará, por meio de entrevistas semiestruturadas com dez pessoas com estomia intestinal, segundo o pensamento fenomenológico de Merleau-Ponty. **Resultados:** emergiram duas categorias da análise: O corpo que eu tenho, no qual as sensações de deficiência, imperfeição e odor ruim somam-se ao sentimento de estranheza para com o próprio corpo, afetando o modo de ser no mundo de cada depoente; e O corpo que os outros percebem, em que o estoma é visto como uma experiência constrangedora e complexa, uma vez que dificulta as atividades cotidianas e o convívio com outras pessoas. **Considerações finais:** a consciência corpórea de Ser-estomizado-no-mundo exige o movimento de reconstruir os sentidos do corpo a partir do corpo que eu tenho e daquele que os outros percebem.

**Descritores:** Consciência; Imagem Corporal; Estomia; Estomas Cirúrgicos; Enfermagem.

### RESUMEN

**Objetivo:** describir la consciencia corpórea de personas con estoma. **Método:** estudio descriptivo con abordaje cualitativa, realizado en la Asociación de Estoma del Estado de Ceará, por medio de entrevistas semi estructuradas con diez personas con estoma intestinal, según el pensamiento fenomenológico de Merleau-Ponty. **Resultados:** emergieron dos categorías del análisis: El cuerpo que tengo, en el cual las sensaciones de deficiencia, imperfección y olor malo se suman al sentimiento de extrañeza para con el propio cuerpo, afectando el modo de ser en el mundo de cada deponente; y El cuerpo que los demás notan, en

que el estoma es visto como una experiencia embarazosa y compleja, una vez que dificulta las actividades cotidianas y el convivio con otras personas. **Consideraciones finales:** la consciencia corpórea de Ser-estoma-en el-mundo exige el movimiento de reconstruir los sentidos del cuerpo a partir del cuerpo que tengo y de aquel que los demás notan.

**Descriptores:** Consciencia; Imagen Corporal; Estoma; Estomas Quirúrgicos; Enfermería.

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## INTRODUCTION

In the biomedical view, the body is approached from a mechanistic perspective, since it is conceived only as a site harboring the disease. However, other currents study the relation of body as a phenomenon. It is observed that the corporeal consciousness of the Being-stomach-in-the-world contrasts with the labels imposed by society on the perfect and efficient body.

Ostomy is the surgery that essentially results in redefinitions of pathways of a biological subsystem, but with aesthetic, emotional, socio-familial and quality of life repercussions<sup>(1)</sup>.

The necessity of performing the stoma and extractively implanting a collection bag results in a veiled statement on the part of the medical collective that there is incompatibility of current states of functioning of the body with the maintenance of life by virtue of a disease, accident or aggravation of any species. Although this leads to fears, adjustments are necessary and will impose suffering, and require a wide range of physical and cognitive responses to the new condition of this body<sup>(2)</sup>.

Thus, unconscious psychic phenomenon, but common to the person with stoma, is the 'deconstruction of the body image as a relational instrument'. Subsequently to the stoma, the person is prone to isolation<sup>(3)</sup>, which makes body image a critical issue in the order of public health priorities. In addition to the psychosocial difficulties resulting from changes in the presentation of the body, patients are also often reluctant to discuss these issues with the health team<sup>(4-5)</sup>.

In this essay the voice is given to people who have sought to transcend the physical structure of the body, to speak of its meaning as a way of relating to the world based on experiences with the stoma - it is a question of approaching the body phenomenon or 'phenomenal'.

Existential phenomenology<sup>(6)</sup> is assumed as the basis of reflections on this corporeal awareness. Corporeity, or corporeal mind, is a term that falls within the perspective of Merleau-Ponty, whose philosophical thinking considers the physical universe, that of life, and the anthroposocial universe as indivisible (or indivisible) entities. Although the philosopher has not elaborated a 'phenomenology of the body', it emerges in its presuppositions as a central element to the genesis of the consciousness that there is a 'self established in the world', whose transcendent dimension will always be revealed to the person through verbalization of experiences.

Thus, recourse to the Merleau-Pontyans' presuppositions, entering the universe of people with stomies, means, among other things, the art of enabling the emergence of narratives that expose before us their bodies as experiential structures lived in terms of 'context,' 'middle "and" end,' cognitive mechanisms of perceptions and, of course, confrontations. It is a matter of bringing awareness to the situation of corporeity in the health-disease process<sup>(7)</sup>.

Thus, the objective of this study was to describe the bodily awareness of people with stomies.

## METHOD

### Ethic aspects

The study was previously submitted to the Research Ethics Committee (CEP) of the University of Fortaleza (UNIFOR) with a Certificate of Ethical Assessment, in compliance with Resolution 466/12 of the National Health Council (CNS).

### Theoretical-methodological reference and type of study

A descriptive study, conducted under the aegis of the qualitative approach, adopted the Merleau-Pontyana phenomenological perspective as a theory and method that allowed us to access the experiences of people with stoma, describing them with rigor, as perceived by these people. Merleau-Ponty develops his work on the basis of the conception that all present knowledge in our consciousness passes, a priori, through perception<sup>(6)</sup>.

Phenomenological research has been increasingly incorporated in the field of health and other disciplines that are daily involved with the human being, needing to understand it in its historical exposition, in the social constructions, in order to build knowledge about its lived world and perceived<sup>(8-9)</sup>.

### Theoretical-methodological procedures

#### Scenario of the study

The research was based on the Association of Ostomates of the State of Ceará (AOECE), located in Fortaleza / CE, Brazil.

#### Data source

The participants of the research were people with intestinal stomies, enrolled in the AOECE, from 18 years of age, with at least six months of surgery. It was also adopted as criteria that these people had the physical and emotional conditions to participate in the investigation and to sign the Informed Consent Term (TCLE).

The selection of the participants is one of the items in the phenomenological research that most causes dubiety to the researchers because the phenomenological interview is mediated by the empathy and interaction between the researcher and the researched. Thus, the recruitment took place through previous contacts, during which the ideal conditions of approximation were created and the attendance of each one in the routine consultations or of all in monthly meetings of a group that had been acting with institutional initiative. The interviews were scheduled on these occasions, agreeing day, time and place, according to the availability and interest of each one.

The sample was delimited for convenience - the purpose was to listen to people willing to compromise our purpose in talking about their experiences with that 'new body'<sup>(10)</sup>.

### **Collection and organization of data**

The path of phenomenological investigation begins with guiding themes. Thus, the data were produced by listening to ten people during the months of September and October 2015 on the subject: the body that I have and the body that others think I have. In addition, a field diary was used to record the relevant aspects observed during the interview, in order to portray the subjects and reconstruct the dialogue (words, gestures, expressions and pronunciations), among others, that could complement the analysis.

In-depth interviews were conducted in a single moment, with a mean duration of 40 minutes each, by the principal investigator, recorded with the aid of an MP4 device and later transcribed in full. The interview is the most used feature in phenomenological research because it is very flexible, allowing adaptations according to the singularities and peculiarities of the interviewees, besides allowing them to express their experience and formulate timely questions during the interview<sup>(10)</sup>. To ensure anonymity, the participants were identified by the letter (D) of deponent, followed by an Arabic numeral corresponding to the chronological sequence of interviews.

### **Data analysis**

Data analysis sought to understand the phenomenon in light of Merleau-Ponty's phenomenological framework<sup>(6)</sup>. The speeches were the starting point, in front of which a position of suspension was adopted, trying to distance itself from any pre-constituted idea. Several re-readings were made taking as reference the three moments of the phenomenological trajectory described by Martins<sup>(11)</sup>: description, reduction and understanding. During the phenomenological description, the researcher questions the participant so that he can freely talk about the phenomenon researched. At the moment of the phenomenological reduction, the researcher distances himself from all pre-established conceptions and knowledge, searching for parts described as essential. Phenomenological understanding, however, is the moment when one attempts to obtain the essential meaning in description and reduction. It should be emphasized that the data were discussed in light of the literature on the subject.

The COREQ (Consolidated criteria for reporting qualitative research (12) checklist was used to conduct this research.

## **RESULTS**

Ten people with intestinal stoma participated in the study, six men and four women, with a minimum age of 21 and a maximum of 78 years, mean of  $49.0 \pm 20.27$  years. As for marital status, seven participants were married, two were single and one was separated. The respective levels of education varied between illiterate (one), incomplete elementary school (two), complete fundamental (three), incomplete secondary education (two), incomplete higher education (one) and superior complete (one).

Regarding the type of stoma, seven had colostomy and three had ileostomy. The living time ranged from six months to 12 years.

Regarding the origin of the stoma, in two participants there was colorectal cancer; Crohn's disease, white-hole puncture, trauma, intestinal tumor, diverticulitis, ulcerative colitis, and endometriosis (one in each).

In order to understand the meanings attributed by the deponents to their bodily consciousness, several re-readings of the transcribed statements were made in order to apprehend the essence of each speech. It was tried to adopt a posture of suspension of previous knowledge and values in relation to the phenomenon, as well as for the detachment of world views and any and all pre-established idea.

The analysis allowed to construct two categories, which will be presented next: The body that I have and The body that the others see.

### **The body that I have**

The initial strangeness is part of the process of perceiving the new body with the forms it acquires:

*It caused me strangeness to come back from surgery and see that business in my belly and feel that plastic, that thing glued to my belly. So I did not take it very well. (D10)*

According to the above account, the person is in a phase of denial that his body has changed or acquired new conformation. There is, in the perception of this deponent, 'a business', 'a thing' that is not his, but that put there. The bag is something hitherto refused, and the person is not seen in the world so that that artifact can be considered his complement and for the rest of his life.

This occurs even when the person is informed and seems to accept the new condition without major inconvenience, as expressed in the following statements:

*I think it's wonderful! I do not think anything imperfect about me, no! There's only the bag. (D05)*

Or when observed humorous receptions in the first period of surgery:

*I asked to hit a photo [laughs]. With me, I had no problem with that. I showed, I put it on the internet for everyone to see. (D01)*

It is the case to pay attention to the fact that, to this apparent acceptance, dissonances merge, like the one mentioned in the following statement:

*But, I am particularly a person who has a lot of disgust, fear of a needle [...] And I was wondering: how can I change that if I have disgust? (D01)*

It is understood that the apparent acceptance comes from holding a belief that the stoma, as well as the collection bag, is somewhat provisional. Another statement is revealing of this facet:

*[...] I was shocked when the doctor said I would do this [stoma] [...] I started crying [low slang word], my brother, I do not think so, I'll use a purse. He said: calm down! This is for a little while. (D07)*

*I never thought I'd ever use a purse. I thought it was something from the surgery itself, and that, with more days, it would come out. Once I knew it was final, that's when the chip fell. It was a shock!* (D08)

It is understood, therefore, that the feeling related to the body that first the person has post-surgery is the irony associated with the shock. Subsequently, you may come to an apprehension as to the conditions associated with the medical remedy to recompose the system. The feelings of rejection and social malaise caused by this body in the world are not inserted until then, because the phase of the 'falling token' has not yet been exceeded. Until then, purse and stoma make people with ostomy only (re) visit innumerable times, and by several prisms of thought, their condition of sick; are strong memories of the presence of death and also search for an acceptable formula to escape it:

*The purse is ... You can not live without it. She's saving me, man!* (D08)

Finally, the person perceives himself in his real condition:

*The bag is a boring thing. In a way it's a nuisance, it seems like crazy people!* (D08)

From all this comes a need to resume a "normal" body condition, healthy, without stoma and purse, therefore:

*I want to be a normal person, take that purse, be like I was before.* (D02)

*I find it strange because of this bag, I'm disgusted, too. I intend to take it back and be normal again, as I was.* (D03)

With some caveats, at some point the person with the stoma simply does not accept the body as it now is, precisely because it is not the ideal body:

*My problem is this: I can not accept it!* (D02)

### **The body that others see**

The ideal image is a social conception. For each space, the idealized image changes according to expectations of the gaze of others with whom relationships are generated. The body of the deponents is perceived by the others of their relation as difficult to be looked at, strange, better already was, transformed by the appearance of the ostoma. According to the speech of a person with ostoma:

*There are people in my family who said, 'Did you have the courage to show it? It's very disgusting!' What can I do?* (D01)

Now he is facing a body that does not deserve to suffer from vanity, which must be hidden:

*It is difficult to find such a new person with the courage to exhibit. Especially because women tend to be more vain [...]*

*You get a cut like this, an exploratory laparotomy in the whole belly, a stoma here, these things will affect the look.* (D01)

People with stomies emphasize the constant prying, prying eyes, speculators of people close to them, including family members.

*At the first exchange of the bag everyone who was in the infirmary, the attendants who were there were all around wanting to see.* (D01)

In the speeches of other interviewees, the phenomenon is described as follows:

*We feel a little different because, unfortunately, there are a lot of people who are indiscreet. They look and do not disguise. They look and even look! But already those people who are more discreet, from my bond of friends, they look disguised and then look no more.* (D10)

*Only my family knows [...]. At work nobody sees, but leaked and had no other bag, had to use a plastic bag, and they [work colleagues] said that there was a smell of sewage.* (D04)

*Whether or not we suffer because we notice the prejudice. So, I do not give satisfaction that I am colostomized. Not everyone in my family knows I am. When I went to surgery I gave an order: Look, nobody's going! Everyone stays here at home!* (D09)

Self-assessment reflects values attributed by the social world to the person and their roles in society.

*Nothing strange because I have no more vanity. I am 61 years old, I am no longer that person of worrying about the body [...] I am no longer for these things, to be exhibiting my body and preoccupied with sex, with sex life.* (D06)

As a mechanism of resolution, ways to conceal or disguise the 'deficiency' - presence of the pouch and the stoma -, people with stomies resort to the use of wide, dark and body-less clothing. They also use objects of big size, for example, bags, in order to overlap them to the ostoma:

*When I go out, I wear a pair of shorts and a big blouse, the person is embarrassed.* (D03)

*My biggest concern is with clothes that do not disguise. When I go to buy clothes it has to be a comfortable outfit. I'll do anything to try to disguise myself, I'll put my hand or even the money bag close by to try to camouflage a little bit.* (D10)

However, these strategies often only contribute to worsening aesthetic damage, causing violation or reinforcing the negative image of the stoma and what it forces to impose in terms of behavior - one continues to refuse their appearance:

*I just wanted to be free of the bag. But, unfortunately, this was not possible until then. So even disguising with the clothes, I am not 100% accomplished. I'm not happy about it.* (D10)

The ways of acting individually not only guide actions in the world, with direct consequences brought about by their transformation, but also generate a new perception of themselves and their place in the world or space of action in this new world. In this sense, one interviewee states:

*I understand today that the bag is part of my body [...] it is indispensable for collecting feces. (D09)*

The pouch and ostoma begin to assume body meaning for people with an ostomy.

*It's my body now! The stoma is an extension of my body now. (D01)*

The following statement expresses this perception:

*Happy with the body that I have I am not [...] he has been mutilated, he has been transformed, he is modified. But, my life goes on. My life has been preserved and I can lead a normal life like any other person. I now accept myself with the body I have! (D10)*

## DISCUSSION

Although stomization is a therapeutic resource, it is perceived by people who have it as an embarrassing and complex experience, since it makes daily activities and living with other people difficult. Sensations of deficiency and bad odor add to the feeling of strangeness towards one's own body, affecting the way of being in the world of each deponent. Before being an object, the body is our way of being-in-the-world, recognizing itself as an actor and co-author of its own history, alongside the other meanings<sup>(6)</sup>.

Phenomenology helps to understand this moment as being related to self-concept. Body image is intimately linked to esteem by a socially shared image of perfection - it is the concept of good or beautiful. There is, therefore, a true body schema designed by society, an inseparable component of the formation of a self-perception, of an identity. It is about 'identifying with': with the peers, with the activities to be performed, with the spaces that the person occupies in the various networks of sociability, with the prerogative of being human and of humanity.

Merleau-Ponty points out that: since it is necessarily 'here', the body necessarily exists 'now'. For the author, it never remains fixed in the past<sup>(6)</sup>, which implies that just as in adulthood the memories of our body from when we were children are gaps in memory, in health we can not preserve indefinitely memories of the condition of the patient.

In addition to having to live with the presence of the stoma associated with the collection bag, these people still experience new sensory phenomena and feelings of strangeness, related to the exhaled smell, the produced sound, the visualization and the touch. In turn, these are perceived as symbols of pollution and filth and, thus, the loss of physiological control involves the transgression of bodily limits; the perception of the stoma and the pouch becomes represented by a negative body image, physical and sexual invasion and, in some cases, marital adjustment and social isolation<sup>(13-15)</sup>.

The scars resulting from the surgical intervention leave not only marks on the body; they express a story that transcends surgery and unveils a debilitating form that imprints itself beyond the skin, making people with stoma hostage to the perception others have of them - especially when the gaze is ruthless, stigmatizing, and excluding social interaction.

The body is perceived by many as an object of fascination and fear, considering the healthy body, the "cultural body", object coveted by representing the good, virtue and law of order. The diseased body, however, denotes chaos. Man (gender) does not deal well with chaos. One of his greatest fears is precisely to face what he can not control and, by protection mechanism, he will avoid becoming a hostage of the body<sup>(16)</sup>.

The purpose of hiding the stoma and collecting bag seems to feed the farce of the healthy body, symbol of what is "normal" for others. A disease that materializes or leaves an exposed part is not desired, especially in the condition in which there is no possibility of choice or control<sup>(16)</sup>.

Thus, in the conception of some authors<sup>(17-18)</sup>, women with ostomy are the most affected and undermined by surgical treatment, directly interfering with female vanity, since they feel less desired as women.

On the subject, Merleau-Ponty points out that if the patient 'coldly perceives the situation, it is, first of all, because he does not live it and because he is not involved in it'<sup>(6)</sup>. Therefore, the person with the stomach can experience feelings of emotional disorganization, as well as assuming a position of alienation about the phenomenon experienced and the body itself - both for being informed about it (the body) and for perceiving itself 'deformed' after the surgical procedure, as well as by a social representation that surgery no longer interferes with the role that is expected of a 'Being-in-the-world.'

The perception of the body and its position in the present imply to apprehend and reinterpret these values, relying on the temporal structure of memory. Values are therefore social parameters with the potential to create stereotypes. Hence the negative perception of 'being-stomized', with consequent absence of eigenvalue and other imbalances in daily life-the body image affects both the physical and the social, the temporal and the spatial.

In other words, in one way or another, it is common for a person to experience, at some point, a diminished sense of confidence and negative self-assessment - even if this phenomenon is gradually and comparatively compared to others in the relationship and according to the evaluation they make (self-image mirror)<sup>(13)</sup>.

To assume that I am what I am, and also to assume what I am as sufficient to exist in a world that I construct every day for myself, seems to be the great liberation of the ostomized being in relation to the stereotypes, as well as to the 'outward visions'<sup>(19-20)</sup>. However, there is a key to this path of freedom. Finding and using it is both a challenge and can present distinct ways of doing, when we consider the singularities of each person or their ways of coping (resilience)<sup>(21)</sup>.

Based on this new awareness, it is about making the world different for us or for our new condition of being. With this, the stimuli are extended so that the external world that perceives us - and that is a mirror for our self-perception - is also 'our world'<sup>(16)</sup>.

This is because there is always the possibility of transcending the physical body by re-evaluating its usefulness and position in the world<sup>(22)</sup>. This perception is based on the interpretation of 'things' in the body-in-the-world: 'The thing is the correlative of my body and my existence, of which my body is only the stabilized structure, it is constituted in the power of my body over it is not in the first place a meaning for understanding, but a structure accessible to the inspection (or new interpretations) of the body'<sup>(6)</sup>.

Living the world through the body is a natural process and suffers alteration throughout our life trajectory, either by the physiological process inherent in aging, or by the health-disease process. The body is often seen as a place that houses the disease, and through it are experienced situations that lead people with ostomy to feel different. This fact is based on the perspective that the body is instigated by the purposes of the conscience, and is also the mediator of an interaction with the lived world, in which its purposes are modified and reiterated.

#### Limitations of the study

The limiting factors of this research involve the lack of collecting bags and other auxiliary materials faced at the time of data production by the AOECE, as well as the prolonged absence of material resources, which caused the restriction of the number of participants.

#### Contributions to the area of Nursing, health or public policy

It is hoped that this study will elicit reflections about the way of caring, transcending the object body and making it technical, in order to improve the interaction with the person

with ostomy for the recognition in its totality and to contribute so that it can better adapt to its new existential condition.

#### FINAL CONSIDERATIONS

Changes in the health status of people with ostomies produce healthy body loss, generating feelings of vulnerability and lack of control over their existence. In this context, surgery emerges as a time divider, an aspect expressed by the expression 'I was'. It was evidenced through the testimonies that the surgery for these people causes a strong rupture in social relations, which was mentioned by them as fear of generating strangeness and led to the inevitability of concealing the presence of the stoma and the pouch or to resort to the technique of camouflage.

The perception of being-ostomized becomes understood, even if involuntarily, as a movement to counteract the labels imposed by society on the perfect body and efficient body, for the act of experiencing feelings of alienation and transfiguration in relation to one's own body harms the consciousness of being-ostomy-in-the-world.

In the context of health, the provision of care to the person with stoma can not be restricted to perceiving it as an object to be manipulated by the health professional. It is necessary above all to transcend the object body and to perceive it as a holistic being based on the premises of humanization and integrality of care. It is also necessary to promote the health of the person with ostomy and help her to better understand her body and its corporeity as a moving subject, that is, to bring body and consciousness closer to the body.

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