

Meanings attributed to the perception of to be-ostomized-in-the-world

Significados atribuídos à percepção de ser-estomizado-no-mundo

Significados atribuidos a la percepción de ser-ostomizado-en-el-mundo

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ABSTRACT

Objective: To understand the meanings of the experience of to be-ostomized-in-the-world through Merleau-Ponty phenomenology.

Method: Descriptive study with a qualitative approach, in the merleau-ponty phenomenological perspective, conducted through interviews with ten people with intestinal stomas assisted by the Association of Ostomized of the State of Ceara. The IRaMuTeQ software was used. Similarity analysis and word cloud were adopted. **Results:** The words 'person', 'much', 'how', 'see' and 'bag' was identified by discourse analysis, which gave rise to 'say', as central nuclei. The 'person', as be-ostomized-in-the-world, perceives itself as 'being-sick' that 'reluctantly 'senses-motor sensations (feces and odors) that cause' repulsiveness', marked by the presence of the ' (stoma and bag). The words most often in the cloud were 'bag', 'life', 'God', 'people' and 'surgery'. The collector bag evidences 'abnormality' and bodily imperfection. **Conclusion:** The perception of be-ostomized-in-the-world is marked by the presence of the collector bag of stoma, being perceived as new element of its body.

DESCRIPTORS: Stoma; Surgical stomas; Perception; Adaptation; Stomatherapy.

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RESUMO

Objetivo: Compreender os significados da experiência de ser-estomizado-no-mundo por meio da fenomenologia de Merleau-Ponty. **Método:** Estudo descritivo com abordagem qualitativa, na perspectiva fenomenológica merleau-pontyana, realizado por meio de entrevistas com dez pessoas com estomias intestinais assistidas pela Associação dos Ostomizados do Estado do Ceará. Utilizou-se o *software* IRaMuTeQ. Adotaram-se análise de similitude e nuvem de palavras. **Resultados:** Identificaram-se pela análise de discurso as palavras 'pessoa', 'muito', 'como', 'ver' e 'bolsa', que deu origem a 'dizer', como núcleos centrais. A 'pessoa', como Ser-estomizado-no-mundo, percebe-se como 'ser-doente' que 'reluta' contra sensações sensorio-motoras (fezes e odores) que causam 'repulsividade', marcada pela presença da 'coisa' (estomia e bolsa). As palavras com maior frequência na nuvem foram 'bolsa', 'vida', 'Deus', 'gente' e 'cirurgia'. A bolsa coletora evidencia a 'anormalidade' e a imperfeição corporal. **Conclusão:** A percepção de Ser-estomizado-no-mundo é marcada pela presença da bolsa coletora de estomia, sendo percebida como novo elemento de seu corpo.

DESCRIPTORIOS: Estomia; Estomas cirúrgicos; Percepção; Adaptação; Estomaterapia.

RESUMEN

Objetivo: Comprender los significados de la experiencia de Ser-ostomizado-en-el-mundo por medio de la fenomenología de Merleau-Ponty. **Método:** Estudio descriptivo con enfoque cualitativo, en la perspectiva fenomenológica merleau-pontyana, realizado por medio de entrevistas con diez personas con ostomías intestinales asistidas por la Asociación de los Ostomizados del Estado de Ceará. Se utilizó el *software* IRaMuTeQ. Se adoptaron análisis de similitud y nube de palabras. **Resultados:** Se identificaron por el análisis de discurso las palabras 'persona', 'mucho', 'como', 'ver' y 'bolsa', que dio origen a 'decir', como núcleos centrales. La 'persona', como Ser-ostomizado-en-el-mundo, se percibe como 'estar-enfermo' que 'lucha' contra sensaciones sensorio-motoras (heces y olores) que causan 'repulsión', marcada por la presencia de la 'cosa' (ostomía y bolsa). Las palabras con mayor frecuencia en la nube fueron 'bolsa', 'vida', 'Dios', 'gente' y 'cirugía'. La bolsa colectora evidencia la 'anormalidad' y la imperfección corporal. **Conclusión:** La percepción de Ser-ostomizado-en-el-mundo está marcada por la presencia de la bolsa colectora de ostomía, siendo percibida como nuevo elemento de su cuerpo.

DESCRIPTORIOS: Ostomía; Estomas quirúrgicos; Percepción; Adaptación; Estomaterapia..

INTRODUCTION

The intestinal stoma results from a surgery in which the exteriorization of a segment of the large or small intestine to discharge fecal material¹⁻² relieving symptoms, limiting or blocking the evolution of a disease and resulting in alteration of biological functions with emotional, social, physical repercussions and family³⁻⁵.

Although it is a relatively simple surgery from the medical point of view, people submitted to this procedure experience the reconfiguration of their anatomy and the consequent change of life due to modifications of their daily bodily functions. Suddenly, the elimination of feces occurs in a totally different way - through a stoma¹.

Surgical intervention for the construction of the stoma is aimed at clinical therapy; however, it produces a new sense of reduced and stigmatized body. This is because the person with the stoma can develop alienating behaviors of their body by feeling dissimilar. Such a condition affects the perception of the body itself, which directly implies changes in the body image⁶. The presence of the stoma is now associated with a reminder of the disease⁷.

For Merleau-Ponty⁸, the body is the way that the subject is embedded in the world. It gives meaning and constitutes the subject in the world. Therefore, every perception passes through this. This is only possible by the uniqueness of object-body. Thus, perception is sedimented in the experience of the incarnate subject, of its visions and senses, which takes the experience of the phenomenal body, which makes recognition of space as expressive and symbolic.

Interest in the topic arises from the experience of the study's principal investigator, as nurse stomatherapist in the clinical care of people with stoma, both at hospital and outpatient level. The construction of a stoma causes alterations in the perception of the body image, impacting psychosocially the life of the individual with the stoma, requiring adaptation to this new condition and emanating new experiences. Understanding the meanings of to be-ostomized-in-the-world provides the nurse with sustainable attributes for the dialogic relationship in the caring process.

Thus, it was sought the answer of the following question: What are the meanings attributed to the experience of to be-ostomized-in-the-world? It is essential to understand the meaning of the stomization experience in the perspective of the care process in nursing and health, in the cultural and humanized context of caring.

OBJECTIVE

The aim was to understand the meanings of the experience of to be-ostomized-in-the-world from Merleau-Ponty phenomenology.

METHODS

This is a descriptive study, of a qualitative nature, based on the merleau-ponty phenomenology⁸⁻⁹. Ten people with intestinal stoma participated in the study. The scenario to produce data was the Association of Ostomized of the State of Ceara (AOSCE), located in Fortaleza (Ceara, Brazil).

Inclusion criteria were defined as people with intestinal stoma, registered in the AOSCE, from 18 years of age and with at least six months of surgery. Excluded were people with some complication of the stoma or with physical weakness. The sample size was delimited by discursive recurrence (repetition of the oral discourse).

Data were collected between September and October 2015. Participants were recruited through contact between routine visits or in monthly group meetings. The interviews were scheduled on these occasions, agreeing day, time and place, according to availability. These were performed individually and had an average duration of 40 minutes. They were recorded in audio and transcribed later; were based on a semi-structured script previously elaborated by the main author, composed of questions of identification of the participants and subitems in the form of questions about life before and after the construction of the stoma, the “perception of lived experience”. In addition, a field diary was used to record relevant aspects observed during the interview, aiming to portray the subjects and reconstruct the dialogue (words, gestures, expressions and pronunciations, among others, to complement the analysis). To guarantee anonymity to the participants, the deponent letter (D) was chosen, followed by an Arabic numeral in the sequence of the interview.

The interviews were transcribed in full for the LibreOffice program. The corpus (the only file that gathers the texts originated by the interviews) was elaborated, and then the processing was done in the IRaMuTeQ software (Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires). This software allows different forms of statistical analysis on the textual corpus and the tables of individuals by words. To perform classic lexical analyzes, the software identifies and reformats the text units, which are transformed from the Initial Context Units into Elementary Context Units. The vocabulary research is then realized, reducing to words, based on its roots (lemmatization), creating a dictionary from the reduced forms and identifying the active and supplementary forms¹⁰.

In addition to classical textual statistics, this software performs group specificities searches; the descending hierarchical classification; and analysis of similarity and cloud of words. Among these possibilities of analysis by IRaMuTeQ, the analysis of similarity and the cloud of words (based on frequencies) were chosen. The similarity analysis produces graphs that make it possible to identify the co-occurrences between words and their result, indicating the connection between words. In the cloud, words are grouped and organized graphically according to their frequency, which makes it easy to identify them from the corpus¹⁰.

It should be emphasized that the data generated by the software processing were analyzed by the researchers in the light of Merleau-Ponty phenomenological framework, requiring interpretation, since they do not speak for themselves. In the works of the philosopher, the body is the central element and represents different phases of thought; it presents the variation of the body as the place of insertion of the man in the world, in which man is the subject of perception and is analyzed in its concrete aspects⁸, the approach of the body in all its ambiguities, which allows a unique interpretation of the world⁹. It should be emphasized that the data were also discussed considering the literature on the subject.

As a qualification strategy of the study, the checklist of COREQ¹¹ (Consolidated criteria for reporting qualitative research) was used.

The research complied with Resolution 466/12 of the National Health Council (NHC), met the ethical and legal precepts and obtained approval by the Research Ethics Committee (REC) of the University of Fortaleza

(UNIFOR) with Certificate of Presentation for Ethical Appreciation (CPEA) N^o. 43624315.1.0000.

RESULTS

In the sample (n=10), the predominance of 60% of men, aged between 21 and 78 years of age, averaged 49.0 ± 20.27 years. As for marital status, the vast majority (70%) of the participants were married. Regarding the type of stoma, 70% had a colostomy. The living time ranged from six months to 12 years. As to the origin of the stoma, 20% occurred due to colorectal cancer and the others (80%) had a varied distribution (Table 1).

The discourse analysis generated a semantic range of words more frequent in the text, grouped in central and peripheral zones, which allowed to understand how the person perceives inserted in the world. The word 'person' is strongly surrounded by words such as 'a lot', 'how', 'see' and 'bag', which gave rise to 'say', and are central nuclei. The words 'normal', 'disgust', 'think', 'woman', 'feel', 'sick' and 'fight' are derived from the 'person' zone (Fig. 1).

Thus, the 'person' as be-ostomized-in-the-world, especially the 'women', perceives itself as 'being-sick' that is 'reluctant' against sensorimotor sensations (feces and odors), a situation that makes it want to be a 'normal' person (without presence of a stoma and a collector bag). The word 'very' expresses the idea of quantity and/or indefinite quality of the experience of be-ostomized, having in its surroundings the 'thing' (stoma and bag) that bothers and is 'complicated', which restricts the simple act of coming and going ('freedom), demanding

from this experience the 'getting used to' the new condition. The word 'as' gives us the circumstantial value of the phenomenon; thus, to continue living after the construction of the stoma, the person sees the 'today' as a new opportunity to want to live, attaching to 'God' the gift of life. The act of seeing the process of stomization (materialization) produces unpleasant sensations such as loss of control and elimination of feces and gases, marked by fear of leakage of the device and fear of exposure of the stoma.

They circle around the term 'bag' terms like 'feces' and 'use'. It is inferred that they continually depend on the pouch to collect the faeces and present difficulties and/or limitations in their 'handling' (change). The word 'say' is also derived from the bag, which has in its turn the process of stomization in the 'hospital' setting and, consequently, the condition of to be 'colostomized' or 'ileostomized'.

Fig. 2 shows the cloud of words from the textual corpus obtained in the present investigation. It is emphasized that the word cloud feature groups the words according to their frequency. It is a simple but relevant lexical analysis since it allows quick identification of the corpus textual keywords¹⁰.

As for the words most evoked by people with a stoma, the following stand out sequentially: bag (frequency: 78), life (34), God (31), people (30) and surgery (24). Other words cited include: use (frequency: 25), normal (24), after (24), house (24), exit (24), now (23) and look (18).

The necessity to use the collector bag proved to be representative of great impact, to which the interviewees attributed the characterization of 'abnormality' and body imperfection and on which they express hopes of their

Table 1. Distribution of participants according to order of interview, gender, age, marital status, type of stoma, time of conviviality with stoma and origin. Fortaleza, Ceará, Brazil, 2017.

Deponent	Gender	Age (years)	Marital Status	Type of stoma	Time of conviviality	Source
1	Female	21	Single	ileostomy	6 months	Bowel obstruction
2	Female	47	Married	Colostomia	7 months	Crohn's disease
3	Male	23	Single	Colostomy	6 months	Firearm perforation
4	Male	71	Married	Colostomy	5 years	Colorectal cancer
5	Female	46	Married	Colostomy	3 years	Trauma
6	Male	61	Divorced	Colostomy	1 year and 6 months	Colorectal cancer
7	Male	70	Married	Colostomy	3 anos	Intestinal tumor
8	Male	38	Married	Colostomy	6 months	Diverticulitis
9	Male	78	Married	ileostomy	12 years	Ulcerative colitis
10	Female	35	Married	ileostomy	3 years	Endometriosis

Fonte: Os autores.

Still, in the case of the word ‘bag’, the interviewees’ speech revealed another perspective: that of survival/guarantee of continuity of life. In this context, the word in question is accompanied by the word ‘life’, in the sense of expressing the gratitude of people with stoma for the gift of living, made possible by stomization and visually manifest, contradictorily, by the use of the collecting bag.

“The bag is important because if it were not for it we had no life.” (D7)

“The bag is a boring thing, in a way it’s a nuisance ... it seems like crazy people ... but it’s saving me!” (D8)

“The bag ... you cannot live without it, it will collect the feces. Today the bag is part of my body.” (D9)

Although the surgery for the construction of the stoma is considered by many as the surgery of life, living with the stoma, the collector bag and the body changes denotes the materialization of a modified body due to illness, accident and/or injury in health.

“I was more reserved like that, because after I did the surgery I did not like to show the belly or anything of the type, after I did the surgery I wide open.” (D1)

[...] after that last surgery that put the stoma out I got a lot better. Because I could not leave the house, I had to go to a place that had a bathroom, every time I was in the bathroom [...]” (D2)

“What has changed is that after the surgery I eat a lot ... The surgery was important for me not to die, it was for me to live longer.” (D4)

“These surgeries left a lot of marks on my body, because they cut a lot.” (D6)

The testimonies evidence the primacy of the body as an organic object transfigured and injured by the incursion of the stoma and the bag, implying in the perception of the current body, imbricating it by the health-disease process.

DISCUSSION

The perception of to be-ostomized-in-the-world shifts to corporeality (to the body-world relationship); what is incorporeal (subjective, internal) becomes a concretized project (stoma and bag) by the body that “lives”, that “moves”, that is “expressed”, that “creates” in context and historical determined.

Expressing itself on the senses, Merleau-Ponty⁸ affirms that “in general, the body itself presents the mystery of a group that, without abandoning its particularity, emits, beyond itself, meanings capable of providing its frame to every series of thoughts and experiences.

Thus, it can be stated, as revealed by the interviewees, that the term ‘bag’, the most quoted and central term, can be considered what best represents ‘stomization’ and characterizes the reality of to be-ostomized-in-the-world for these people. Diniz¹² tells us that the bag collecting feces and urine indicates a notorious difficulty in social interaction. Merleau-Ponty⁹ states that our whole perception is altered by virtue of bodily modifications. “My body does not perceive, but it is as if it were built around the perception that is evident through it⁹”.

The bag and the stoma now have body meanings for people with stoma. This perception is based on Merleau-Ponty⁸ following explanation of the body-in-the-world interpretation of ‘things’: ‘The thing is the correlative of my body and of my existence, of which my body is only the stabilized structure’.

In this way, the conception of perception becomes understood as the action of the body “before the science of the body - which implies the relation with the other - the experience of my flesh as a denim of my perception taught me that perception is not born in any another place, but it emerges in the recess of my own body⁹”. We understand that the sensory phenomenon implies or is implied in the worldly relationship with its pairs.

People with a stoma show numerous difficulties in adapting to the collector bag, and even after they have adapted, they may still have difficulties with their use in terms of aesthetic aspects and insecurity due to the fear of leakage and of causing annoyance to those with whom they live¹². Thus, the great fear concerning living with disorders of the bag, especially in spite of the elimination of its excrements, constitutes a necessity that goes beyond

the biological sphere, strongly affecting the social sphere of its 'existence-in-the-world'¹³.

For Merleau-Ponty⁸ experience (stomization) promotes new meanings and interpretations. The lived-body (self-body) is what gives us only the thought of the body or body in idea, not the experience of the body or body in reality.

About the high frequency of the word 'God', it was perceived that this is related to the religiosity of to be ostomized. It is known that the confrontation of the coexistence with the stoma implies a great internal struggle between the physical, emotional and spiritual aspects. In view of this, the great mention of the word 'God', in the discourse of people with a stoma, evokes, in addition to the spiritual mobilization for coexistence with the stoma, an expression of the desire for healing, based on religious belief¹⁴. Faith or the search for the divine facilitates the search of the person with the stoma for coping resources, as a source of resilience or part of the struggle to adapt to body changes after surgery¹⁵⁻¹⁶. Clearly, approaching 'God' has an action of individual internal strengthening to support the said situation.

It evokes the necessity to awaken the experience of the world as such as it appears to us during the time in which we are in the world by our body. But to resume contact with the body and with the world, as well as ourselves, which we will reconnect, since if we perceive as our body, the body is a natural self and as the individual of perception⁸.

The Merleau-Ponty conception of the phenomenology of the perception of the body as be-ostomized-in-the-world, being the perception constituted from the body, promotes intense discussion about the body-lived, its motricity, its expression, and the body as a work of art, transposing the reflection of body derived from their experiences, their perceptions, their movements, expressions and creations.

To the detriment of the restricted number of study participants and their variables, as well as the types of analysis chosen, it is not possible to generalize the meaning of be-ostomized to the entire population with stoma, since the meanings here attributed by the deponents of this research are peculiar and are not similar or similar to those found in other studies, moments and socio-cultural and environmental contexts.

The article promotes discussion of the meaning of be-ostomized-in-the-world, rehearsing a better understanding of how a person 'feels', 'sees' and 'perceives

itself inserted in the world'. From a better understanding it becomes possible a more significant interaction with the individual with stoma, providing changes in the form of care of health professionals to valorize humanized care.

In this context, the nurse becomes an ally within the perspective of understanding and accepting their current condition, effectively seeking strategies to confront the barriers assigned in the universe of deflagrated meanings. It transcends, therefore, the care expressed by the accomplishment of techniques and procedures, crossing the psychosocial care and contemplating the integral clinical care.

CONCLUSION

The foundations of Merleau-Ponty choose the corporeal subjectivity constituting it in a multifaceted aspect, manifesting multiplicity of interpretations. It is through the body that we become aware of the world and thought forms in an existential unity.

The collector bag and the stoma are new parts of their body, a condition of the continuity of life, as well as a place of materialization and remembrance of the disease, conditioning their world. The possibility of reversion is considered, as the hope of restoring the perfect and healthy body, enunciated in some moments of the phenomenological interview by the participants of the research. This conception of the ideal body hinders the acceptance of its new condition of life and corroborates with the chain of stigma. Thus, the perception of the bag and the stoma is a new way of perceiving, of experiencing, of relating, of moving, of being body and therefore being subject in the world.

AUTHOR'S CONTRIBUTION

Conceptualization, Marques ADB and Amorim RF; Methodology, Marques ADB; Amorim RF; Mesquita NS; Fontenele FMC; Pereira MLD and Moreira TMM; Investigation, Marques ADB; Writing - First version, Marques ADB; Mesquita NS and Fontenele FMC; Writing - Revision & Edition, Marques ADB; Amorim RF; Mesquita NS; Fontenele FMC; Pereira MLD and Moreira TMM.

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