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Research Article

# "*Mens Sana in Corpore Sano*": The Concept of Health and Illness in Colorectal Cancer Patients

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## Abstract

Colorectal cancer is the most frequent cancer in Portugal. As such, the present research project studied colostomies patients, with temporary or definitive stoma so as to examine the internalized imago of 'healthy person' and 'sick person'. A descriptive and exploratory study with a qualitative methodological strategy was carried out. Our sample comprised 46 ostomy individuals of both sexes, aged between 36 and 91 years. All participants answered to a brief socio-demographic and clinic survey and to a protocol that involved producing a pictorial representation of a healthy and sick person and provide a written answer on these concepts. The results shown that patients resort to a projective identification mechanism and attest to a connection between being healthy and being young, whereas the 'sick person' is often represented in rigid postures. Ostomies and related prosthetics were but rarely depicted, which may point towards an unconscious and concealed denial of the body amputation experienced by the participants. Our findings can be used as indicators for post medical treatment care, and further lead to the implementation of strategies that can better prepare colorectal cancer survivors for the meaning of the changes – physic and symbolic losses – that they experience.

***Keywords:*** *Colorectal Cancer Patients; Ostomy; Health; Illness; Drawing; Content Analysis*

## Introduction

"Colorectal cancer patients with stomas face both physical and psychological stressors. Findings indicate that most patients with stomas express difficulties in coming to terms with the ostomy, have negative perceptions of their body image, and continue to consider their experience as traumatic" [1].

Colorectal cancer is the second most common form of neoplasia in the western world and the leading cause of cancer mortality in Portugal [2], with an incidence of 16.1% and a prevalence estimated at 5 years in our country - 1296.8 cases per 100,000 inhabitants [3,4]. It is therefore a serious problem in Public Health.

The risk group includes asymptomatic individuals over 50 years old. It should be noted that age, family history, genetic alterations, eating habits, sedentary lifestyle, obesity and smoking are major risk factors for colorectal cancer [2,5].

Surgery can be considered as the only therapeutic weapon that can lead to a cure, which often involves an elimination ostomy - involves the presence of a stoma, i.e. a surgical opening made in the skin, resulting from the exteriorization of the small intestine (ileostomy) or of the large intestine (colostomy). Through the stoma, feces are ejected directly into a collecting bag adapted to the skin, which may be temporary or permanent [6].

After surgery, the loss of control in the feces elimination process and the need for the use of an external collection device (collecting pouch), confronts the Sick Person with physiological changes and the necessity to incorporate new experiences at the intra-psychic level.

The current study set out to explore the views of ostomy patients (colorectal cancer survivors) regarding concepts and cognitions on health and illness, aiming to answer the following questions: What is a healthy person? Is it the absence of illness? Or is it having a body that acts, interacts, appears, experiences and emotes in a manner that a person has become accustom to? If so, what is a sick person? Can one have a chronic illness and still have a body that performs according to one's expectations? Is our understanding still limited regarding patients' own perceptions of health/illness, towards optimum health care delivery for cancer survivors?

Data on body image was collected from colostomies' patients, with temporary or definitive ostomy, so as to examine the inherent to the internalized imago of 'Healthy Person' and 'Sick Person'.

From this data analysis, we intend to characterize a mental profile of 'healthy person' as opposed to 'sick person'. Is the body skin the envelope that translates one's identity? Does mental representation (imago) constitutes itself as a psychosomatic unit, polarized in a permanent dynamic between real and phantasmal fiction? Can the body become the material referent of one's self-image in health and illness for ostomy patients? What are the views of ostomy patients regarding concepts and cognitions on health and illness? Can we trace a meta-profile of a healthy and of a sick person as a mental representation made by colorectal cancer patients? Do patients resort to a projective identification mechanism when defining health and illness? Is there a mechanism of projective identification regarding the concept of "Sick person" and "Healthy person" according to the figure depicted, in terms of gender and age? Is the representation of portrayed "ostomies" more common in the figures of healthy or ill bodies?

Although cancer survival rates have led to increasing attention being paid to patients' own perceptions of health/illness and quality of life, our understanding of optimum health care delivery for cancer survivors is still limited by the lack of a patient-centered perspective. Our findings can be used as indicators for post medical treatment care and further lead to the implementation of strategies that can better prepare colorectal cancer survivors for the meaning of the changes – bio-pshyco-social and symbolic losses – which they fully experience. A person's perception on his/her body image is a key feature in understanding subjective representations of the body [7-10]. The current study aims at gaining access to the mental representations of the notions of "*Healthy Person*" versus "*Sick Person*" via the projective technique of drawing. Drawings of the human figure have been one of the most popular instruments in gaining access to individuals' mental representation on the body image (imago) and consequently onto the workings of deeply unconscious and cognitive processes [11,12]. Communication with the use of drawings takes a basic and universal language form [13,14]. The use of drawings as a projective technique was established as a resource used in many empirical fields, in the extent that it is a form of access to thought and interpersonal and intrapersonal communication and to the most hidden emotions of the Self.

From the literature review presented, there was an absence of studies with patients with a specific pathology that showed how the knowledge of the healthy and sick human body is mentally represented. The study of Lev-Wiesel, Ziperstein and Rabau [15] focused on the same pathology group although their study objectives differed.

To have access to the internalization of the concepts of Health and Illness and to understand how the experience of transient or definitive stoma affects the survivors of colorectal cancer is determinant to improve the specialized health care provided to these patients and to promote their quality of life. In accordance, the central guiding question of this study is to understanding the representation of the concept of Health and Illness in patients with colorectal cancer who have a transient or a permanent stoma.

## Materials and Methods

### Participants

A cross–sectional study was carried out in a hospital at the Lisbon metropolitan area in Portugal. This study was of exploratory nature, field descriptive, of the qualitative and quantitative type. The convenience sample consisted of 46 ostomized individuals with colorectal cancer of both genders (16 males and 30 females), aged between 36 and 91 years old. The following inclusion criteria were defined: individuals of both genders, aged over 18 years old, that have undergone surgery for colorectal cancer and have been ostomized, transiently

or definitively; and the exclusion criteria as well: cognitive deficit or other limitations that impeded the signing of the informed consent or the autonomous completion of the protocol.

**Instruments**

A research protocol consisting of two parts was originally developed: Section I) drawing a pictorial representation of a Healthy Person and of a Sick Person and answering two open-ended questions: "*What is a Healthy Person for you?*" and "*What a Sick Person is for you?*"; Section II) Demographic questionnaire (e.g. gender, age).

**Procedures**

After the study approval by the Ethics Committee of the hospital, the discharge summaries from the Internal Surgery Department were consulted and the participants were recruited from the External Consultation of General Surgery. The collaboration of each participant was requested voluntarily, questions clarified and the anonymity and confidentiality of the data were guaranteed, through the Informed Consent. Participants were also informed that there were no correct or incorrect answers, that they would have a time limit of 30 minutes to complete the protocols and that they were not allowed to use colored pencils or pens nor rubber. All participants were accompanied by researchers who recorded their written responses and subtitled the drawings produced.

A total of 92 drawings were collected from November 2012 until March 2013. The drawings were analyzed to evaluate the mental representation of health and illness attained by these patients and scored using a content analysis grid designed originally by a multidisciplinary team constituted by 2 Psychologists, 1 Speech and Language Therapist and 1 Architect. The scoring was done independently by two researchers.

**Content Analysis of Drawings**

The content analysis of the drawings was carried out from a set of content analysis categories, specifically designed based on the contents presented or referenced by the participants. In this way, an Analysis Grid was constructed, composed of 6 analytical categories regarding the interpretation of the pictorial representations made by the participants. These analytical categories were the following: gender, drawing of the body figure, phase of the life cycle (age), appearance, family support and setting. In the category "appearance", the following sub-categories were comprised: complete / incomplete body figure, transparency, position, anatomical structure, body image, presence / absence of ostomy, wounds, head (eyes, mouth, smile, nose, beard, ears, face expression, posture and attire) and in the category "*setting*", the sub-categories outside / inside space and clinical instruments were included.

The mentioned categories and subcategories were then subject of a descriptive analysis as well as of a second analysis that sought to find associations between the variables under study. For the treatment of the data, we used the SPSS software, applying the statistical test chi-square ($\chi^2$). The chi-square was chosen as it is the data was presented in the form of frequencies in discrete categories and we aimed to determine the significance of differences between two independent groups measured in a nominal scale.

**Content analysis of the answers to open questions**

According to the content analysis of the answers to the open-questions given in writing by the subjects, the results of the identified categories were analyzed through a statistical program of the software for Qualitative Data Analysis - ATLAS.ti.7.

## Results

**Life cycle stage**

The profile of the Healthy Person is represented with an average of 31 years old and may be considered as a young adult, as illustrated in figure 1. The profile of the Sick Person is represented with an average age of 49 years old and may be considered as a mature adult, as exemplified in figure 2.

Table 1 characterizes the depicted gender represented in the healthy and sick person profiles and their life cycle stage.

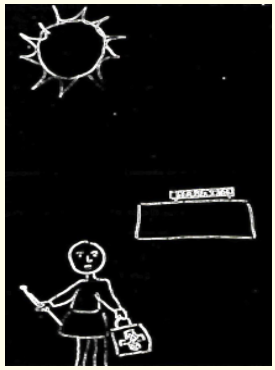


***Figure 1:*** *Young Adult as a Healthy Person.*

***Figure 2:*** *Mature Adult as a Sick Person.*

| | | HEALTHY PERSON PROFILE | | | | SICK PERSON PROFILE | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | Male | | Female | | Male | | Female | |
| | | N | % | N | % | N | % | N | % |
| Gender | Male | 11 | 68,80% | 10 | 33,30% | 10 | 62,50% | 13 | 43,30% |
| | Female | 5 | 31,30% | 20 | 66,70% | 6 | 37,50% | 17 | 56,70% |
| Life cycle | Child | 0 | 0,00% | 6 | 20,00% | 0 | 0,00% | 1 | 3,30% |
| | Adolescent | 2 | 13,30% | 4 | 13,30% | 1 | 6,30% | 2 | 6,70% |
| | Young Adult | 2 | 13,30% | 6 | 20,00% | 0 | 0,00% | 0 | 0,00% |
| | Adult | 10 | 66,70% | 13 | 43,30% | 9 | 56,30% | 21 | 70,00% |
| | Elder | 1 | 6,70% | 1 | 3,30% | 6 | 37,50% | 6 | 20,00% |

***Table 1:*** *Characterization of the drawings regarding the life cycle stage.*

**Face expression**

In the profile of the healthy person the mouth is drawn with a cheerful smile (75% for males and 83,3% for females) and a happy expression (56,3% for males and 80% for females), as shown in figures 3 and 4. In contrast, in the profile of the sick person the mouth is drawn with a sad smile (56,3% for males and 63,3% for females) and a sad expression (43,8% for males and 63,3% for females), as portrayed in figures 5 and 6.

The sickness seems to be mirrored in facial expression (in the face) through the subjectivity of the happy and sad expressions.

***Figure 3:*** *Happy Smile in Healthy Person.*

***Figure 4:*** *Sad Smile in Sick Person.*

***Figure 5:*** *Happy smile in healthy person.*

***Figure 6:*** *Sad smile in sick person.*

**Ostomies/Stomas**

In the Sick Person profile, only 13% of subjects (all females) represented ostomies in their drawing figures, as pictured in figure 7. Curiously in the healthy person profile no ostomies or injuries were represented (0%).

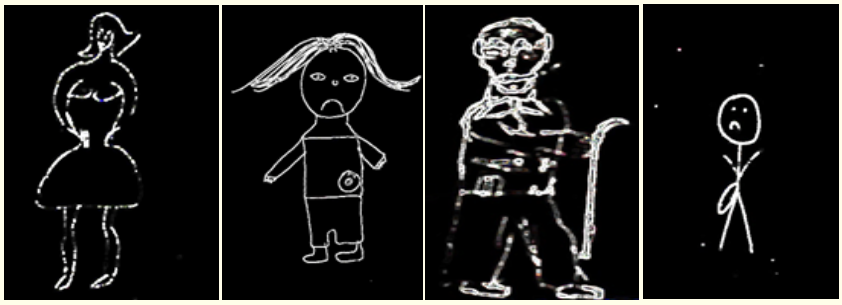
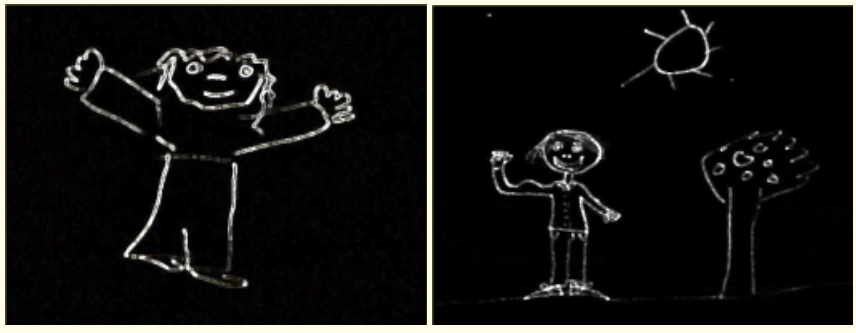


***Figure 7:*** *Drawn ostomies in the sick person drawing.*

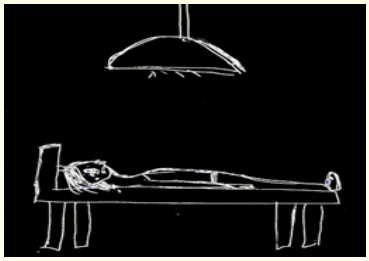
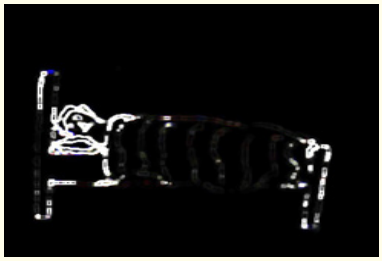
**Body gestures**

In the Profile of the Healthy Person the body gesture (posture) is represented both in movement and in stiffness (both categories with 37,5% for males and 43,4% for females), as expressed in figures 8 to 11. On the other hand, in the Profile of the Sick Person the body posture is mostly represented rigidly (37,5% for males and 56,7% for females), as symbolized in figures 12 to 14.

***Figures 8 and 9:*** *The Movement in Healthy Person Figure.*



***Figures 10 and 11:*** *Healthy Person- associated to Movement (synesthesia).*

***Figures 12 and 13:*** *The Stiffness in Sick Person Figure.*

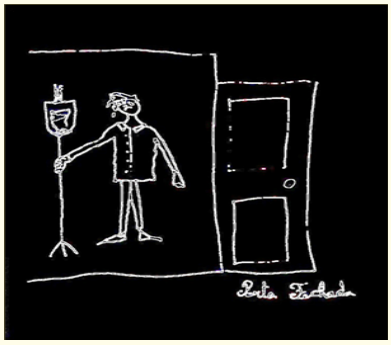
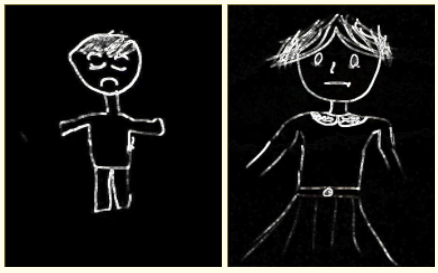


***Figure 14:*** *Sick Person: associated to stiffness of movements.*

**Body figure**

The profile of the Healthy Person is drawn as a Full figure (43,8% for males and 56,7% for females), as represented in figure 15. Unlikely, the profile of the Sick Person (56,3% for males and 46,7% for females), emerged fragmented and with notorious amputations of the upper and lower limbs, namely of hands and feet (up to 25% in "sick person" males), as illustrated in figures 16 and 17.

***Figure 15:*** *Healthy Person- Figure complete*



***Figures 16 and 17:*** *Sick Person: amputation of upper and lower limbs (hands and feet).*

***Open answer questions***

Table 2 presents the answers grouped in categories given by the subjects regarding the questions of what they considered to be a healthy person and a sick person.

| HEALTHY PERSON PROFILE | | | SICK PERSON PROFILE | | |
|---|---|---|---|---|---|
| | N | % | | N | % |
| Without diseases | 7 | 5% | Sad | 24 | 23% |
| Happy | 39 | 28% | Emotional instability | 13 | 13% |
| Bio-psycho-social well-being | 25 | 18% | Without hope (defeated hope) | 15 | 15% |
| Autonomy | 4 | 3% | With diseases | 11 | 11% |
| Sublimation / hope | 16 | 11% | With suffering | 10 | 10% |
| With health / feeling strong | 13 | 9% | Without bio-psycho-social well-being | 7 | 7% |
| Healthy lifestyles | 10 | 7% | Sublimation/hope | 2 | 2% |
| Without suffering | 5 | 4% | Without autonomy / with restrictions | 12 | 12% |
| Emocional stability | 21 | 15% | Weak (without health) | 9 | 9% |

***Table 2:*** *Healthy person and sick person profile – written answers.*

It is significant that the Healthy Person Profile is mainly characterized as a cheerful person with bio-psycho-social well-being and emotional stability, contrary to the Sick Person profile which is characterized as a sad person without hope and with emotional instability.

## Discussion

From the content analysis of the drawings, we can subjectively interpret that the *Body* and the *Self* (seen as a unit) seem to be caught in a "fatal trap" in the case of the ostomized patients.

The predictability of body rhythms (*synesthesia* category), which in our study appears associated with the subcategories of rigidity and movement [16], emerges notoriously altered. That is, the results of the present study point to a dichotomy of the drawn figures in which two typical states are strongly marked - *rigidity associated with the sick human figure and movement associated with the healthy human figure*.

However, in previous studies developed by the team Egas Moniz - Center for Multidisciplinary Research in Health Psychology within the framework of the project "*Mens sana in corpora sano*", this dichotomy appears subjectively coupled with results that point to: i) the movement being associated with individuals represented through the drawing of healthy figure, who practice outdoor sports (e.g. running, bodybuilding); ii) the *rigidity* of the movement that appears associated with the drawing of the sick figure, in a *setting* that refers to the immobility of the subjects (e.g., bounded with ligatures, attached to the bed, dependent on serum and of other clinical instruments) [14,17].

The disfiguring nature of this type of surgery seems to involve a deep sense of loss of the *Self* and of identity changes of subjects. In fact, colostomies can create in the subjects feelings experienced as *social disgust*, because subjects somehow see their intimate space violated – this space is defined by Raubolt [18] as the limit of the skin. There is a re-signification of the bodily sensations – such as smell, loss of fecal control and of gas elimination - that begin to interfere with the daily activity of the subjects, who now have to deal with a sabotaging body. Thus, smell imposes its presence as a "natural" barrier and impels patients to a social and stigmatizing isolation [19-22].

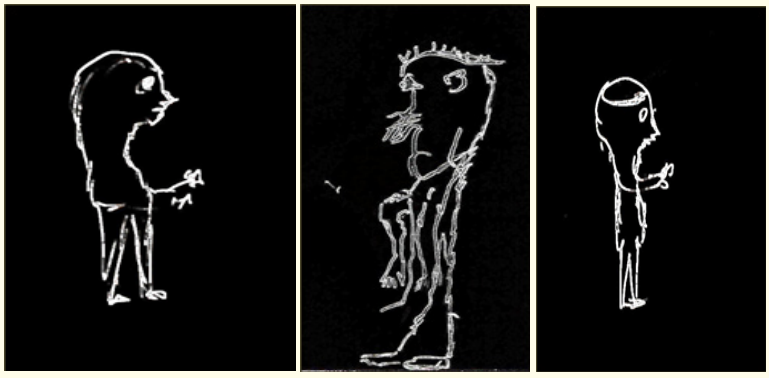
The rarely drawn stoma and collecting pouch are identified as a symbol of pollution and filth – the loss of control involves the transgression of the bodily limits and may represent a physical invasion in the realm of sexuality [23]. Hence, patients may experience a loss of the bodily pleasure, a pleasure that now seems to be denied or linked to the instability of the new identity [19]. In this sense, the use of collecting pouch appears as the phantasmatic representation of the mutilation suffered and as the loss of the patient's capacity.

In this manner, we witness to a real "collapse of hope" – in which a place of silence is installed in the daily life of patients, who allow themselves to socially self-segregate [20,22,24].

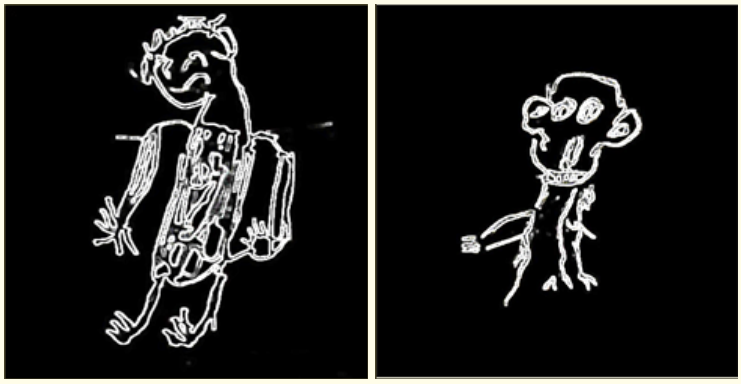
The body that once was felt as intimate and familiar, becomes a foreign object as changes occur - changes that are too quick to be psychically internalized [25]. In this case, the stoma seems to become an alien extension of the *Self,* invading the Body *Self* and the skin-*self* [26]. The (in)organic body becomes unknown to the subject [27].

The lack of hands and feet in the depicted figures in the drawings points to a covert and unconscious form of the amputation of the body [27] referring to the original castration complex.

On the other hand, some of the sketched drawings were so stereotyped and indecipherable that they could not be quoted, they were mere wobbly stokes, in which the contour of the figures seemed to indicate the distortion of the body image experienced by the subjects [28,29], as shown in figures 18 to 22.



***Figures 18, 19 and 20:*** *Bizarre figures that depict the distortion of the body image.*



***Figures 21 and 22:*** *Bizarre figures that depict the distortion of the body image.*

The significant presence of disproportionate drawings seems to be an indicator of the body image distortion experienced by the subjects, suggesting signs of the impairment of the body image (amputations) and difficulties from ostomy patients to represent symbolically their body image [24,30]. In fact, the subjectivity involved in the production of the drawings can be seen in trembling strokes, in disproportionate features, distorted forms, mutations, all suggesting marked deficits in the realm of the self-image of the subject.

The mutilation of the ostomy and the existence of a prosthesis makes the patient clash with the 'damaged' representation of an ideal body - a physical wound that is projected into a psychic wound – and to be face to face with the sabotage and the failure of their own body.

Learning to trust in the new body again takes its time: the (re) experience of hope that has arose in the analysis of contents of the written responses can be considered as a time of (re)significance and reconstruction of the body's identity. Subjects' resilience can help in this task, as Albuquerque [31] highlighted. The healthy patient is one who achieves this task, who incorporates the identity of the diseased part of the body. The stoma is thus the residual part that gives visibility to a body that was once familiar and that now is damaged and unknown.

The skin also appears as a barrier to the perception of disease - the existence of a stoma implies dramatic and immediate consequences in terms of self-image, self-esteem and social interaction of the patient. The subject has "pierced" in the body the existence of the disease. Thus, the greater the physical mutilation, the greater the psychological, social and cultural maladjustment.

The skin serves as a fictionalized interface, a place of connection between the body and the various devices that can be attached to it.

From the body prosthesis to hybrid body [32] the prosthesis becomes part of an ensemble with the body, that is, it gains an adhesion and a flesh status, so that the subject starts to extend his field of subjective perception to this element attached to the body, thereby transforming the body into a POST-HUMAN body [27,33], a mutant body that incorporates the prosthesis [34] (v.g. figures 23 and 24 embody this transformation, as butterflies released from a jar symbolize the journey of becoming healthy).

***Figure 23:*** *Healthy person.*

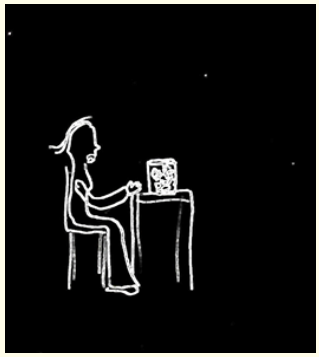


***Figure 24:*** *Sick person.*

## Conclusion

The cancer patient has nowadays a longer survival time. Therefore, oncology health professionals are also responsible for cancers' long term management and rehabilitation, as well as for its treatment and therapeutic iatrogenesis.

The ostomized person is now confronted with the mutilation of his/her physical and mental integrity, body image, often with feelings of self-loathing, of social devaluation and difficulties in facing social isolation.

The body image is of particular importance given that the disruption of body image may emerge during treatment and persist over time. Along these lines, health professionals play a crucial role in identifying concerns about body image, helping patients to cope with emerging feelings, thus promoting self-esteem.

The limitations of this study are mostly related to the collection and size of the sample: the convenience sample was constituted by the patients of the hospital and was institutionally imposed; many drawings have been excluded because they could not be surveyed; the sample was reduced in size and presented data heterogeneity regarding the gender and age of the subjects.

The study is cross-sectional – the protocols were collected after the chirurgic discharge, not allowing to evaluate the mental representation of the body from participants before this traumatic event.

By considering the complications that the ostomy can cause and the problems which patients may encounter after the surgery, one can anticipate in the pre-surgical time the planning of the clinical interventions needed in health care. Whether through the multifaceted adoption of therapeutic modalities or through complementary methods, we must ensure the maintenance of the psycho-functional state of the patient, reducing the impact of bodily and symbolic loss.

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## Conflict of Interest

Any conflict of interest exists.

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