Abstract

This study discusses the psychosocial characteristics of colostomy users’ feelings. Qualitative research with colostomized patients that constituted one of the objectives of the Rectal Cancer Assessment (ACRE) study of the National Cancer Institute José Alencar Gomes da Silva - INCA. Data interpretation had as the main supposition the understanding that interpretations about one’s body are characterized by speeches and representations. The feeling of shame was frequent in the testimonials. The shame of the colostomized body and the desire to hide it are associated with the negative feelings attributed to the “out-of-standard” body and the feces, collective and individual feelings that can be used as a basis for comparison in body interpretation. The colostomized body is still seen as a taboo, which intensifies feelings of isolation, abnormality, and not belonging, making it even more difficult to adapt, promote mental health and develop autonomy.

Keywords

Body; Colostomy; Health Promotion; Colorectal Cancer.

Introduction

Stoma is a Greek-origin word, stóma, which means mouth or opening [1]. It is a nomenclature used to indicate the exteriorization of any hollow viscera through the body [2]. There are several types of stomas: respiratory, gastric, intestinal, and urinary [3].

In the intestine, the stoma can be created in the colon region and is thus called Colostomy. To perform a colostomy, it is necessary to
carry out a surgical procedure for colon exteriorization, through an opening in the abdominal wall. The opening creates another pathway for fecal material elimination. This procedure may be temporary, when the intention is to reconstruct the intestinal tract at a subsequent time, or definitive, when reconstruction of the intestinal transit is not possible [4].

After the colostomy, some complications can occur, such as skin rash on the borders, skin infections, bleeding, intestinal stump necrosis, stoma stenosis and prolapse [5].

With the colostomy, the individual loses intestinal continence, which results in the involuntary elimination of fecal material through the stoma. For this reason, a colostomy bag is required for the accumulation of waste, which brings biological, psychological, social, and spiritual changes to the colostomized individual. Some of the negative effects of losing control of waste elimination, noises and odors are: marginalization, disbelief, discouragement, social isolation, altered self-esteem due to a negative body image [6].

The most common reasons for a colostomy surgery include colorectal cancer, diverticular disease, bowel obstruction, inflammatory bowel diseases (e.g., ulcerative colitis and Crohn’s Disease) and Familial Adenomatous Polyposis [7]. The colostomy can improve a person’s quality of life by reducing or eliminating physical discomforts present prior to the surgery, but it can also negatively affect quality of life, regarding psychological and social issues [8].

The intense concerns of many ostomates is noticeable regarding the need to hide the signs of the collecting equipment, to avoid questions and embarrassment [1].

The experience of using a colostomy constitutes a symbolic mark that delineates the person’s biography, since meanings and experiences need to be re-signified and reformulated, in search of a new meaning for life [9].

In Brazilian studies, results were found on the decrease in quality of life of colostomized individuals. The aspect of social relations was the most negatively emphasized [10, 11]. In Poland, a survey involving 737 patients with ostomies (71%, 18%, 11% with a colostomy, ileostomy and urostomy, respectively) found a similar result regarding the negative impact on social life [12]. The three studies give us indications that the discomfort caused by dietary changes and physical pain resulting from surgery cause difficulties in life; however, interpersonal relationships appear as the greatest difficulty to be overcome.

A systematic review of English-language studies on the psychological discomfort of patients with intestinal stomas, found similar data to Brazilian studies on the negative impact on body image, sexuality, and social life [7].


In Taiwan, a study quantitatively assessed 110 patients with colorectal cancer regarding stoma acceptance. It was found that people with less stoma acceptance had lower level of schooling, shorter disease time, or a more advanced cancer stage [16].

According to Dázio et al [17], life’s temporality, in this context, is an important factor regarding recommitment and acceptance of changes. However, an ethnographic study carried out in Australia found that, although most participants had more than five years of stoma use, they still had great difficulty accepting it [18]. Sharpe et al [19] even affirms that there are situations in which some people with stomata due to colorectal cancer, over time, even worsened the problems with body image.

Given this context, and abdicating a biomedical view of colostomy, the present study sought to understand the psychosocial aspects of the body with colostomy from the perspective of colostomized patients seen at a reference hospital for the treatment of cancer in Southeastern Brazil.
Method
This article is the result of a qualitative study of co-
lostomized patients and was one of the objectives
of the ACRE (Rectal Cancer Assessment) study ca-
ried out at the National Cancer Institute José Alen-
car Gomes da Silva - INCA (Rio de Janeiro, Brazil).

The study was carried out with 30 participants,
who were invited to enroll in the study. The inclu-
sion criteria comprised participants older than 18
years with a permanent colostomy due to colorectal
cancer. All participants who met the inclusion crite-
rion and accepted to participate in the study signed
the free and informed consent form (FICF). To pro-
tect the participants' identity, we did not use their
names, but we preserved all other data.

The study was approved by INCA Ethics Com-
mittee under approval No. (Committee Registration
No. 117-11 CAAE- 0087.0.007.000-11). The ethical
procedures were followed in this study, according to
Resolution 466/12 of the National Health Council,
which regulates the bioethical aspects in research
involving human beings in Brazil.

The study was carried out from July 2014 to Ja-
uary 2015, including data collection, through semi-
structured interviews, data analysis and preparation
and final report.

The interviews were conducted by a single resear-
cher who addressed the following triggering ques-
tions: What are the meanings of having a colostomy,
the perceptions about the body with a colostomy,
the ways to deal with it, the changes after surgery,
and how the interviewee feels at the present mo-
ment. After that, we concluded the interview with
the characterization of the interviewees' profile.

The information collected were processed and
analyzed based on the notion of Social Represen-
tations (SR) proposed by JODELET as a possibility
of understanding the meanings of the colostomi-
ized body [20]. SR theory questions the dichotomy
between individual and collective and describes the
human being as a result of his/her individual his-
tory and the history of his/her society. Discourse
Analysis, which seeks to understand the ideological,
social and historical influences on the production of
meanings, was also used in this study [21].

Four theoretical assumptions were considered
for the interviews and data analysis: 1) the act of
perceiving is not restricted to a mechanical record
of phenomena, 2) at the perception, the connec-
tions between the subject who observes and the
object that is perceived are not radically unilateral
and neutral, as a simple sense-free perception [33],
3) when we perceive, we are already interpreting, 4)
our interpretations are affected by representations
and disseminated by discourses that have effects
on daily life senses and on the subjective plane,
which are effects and not determinations, so the
interviewees' reports do not disclose an individuality
displaced from their socio-cultural environment [21].

Results and Discussion
After the data collection, the following characteriza-
tion of the participants was outlined: regarding the
socioeconomic aspects, there was no great vari-
tion, as the sample was comprised of people from
socioeconomic classes C and D. All of them lived in
the state of Rio de Janeiro. Age ranged from 32 to
79 years, with eight men and 22 women. The time
of colostomy varied from four days to 15 years of
surgery. As for the marital status, seven were wi-
dowed, 16 were married and seven were single. As
for the self-declared religion, 9 were Evangelicals,
16 were Catholics, one was a Spiritist and four did
did not report any religious denomination.

We observed, during the literature review and
field work, that the feeling of shame was recurrent
in the testimonies of these colostomized individuals.
At first, it seemed obvious to us that feelings of
embarrassment, inadequacy and psychic malaise
appeared in adults who lost control of the elimi-
nation of stool and intestinal gases and who also
underwent a "no-choice" bodily change, as well as
changes in life habits (food, clothing, among others).

We know from research and empathically un-
derstand that this shame is associated with feces
and with a body that is out of the hegemonic patterns of Western culture. The stool generates shame for fear of causing disgust and repugnance, and a non-standard body produces shame due to the possibility of causing feelings of inferiority and inadequacy. By exercising the difficult task of denaturalizing what seemed obvious to us, we asked the following questions during our analysis: Why is stool exposure so embarrassing? Why is colostomy a taboo? What are the senses of a colostomized body? Why, for many individuals, the colostomized body should be hidden?

Many issues related to living with a colostomy appeared, but our focus was on the meanings attributed to the colostomized body, not only the feelings reported by the participants, but also the cultural senses that feed our representations. We could, based on the results of the research, write several articles if we explored each topic. We did not, however, have the aim of venturing into every topic, due to the possibility of losing our primary purpose.

According to our observation, the category shame was present in several topics of the interviews. People that isolated themselves, those who had difficulties with their sexuality, those who hid the colostomy or had problems related to self-esteem and body image showed something in common: the shame of their modified bodies and the shame of carrying the stool collection bag.

For this reason, we chose to study the senses that underlie this shame of the colostomized body, starting from the speeches of the research participants.

According to the Houaiss Dictionary of the Portuguese Language, p.766, the word shame means: 1) feeling of outrage; humiliation, (2) painful feeling of insecurity; shyness, (3) indecent, dishonest attitude [22].

Araújo [23], in his study “The feeling of shame as a moral regulator”, points out the relevance of further studies on the feeling of shame. This author characterizes shame as the basis for psychic function, as well as for the understanding of human morality, since shame, as regulator of human relations, can be considered one of the most relevant feelings for experiences with the world and with people. Historically, Psychology has not put much effort into understanding this feeling, but this has started to change in recent years. In the field of health research, this concern is still much lower, as we did not find studies that assessed this topic.

Charles Darwin, in his book “The expression of the emotions in man and animals (1872/65)” studied shame in human behavior and devoted part of the study to the fact that only humans have the physical characteristic of blushing when they feel embarrassed. For this reason, Darwin characterized shame as the most peculiar and most human of feelings [23].

The onset of shame depends on two relevant points: the reflection on oneself of some characteristic of personal appearance; and thinking about what others think about us [23]. To feel ashamed, we need a referential, constituted and transformed by the person and the social environment.

Lewis [24] also reinforces the sociocultural understanding of shame when it expresses a separation between primary and secondary emotions. For the author, the primary emotions are the ones that do not need an insight or self-reference, which are happiness, sadness, anger, surprise, fear, and disgust. Secondary emotions are feelings that involve an awareness of the self. This group comprises shame, guilt, envy, jealousy, empathy, embarrassment and pride.

For this reason, shame involves a reflection based on individual and collective beliefs and values. Shame is related to senses attributed to a particular theme. Le Breton [25], however, does not distinguish between primary and secondary emotions; for him, all emotions, including shame, are not spontaneous, but ritually organized and meaningful. The feelings and the way we experience and feel them physically are rooted in collective norms.
For Le Breton [26], the emotions and interpretations of bodily experiences are related to the environment where we live or the group we belong to. Our relationship with pain, shame, sadness, among others, goes through an assessment of collective beliefs and values. Studies in Anthropology and Sociology show the different ways of interpreting the body, depending on culture, social class, gender. We are not, however, a blank paper for social beliefs. There are individual differences that interfere with the perception and absorption of collective beliefs.

We feel shame because we interpret something negatively. The shame of the colostomized body and the desire to hide it are associated with the negative feelings attributed to the non-standard body and to the presence of feces, collective and individual feelings that serve as an assessment for body interpretation. Our analyses will be followed by the presentation of some themes that support this negative interpretation.

The taboo and the shame of the colostomy together constitute the taboo of the feces. The colostomy brings with it some metaphors and symbolisms, as the exposed feces are shunned in our culture (western, capitalist, and urban), which tries to hide the ugly, the unpleasant, "what smells bad", even if it is common to all. We perceive the strong emphasis in social networks of the display of happy lives in contrast to the high number of individuals with depression and anxiety.

Because of this taboo, many people hide their colostomies, which contributes to the lack of understanding about this surgery by the general population, which may intensify feelings of isolation, abnormality, and non-belonging, making it even more difficult to adapt. Additionally, by normalizing that something is "abnormal" or normalizing the feeling of shame, we lose the possibility of fighting for improvement, for respect and public policies that promote environments that are more welcoming and favorable to the integral health of these people. The frequent preoccupation with concealing the colostomy increases anxiety and unhappiness in these individuals, since the concern on not being "discovered" or exposed to the judgment of others increases tensions and discouragement.

I do not like to talk to people about it. I think it is very intimate. Only my family knows about it. After my sisters-in-law got to know about it, they stopped coming to my house.

I know that after I told my friends about it, they became distant; nowadays, I do not like to talk to many people anymore. I only talk to my family about it, and not everyone.

I've never seen anyone with it, I do not know anyone that has it. I've never talked to anyone like that. Today I even think it would be good for me to talk to another person (with a colostomy) because I feel alone, very different, but I was too ashamed to talk about it and even more ashamed to show it. Only now I can speak a little more about it.

Adults that have a colostomy face the challenge of reorganizing their new intestinal function, as they lose bowel movement control. Additionally, some of their childhood beliefs are to be faced with the use of a colostomy. Feelings of infantilization, feminization (in men), frailty, loss of autonomy and body inadequacy can arise with the use of a colostomy.

It is very strange to walk around knowing that I am carrying stool. It is very bad; once I was in church and then out of nowhere we heard that farting noise. When you least expect it, you have to go through such a situation.

It was a great disappointment. I got a letter saying that I would have a normal life, but I do not have a normal life. I cannot lift a pot, I cannot wash clothes because I feel a lot of pain. In the booklet that I received, they even talk about exercise, but in fact I feel very dependent nowadays.
Far from objectifying a psychological analysis or infantilizing our interviewees, we can say, metaphorically, that people with a colostomy go through a new anal phase in the Freudian sense, or autonomy versus shame and doubt phase, in E. Erikson’s theory [27]. After the colostomy surgery, people need to re-signify and understand new body functions.

Freud [28], when describing the anal stage of human development, indicated in his theory the emotional impact related to sphincter control. At this stage, by the age of two, the child begins to receive guidance on bowel and urinary control. The anal phase is related to the concern about the ability to control sphincter muscles. In this period, one forms the opinion and beliefs about what kind of person one is, about one’s power, one’s worth, how one feels about oneself, what kind of person one is.

It is noteworthy that the so-called anal phase is associated with the perception of one’s value, as the child experiences anxieties and is recognized and valued as he or she can control the sphincters, which makes us internalize an association between personal value and sphincter control. Sphincter control is seen as our first social act.

This phase is directly associated with the physiological changes that give us more autonomy in relation to the world - walking, talking, “conquering the world”. We have the possibility of greater autonomy and greater independence, but we realize that there are things greater than ourselves and that are beyond our will.

It would be a cliché to say that hygiene training affects our development and our lives in general, but during the anal phase we can be affected more markedly, as hygiene issues recur during this period, just like after a colostomy surgery. We noticed during the interviews that the hygiene training during the colostomy bag exchange, emptying the bag, are subjects that leave the interviewees anxious, especially in the recently colostomized ones. Many have reported the fear of not properly doing their hygiene or being dependent on someone. Others preferred their children or wives to make the change, as they did not have the courage to deal with the feces. Others reported the fear of leaking stool.

It is a very arduous thing, you have to change it, it is not a natural thing, it is very bad. As an outcome, it was very good, the surgery was very well performed, but the difficulty in changing the bag, to take a shower… Well, it is not good and it is not natural, my daughters change it every four days because it gets very disgusting.

This is very disgusting, I think it is very strange. And I’m not changing it yet, my girl is doing it. I get disgusted (moment of silence and her eyes filled with tears).

I am always tense. I never completely relax. When I travel by bus I am always afraid of leaking and smelling bad. I never relax. I’m afraid people will look at me.

Life changes a lot. What I am going to eat, I always leave home and carry with a reserve bag, if it is well placed, if the clothes did not get dirty. I had to go back home from a place once because it had leaked and soiled my shirt.

It is better now. Over time you get to know what the best bag is, how to put it right so it will not leak, but I left the hospital and they did not tell me anything, how to do it, how to clean and they did not tell me I would have to keep it forever.

The “potty training battle”, as some development theorists name it, is actually a symbol of the conflicts and situations we experienced in this period when we are given instructions on how we will become sociable by controlling the sphincters. During the interviews, we identified the fact that the greatest difficulty in adapting to the colostomy comes from the field of interpersonal relationships and the fears regarding hygiene care, as if metaphorically the person had to go through a new anal phase.
In the beginning, it was difficult ... Learning to change the bag ... We are afraid of how people will look at us, afraid of prejudice, not from my family, but from other people, friends, relatives, colleagues because the ones I considered as friends, are all gone. I think they disappeared because of the bag; when I was healthy, paying for beer, my house was full of people; my sisters-in-law do not go to my house anymore. I also think it was because of the surgery. I do not know if they feel disgusted, if they think I am going to smell bad. Honestly, I do not know ... I perform my hygiene perfectly, I never smell bad. They only get to know about it when I tell them, it is prejudice, because they think the person who evacuates through the bag will smell bad. People are very prejudiced. A lot of people went away, even those whom I thought were friends, people I had known since I was a child. And now life goes on...

Curiously, within the scope of the Psychoanalytic Theory, hygiene training is also related to creativity, because as children, we are proud of our feces, since they are the first things we realize that we made, that our body produced, they are our "work", a name used by some people to refer to feces or "I will work"; therefore we are not ashamed, we can play with them, take them, eat them.

We end up learning, however, to consider them as ugly and unpleasant. Culture, represented by parents, caregivers, and school, teaches us that feces pollute, bring diseases, go out through the anus and need an appropriate and discreet location for their elimination. It is a fact that these values also vary depending on the social environment.

One of the patterns that manifests during the anal phase is about what we produce and how we deal with our creations. During this period, we discover the existence of things we do and are not appreciated by others.

Erik Erikson [27], in the middle of the 20th century, started to create his psychosocial theory. Without denying Freud's theory, he changed the focus from sexuality to social relations. He anchored his theory of development on the sociocultural context, considering the human being as a social being who lives in a group and which, therefore, is under the pressure and influence of the social environment. His psychosocial theory of development grants importance to the childhood phase, but states that personality is not totally fixed and therefore can be partially modified, depending on the experiences of life and the social environment. The individual undergoes constant resignifications.

E. Erikson’s theory drew our attention in this study. This author explains the human development in phases, one of which is autonomy versus shame and doubt. These poles are precisely the anxieties of some of the interviewees: feeling autonomous again versus feeling ashamed.

According to the aforementioned author, the subject develops based on the internal demands of his ego, but also on the demands of his social environment. Each stage of development constitutes a stronger or weaker ego. The phases described by Erikson are: basic trust versus distrust; autonomy versus shame and doubt; initiative versus guilt; diligence versus inferiority; identity versus identity confusion; intimacy versus isolation; generativity versus stagnation; integrity versus despair.

We will limit ourselves to explaining the autonomy versus shame and doubt phase, as it is related to our subject. This phase corresponds to the Freudian anal phase, that is, as we described earlier, when children begin to develop body control, with their walking, talking, running movements. Therefore, children start to direct their focus toward experiences during which they can explore the world and gain autonomy.

In parallel, however, the child begins to understand that the world has rules and limitations. It is a phase associated with bowel and urinary control,
but also of instinctual impulses. Children learn what to hide and what to show. They learn what they have control of and what they do not need to control, to whom they can show their ugly side and still be loved. Therefore, during this period, we learn the notion of value, including our own.

A relevant point observed by this theory is that, to teach the child certain rules, adults make use of shame or encouragement for autonomy. In some situations, the use of authority can shame. The key point for understanding this phase is that everyone goes through moments of autonomy or shame, but some are more in the polarity of shame and others in the polarity of autonomy, a fact also observed in the interviewees. Those who demonstrated more autonomy regarding the colostomized body affirmed that they had the support, welcome and encouragement of friends, family, and church members. Those who felt more shame, on the other hand, usually had less support and ended up isolating themselves even further, intensifying the discomfort.

At the autonomy versus shame and doubt phase, the great challenge is to find the measure: “neither repress too much, nor permit too much.” With the reports of the participants, we associated the fact that a better interpretation of the colostomized body is related to greater autonomy in self-care. We perceived with the testimonies the importance of a good preoperative and postoperative guidance aimed at a good development of autonomy in self-care, as well as the importance of meeting other people going through similar situations. Of the 30 interviewees, however, none was participating or had participated in meetings sponsored by the Ostomate Association. We also highlight the idea that the preoperative period is characterized by many fantasies and instabilities, so that some information is not fully absorbed during this period. We stress the importance of follow-up and further guidance.

According to Pitanguy, the body change seen as a negative one affects the behavior of the person and the group. The author emphasizes that the group interferes with the interpretation that the person will assign to the change. A scar or mutilation can be a source of pride in one culture and reason for shame in another [29]. In the history of mankind, however, there are many examples of rejection of deformity and difference. The Spartans, some indigenous tribes, nomadic Arab peoples, for instance, eliminated deformed individuals by killing them or condemning them to social isolation.

As Rodrigues points out, societies are capable of bringing members to death, through purely symbolic means: by instilling in them the loss of the will to live, by making them depressed, by undermining them, by consuming their physical energies, by socially marginalizing them, by depriving them in a way that in at a certain point, death becomes a simple biological detail [30].
I was very ashamed when I was with my husband, I felt very ashamed of myself when he came for me, I put a cloth on top of me to cover myself, I felt ashamed; but not nowadays, he also accepts it fine, it is me that still try to preserve myself a little.

(...) dealing with this surgery was more difficult than dealing with the news of the disease; as for the bag, I always took care of myself, I had my nails done every week, my hair, I was always well-dressed and suddenly I see myself in this situation... I can only wear dresses now, and I never like to wear dresses, I cannot wear shorts, because if I wear them, I have to put the bag down there, it is very bad and all this... but now I am better because of the people here with me, we get used to it, I’m already getting used to the bag.

I feel weird about myself. With the colostomy, I changed a lot, I don’t go out anymore, I think it changed everything, I do not like to go out anymore, I’m afraid. Regarding my husband, things changed ... my body changed, I think it is ugly, horrible.

As soon as I knew I was going to stay with it forever, I was depressed, unwilling to do anything else, I wanted to stay away from everyone, I was afraid to leak, to be ashamed. I did not want to treat myself, but then I got better. I learned how to change the bag. It is fine nowadays.

There is a lot of prejudice, people think we are always dirty. Friends disappeared, some family members too, but my wife and children always supported me. Without them it would be even worse.

For me, everything is fine. My friends always help me, there are four of us. They go to my house, we eat. They are very important, they helped me a lot during the disease period and after the surgery.

Our idea is that, metaphorically, a more welcoming social environment, with information and respect for differences can potentiate the development of more autonomy to the detriment of shame and doubt and feelings of inadequacy in these people.

Conclusion
During the field research, the fact that the body, even though it constitutes a physical and palpable reality, common to the human species, has a symbolic value that is socially and culturally established, since, depending on the place, time and climate, it can have different representations and senses and thus, different interpretations about its functions and appearance.

We identified the fact that the question of autonomy for self-care was related to feeling better about one’s own body, feeling less embarrassed, as shame was associated with the main negative aspects reported, such as: social isolation, problems in sexuality, self-esteem, and self-image. We also observed that the shame about one’s body cannot be explained with a positivist understanding of subjectivity, as something that is individual, private, without the influence of sociocultural values. Shame is related to a negative interpretation that has as basis for comparison the individual, family, and social environment experiences the person has or had.

Therefore, we consider that the approach of the mental suffering of a colostomized person through the biomedical bias, without a sociological, anthropological, and psychological approach would be a naïve one, since subjectivity itself is a dialectical construction between the subject and the environment. To think about improvements in care and rehabilitation of the colostomized individual, we need to discuss cultural values and beliefs that reinforce feelings of inadequacy and shame in these individuals. To naturalize the shame or to place solely on the individual the responsibility for “going on” with
their lives do not seem to us as efficient measures for Health Promotion of these people, since they make it difficult the reflect on public policy improvements.

In the literature, there are few reports on educational work in health care in which the care and guidelines transcend a technicist model of education focused on the physiological aspect. The perception of a body that is not rooted in culture, values, frustrations, fears, and shames predominates. We consider the importance of programs with interdisciplinary teams that consider the body in its entirety and preserve the dignity and citizenship of the colostomized person.

References


This article is available at: www.intarchmed.com and www.medbrary.com


