

MULTIPLE MEANINGS AFTER STOMIZATION: IMPLICATIONS FOR THE BEGINNING OF SOCIALIZATION OF PEOPLE WITH COLORECTAL CANCER

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ABSTRACT

Objective: to understand the meanings attributed by people with colorectal cancer and by their companions to the surgical treatment with stomization.

Method: an ethnographic study based on comprehensive sociology and short narratives. It was conducted with 22 participants in a surgical and outpatient clinic of an Oncology High-Complexity Center in Pará, Brazil. Collection was carried out between July 2018 and February 2019, by means of observation and recording in a field diary and semi-structured interviews, with subsequent inductive content analysis.

Results: the following was apprehended: Visualization of the bag and the new way of facing their lives; Anguishing feelings; Learning in the post-operative period, the family and instrumental support; Changes in work activities, pleasure activities and threat to leisure and vanity; Personification of the "foreign body" and signs of internalization.

Conclusion: secondary socialization was explained by the concentric circles of socialization. Nursing needs to act by sharing technical-procedural-informational knowledge, informing the sick and those accompanying them of the responsibilities of the macrosocial sphere.

DESCRIPTORS: Colorectal Neoplasms; Stoma; Tertiary Health Care; Socialization; Oncology Nursing.

SIGNIFICADOS MÚLTIPLES DESPUÉS DE LA ESTOMIZACIÓN: IMPLICANCIAS PARA EL INICIO DE LA SOCIALIZACIÓN DE PERSONAS CON CÁNCER COLORRECTAL

RESUMEN:

Objetivo: comprender los significados atribuidos por personas con cáncer colorrectal y por quienes los acompañan acerca del tratamiento quirúrgico con estomización. **Método:** estudio etnográfico basado en la sociología comprensiva y narrativas breves. Se realizó con 22 participantes en el área de clínica quirúrgica y en el servicio ambulatorio de un Centro de Alta Complejidad en Oncología de Pará, Brasil. Los datos se recolectaron entre julio de 2018 y febrero de 2019, por medio de observaciones y registro en un diario de campo y entrevistas semiestructuradas, con posterior análisis inductivo de contenido. **Resultados:** se obtuvo lo siguiente: Visualización de la bolsa y el nuevo modo de encarar sus vidas; Significados angustiados; Aprendizaje en el período post-operatorio, la familia y el apoyo instrumental; Cambios en actividades laborales, de placer o la amenaza al tiempo libre y la vanidad; Personificación del "cuerpo extraño" e indicios de internalización. **Conclusión:** la socialización secundaria se explicó por medio de sus círculos concéntricos. El área de Enfermería debe actuar compartiendo conocimientos técnicos-procedimentales-informativos, informando a los pacientes y a quienes los acompañan cuáles son las responsabilidades de la esfera macro-social.

DESCRIPTORES: Neoplasias Colorrectales; Estoma; Atención Terciaria de la Salud; Socialización; Enfermería Oncológica.

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INTRODUCTION

In 2017, there were 1.8 million cases of colorectal cancer (CRC) and 896,000 deaths; there were also an estimated 19.0 million disability-adjusted life years (95% of life years lost and 5% of years lived with disability) in 2017⁽¹⁾. In Brazil, 40,990 cases are estimated for each year of the 2020-2022 triennium⁽²⁾. Therefore, surgical treatment of CRC with stomization will have negative repercussions⁽³⁾.

Thus, physical-operational needs will be weighted: what about the exchanges?; will the ability for self-hygiene be modified?; how will loss of continence be felt?; eating habits?; fear of prolapse, dermatitis, hernias; and knowing how to identify healthy peristomal skin before discharge⁽⁴⁻⁵⁾.

It is convenient to take a macro-sociological look, integrating the psychobiological, psychoemotional, aesthetic, sociocultural, socioeconomic, sociopolitical and religious dimensions of the stomized patients⁽⁴⁾. The Unified Health System (Sistema Único de Saúde, SUS) cites these determinants as macropolitical, requiring a comprehensive-cognitive effort from nurses, patients and caregivers as agents of the microsocial plan⁽⁶⁾.

The new lifestyle will impact on self-concept, bonds and self-care. To address socialization, this argument was mediated by sociological concepts⁽⁷⁻⁸⁾, providing for the coercion of the individuals to their society by processes such as the formation of the self and repression of instincts, physiological or otherwise, using mechanisms to make them fit to live in a group. It is understood that primary socialization occurs in childhood and secondary socialization throughout the rest of life, encompassing the experience of chronic illness. The interconnection between the self and the body is emphasized, explaining that, in the era of aesthetic standards, it reinforces and induces the veiled discrimination or not of people with differentiated bodies⁽⁷⁾.

Knowing that the surgical procedure associated with chemotherapy and radiotherapy causes side effects, uncovering life events, social support and emotional conditions throughout treatment, in a person-centered approach, improves care⁽⁹⁻¹⁰⁾. Apprehending and recording contacts, verbal and nonverbal communications, and the feelings – the meanings, are achieved by focused ethnography, centered on focused question and context, and aiming at faster changes, encompassing the health policy⁽¹¹⁾.

Given the above, the objective of the research is to understand the meanings attributed by people with colorectal cancer and by their companions to the surgical treatment with stomization.

METHOD

This is an ethnographic study with theoretical support from comprehensive sociology and the methodological strategy of short narratives. Ethnography is an interpretive method and, in health, it converges for its conduction in small units or groups⁽¹²⁾. The social-critical paradigm of short narratives understands that the subjects conduct the research results, not as laymen and passive⁽¹³⁾ narrating events, whether past or present, providing moments of the participants' own reflexivity⁽¹⁴⁾.

The setting was an Oncology High-Complexity Reference Center (*Centro de Referência em Alta Complexidade em Oncologia, CACON*) in the state of Pará, Brazil, between July 2018 and February 2019. The first locus was the surgical abdominal oncology clinic, with eight wards (individual, and with two, three, or four beds). The second locus was

the chemotherapy outpatient service (seven wards).

The population was CRC patients and companions, some in-depth interviews were conducted with both presences conditioned by the clinical condition and post-operative pain. Data were validated with regular contacts, asking what the data represent, not always interfering, and composing the sample aiming at the objective⁽¹⁵⁾, justifying this inclusion.

The sample consisted of 22 individuals: 14 patients and eight companions; it should be noted that six patients felt comfortable answering the questions without assistance. 11 patients and seven companions in the clinic and three patients and one companion in the outpatient clinic were approached. The inclusion criteria were the following: patients hospitalized for surgical treatment with stomization or intestinal transit reconstruction over 18 years of age, stomized patients being followed-up in the antineoplastic outpatient clinic, and companions over 18 years of age; in the clinic, those who returned from the operating room without stomization were excluded. Contacts were made in the afternoon shift.

During collection, the following dynamics was respected: sociological observation with listening and interaction⁽¹⁶⁾ during the preoperative period, avoiding embarrassment and searching for data under the assumption that the information collected in the first instance is superficial. The field diary was used as instrument, recording participant and non-participant observations; the ethnographic notes were typified: dense descriptions, short notes, and reflections by the researcher⁽¹¹⁾, and the participants were invited to provide feedback. The semi-structured interview was the final technique: How was the surgery?; What did they tell you about how you were going to be afterwards?; What did your family think?; What is it like to have a (colostomy/ileostomy)?; What is helping you cope with the changes?

Regarding data organization for triangulation, anonymity was ensured first by applying "P" for patients, "PA" for outpatients ("*Pacientes Ambulatoriais*" in Portuguese), "A" for companions ("*Acompanhantes*" in Portuguese), and "AA" for outpatient companions ("*Acompanhantes Ambulatoriais*" in Portuguese). Data production for P and A occurred at various moments, from two to five contacts in the pre- and post-operative periods, with contact time between researcher and participants ranging from seven to 30 days, due to their stay in the institution. For PA and AA, collection took place on a single occasion at the chemotherapy outpatient clinic due to the high flow of users.

In the focused ethnography, the transcribed data and field notes opened sections in Microsoft Word files, increasing in number until the end of collection, and in which the data was coded⁽¹¹⁾. The analysis followed: transcription, reading and re-reading; generation of meanings; generation of units to encompass the meanings; verifying the connections between the units; generating names (categorization) for each meaning; and report⁽¹⁷⁾.

This study was approved by the Research Ethics Committee of the Health Sciences Institute of the Federal University of Pará under opinion No. 2,692,475.

RESULTS

The characterization of the patients was as follows: seven men and seven women. Seven were aged between 30 and 59 years old and another seven were 59 years old or older; nine participants were married, three were single, one was divorced and one was a widow. The mean monthly income of the group was R\$ 426.25.

The elapsed time from diagnosis to surgical treatment with stomization for four participants was between 1 and 3 months; for two, between 3 and 6 months; for another two participants, from 6 to 12 months; for four, with a waiting time of one year or more;

and for two participants, with a waiting time of two years or more. The surgery performed was resection and confection of intestinal stoma for 12 of these patients; one was waiting for correction of intestinal loop prolapse and one respondent was waiting for intestinal transit reconstruction.

Visualization of the bag and the new way of facing their lives

The first visualization of the bag oscillates between fear, relief, worry, need to learn, and resignation:

I was relieved and concerned with time. (P1 – Intestinal transit reconstruction after two years)

You're forced [to have the bag]. It's different because the way it was with the guy here in the back and now it's forward and that's too complicated! [Diary: P5's daughter asks "Mom, do you think you will find it easy or difficult to clean?"] Difficulty, but you learn as time goes by. (P5)

How is it going to be like?, What clothes will I wear?; after that comes I don't believe. Thank you, my life will come back! I'm afraid of not knowing how to take care of it, but little by little I will learn. (P6)

When I looked at it: Oh, my God. How am I going to live with this here? (P3 – Intestinal loop prolapse)

The ideal that it is the only way for them to be alive, and the suffering prior to arrival at the tertiary level and during hospitalization, helps their acceptance.

The way is to accept, there is no other way of being alive [laughs]. (P3 – Intestinal loop prolapse)

God knows what He is going to do with me, I want to get well because I was suffering so much. (P5)

Remember that I overcame a difficulty. (P2 and PA12 synthesis)

I held on with great hope to the bag. [...] to have hope to live longer, I hold on to it and accept it easy. (P4)

They expressed the probability of intestinal transit reconstruction, so these are the first questions to the team, even in cases of permanent stomization:

A woman doctor here touched me on the shoulder, this bag you don't take off until two years. I said by the name of Jesus it won't happen! But she's the one who has knowledge and tomorrow will be two years. (P1 – Intestinal transit reconstruction after two years)

Doctor, will it return to the rectum? He said probably. [Diary: Intestinal loop prolapse; after the surgical procedure, the bag remained]. (P3)

At first it was hard knowing that I was going to use the bag for the rest of my life, now came the surprise that it will only be for a while. (A6)

Anguishing meanings

Procedures, surgical reapproaches, and the waiting for it to work generate anguish.

They washed me and gave me about five pills, I started to feel a twist, they put in some devices to wash, I started to feel like I was about to vomit. (P3 – Intestinal loop prolapse). I put a little bag here on the side for him to bucket, then the guts fell into the bedpan. (A2)

I don't know what infected the first ileum, they had to open and wash it and did the other one. The colostomy after a period would stay in one place, but it didn't work out and I don't even remember it anymore [...] [looks at the wall]. The last time we were going to get discharged, they had already given the papers and we were going down to get him out of the system, that's when a spot came loose and feces started coming out. They activated the block and took him. Now we're here and it's taking time to work [Diary: After the interview he was reordered for the fourth time and died in the ICC]. (A3)

When you do it, you want it to work and days go by and nothing happens. I can't talk, I haven't seen results [Diary: Not functioning for 12 days; P11 was admitted to the ICU and died 3 days later]. (A7)

In the case of palliative care, stomization was addressed as a relief.

If her children have the idea that she had the surgery to come back healthy, they need to get that out of their heads. Prepare soon your children for [...] [Shakes the head] It was just to make it better. (A4)

Learning in the post-operative period, the family and instrumental support

Handling the bag articulates new ways of feeding, body care, and calls for learning mediated by Nursing techniques, generating empathy.

I would get nervous and think that I wouldn't be able to clean [Did the team help?]. They taught me how to put it on, I was scared and they said no, you must clean it up, because I'm going back home. A nursing technician at a time when I was very fragile cleaned up, she's wonderful! (A3)

The family and community outline the instrumental and emotional support.

Everyone, unanimously, thinks that it was better to have this bag than having him gone. (A1)

Support from a lot of people: I had no idea that you were like this. As the city is small, 80% of the population knows that I'm like this. (P1)

The lack of instrumental support was narrated by an anecdotal case:

There was one there [Capanema city] who died, he was a junkie and didn't use a board or a bag, it was a plastic bag with duct tape and it was on the street that he was living. All the stores gave two reais. I don't know what he died of. I think it gets infected, right? (P1)

Changes in work activities, pleasure activities, and threat to leisure and vanity

Stomization generates abandonment and transfer of work activities:

Things that I did in my job, I can't do now [speaks low]. I'm a mechanic and I can't get up on the truck to hoist it, to get up someone must grab my wrist [...] I have trouble turning around. (P1 – Intestinal transit reconstruction after two years)

He spends time looking at banana, pineapple, tangerine, coconut, lemon, pumpkin plantations [...] Now that he's sick, he's just watching and feeling disappointed [Who takes care of the farm today?]. He has a son, but his son doesn't take care of it like he does. (A2)

After you operate, you can no longer do anything [Diary: I make clarifications]. (P5)

Lots of things are going to change, I'm not going to cook anymore. (P9)

He wants to return to his activities as a bricklayer. (AA8)

Two respondents linked old age to the loss of vanity and leisure, others asserted experiences of isolation and prejudice.

As my son said via WhatsApp: his father is 70 years old, he has no vanity left. (A1)

I can't take a bath on a beach, I just stay at home, it doesn't bother me. Have you ever seen an old man having leisure? I had already stop having it anyway. (PA12)

I'm having difficulty getting out, not because of the bag, it's because the tumor has come out a little and I can't sit for long. (PA13)

He just stays in bed, at home, doesn't get up. Before he wouldn't stop. (AA8)

I had trouble in a bank, they didn't want to let me in [stages a gun with his fingers]. He [guard] has already pointed to my bowel, the volume of the bag, gases are coming out. When I went close to show him through the glass, he stepped back and put his hand on the gun handle and I lifted my shirt and said "It's here! Respect me boy!" And I cursed him a lot. (P1 – Intestinal transit reconstruction after two years)

Personification of the "foreign body" and signs of internalization

The straight case personal pronoun "it" and the common noun "bag" denoted the non-appropriation of the words colostomy or ileostomy.

It [colostomy] clogged and he spent eleven days in the hospital, he couldn't eat. What came out contaminated everything, almost twenty days without coming out, only that ugly old juice came out. (A2)

I started to push and it [colostomy ostium] grew and when I lie down, it [hernia] appears. [Diary: He asks me to pull him up and stands]. I felt it when it broke. (P1 – Intestinal transit reconstruction after two years)

I will adapt to it as it should. (P2)

I want it to stay in there, it doesn't even fit in the bag [intestinal loop] anymore. (P3 – Intestinal loop prolapse)

There was a small possibility that it might not be final. (P4)

Internalization after socialization was seen in PA13's bargaining indicating his new self and comparing himself, and the adaptation referred to by PA12, both outpatients.

It has its advantages and disadvantages [What would the advantages be?]. The other day I was laughing at my husband, he wanted to go to the bathroom and there was someone there. I said: My advantage is that I don't have to stand in line, anywhere... That is the advantage [laughs]. (PA13)

I got used. My son, who is a nurse, used to change for me and then he says that now I can't be there. So, I change it in the bathroom every three days, it opens underneath, when it fills up I take it out, wash it and put the clip back in. (PA12)

DISCUSSION

Socializing is when the person learns to perform the attitudes of the other, when children learn to take care of themselves without the help of their parents in some aspect;

in this study, when the caregiver-patient binomial learns to care for the stoma without the help of the Nursing team. Consequently, identification with social roles is a specific phase, which generates a pattern of conduct. Toilet training for fecal evacuation is determined by socialization, and such an act follows patterns in industrial societies, providing for the transition from one stage of development to another⁽⁸⁾.

Over time, reference groups are selected, and ruptures produce new socializations and lessons. This is explained according to the concentric circles of socialization (Figure 1), from the situations circumscribed to the "inner circle" as being safe, where their peers and who will help are; as distance from the center increases, relational sharpness decreases. The hospital is a territory short of primary socialization and the status quo of the family suddenly changes from a stable environment to aid in the search for (biomedical) territories⁽⁷⁾. They relativize what they learn in life with what they learn in hospitalization, and empathy for the nursing technicians was the crucial bond for the onset of learning.

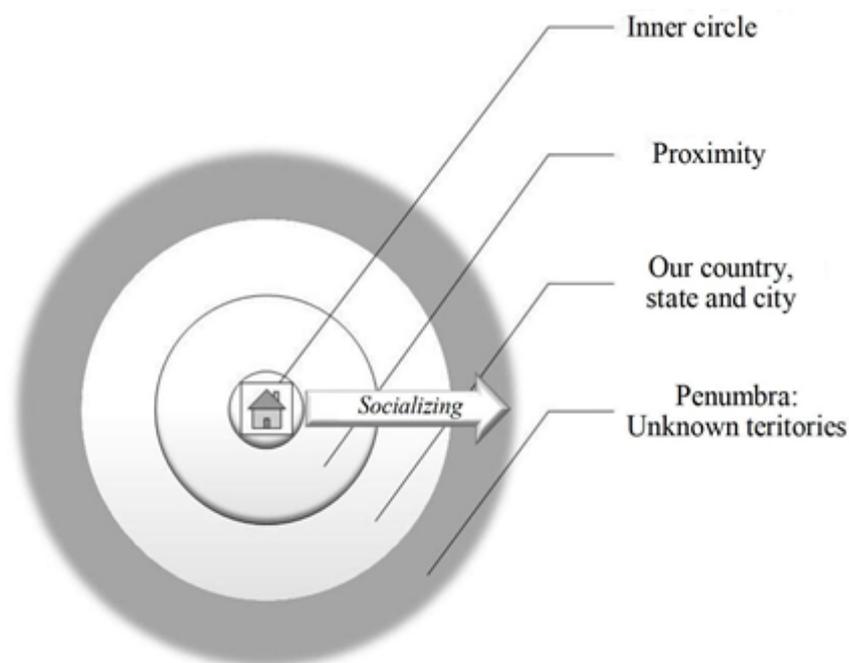


Figure 1 – Concentric circles of socialization. Belém, PA, Brazil, 2020.
Source: Abstraction from Bauman and May⁽⁷⁾.

Social coercion makes them devise ways to hide or disown their stomization. The personification of the bag and/or stoma stands out due to the resistance in using the biomedical lexicon: the "invading" body is established attached to the feeling of unconscious dissatisfaction⁽⁷⁾. In the case of the respondents, the self dissociates itself from the collecting bag, leading them to unconsciously externalize their dissatisfaction with "it" and, paradoxically, to personify it.

The following are notable behaviors: 1) despite the aspiration to live as the "generalized other" (non-stomized people), coexistence and exchange of experiences with the "significant others" (stomized people) should be stimulated under the penalty of not socializing as someone who needs more care; 2) for an uncertain amount of time, two faces of individuality will coexist, I and the "Me", which may not dialog considering that the "Me" is the face molded by society, adapting itself⁽⁷⁻⁸⁾. Internalization came from self-discovery in the return to the inner circle, permeating through the reflection of its

possibilities⁽⁸⁾, allowing PA13 to express his bargain.

The surgery of life⁽⁴⁾ resembles the results, the experience is traumatic in the first few hours; however, this suffering does not override or equal the pleasure of being with the family nucleus^(9,18). The survival ideal escapes the Patient-Cured dyad, which is hardly recommended in post-operative oncology⁽¹⁹⁾, since the idea that the stoma is a price to be paid for survival is surrounded by ambivalence, and they think of the bonus and the burden with an emphasis on dramatic acceptance⁽²⁰⁾ as "overcoming a difficulty".

The most evident was the fear of social isolation and the urgency of instrumental and informational support, in passing on information with appropriate terms and using feedback^(10,18,21-23). The lack of development of integrated interventions, platforms, and communities of practice for caregiver-patient is weighted at the other care levels⁽⁶⁾.

Such support is stratified into shared experience, practical support, emotional support and financial support⁽¹⁰⁾. Support is highlighted as a key element, since stomization brings about new relationships, consequently, as in a United Kingdom study, social support was linked to practical tasks and telephone monitoring, without, however, taking away the person's autonomy and self-confidence⁽²⁴⁾. Weakening of instrumental and informational support comes from lack of family members and confused microsocial networks^(4,6).

They put their instrumental and informational support(s) into perspective with: permanent or non-permanent stomization, boasting an extended family or not, consanguineous or "faith" siblings, and owning a house. Having seen this, it was perceived that communication is a microsocial tool that makes Nursing visible^(4,24).

In relation to the demands such as the durability of the collecting bag and satisfactory hygiene, it is known that these are obtained by the quality of the material and the adequate use of the adjuvants (paste and powder, deodorant lubricant) and accessories like the belt^(4,18). The comparison of some of these products to "gold" is a good example of this urgency. For residents in the inland of the country, the uneasiness is more pronounced, since the care center is located in the capital and the SUS provides bags and the supplies in standard numbers, generating impasses, because the integration among the meso-regions of the state of Pará is complicated.

They are company employees who take over the guidelines close to discharge; however, they do not totally exhaust the doubts, knowing that the assimilation of information occurs in a short period of time^(5,22). Internet access via mobile phone was a mechanism to clear doubts, but it is not known which information is reliable^(4,21). The information in official and unofficial media for people with low socioeducational levels can be vehicles for fake news and reports of despair^(5,21).

One contingency would be to ask about social-interactive needs, nutrition, skin, goals, leisure, and self-love^(4,25). The professional stomatherapist nurse assumes responsibility for the prevention and treatment of problems with the peristomal skin, and teaches about self-management and cognitive resignification^(5,22,25).

The limitation of this research is the fact that there was only one contact with the outpatients and companions.

FINAL CONSIDERATIONS

It is understood that the meanings attributed are linked to the beginning of "socialization". Learning is the interaction with the new, the discovery of ways to deal with fecal evacuations (effluents) and with the generalized and meaningful other, as in the concentric circles of socialization. The apprehension of the sharing of technical-procedural-

informational and self-care knowledge is advocated, mediating the beginning of the new socialization and the expectation of instrumental support in relation to the macro-sphere, in the dispensing of the collecting bag and adjuvants, understood by Nursing in the peri-operative period. The appropriation of pronouns to talk about stomization indicates a foreign entity in the body over which they have no control.

This study contributes to the visibility of the role of Nursing by clarifying the meanings attributed to recent stomization for these people and their caregivers, the psychoemotional markers that permeate the teaching of self-care still in the hospital, and the instrumental support and sharing of knowledge during secondary socialization, as part of the process of integrality of care beyond the functional reductionist model. It is encouraged that future research studies will explore supported self-care, as well as the internalization process in relation to stomas.

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