

THE MEANING OF BEING A MAN WITH INTESTINAL STOMA DUE TO COLORECTAL CANCER: AN ANTHROPOLOGICAL APPROACH TO MASCULINITIES

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This study analyzes the meanings that men with intestinal stoma attribute to their colorectal cancer experience and its treatment. The medical anthropology framework, gender identity and the ethnographic methods were used. A total of 16 men from 40 to 79 years of age, residents in Ribeirão Preto and neighboring cities, SP, Brazil participated in the study. Data collection was carried out through participant observation and semi-structured interviews. Two groups of meanings were selected through inductive data analysis: acknowledging the severity of the disease and the distress of having cancer, and being submitted to surgery and suffering from a stoma. These meanings revealed the tension that develops between traditional patterns of masculinity and the new identities resulting from the experience. The understanding of these meanings from a cultural perspective favors nurse-patient communication and enables planning of care appropriate to these patients' needs.

DESCRIPTORS: colorectal neoplasms; nursing; culture; gender identity

EL SIGNIFICADO DE SER UN HOMBRE COM ESTOMA INTESTINAL POR CÁNCER DE COLORECTAL: UN ABORDAJE ANTROPOLÓGICO DE LA MASCULINIDAD

El estudio tuvo como objetivo analizar el significado que los hombres, con estoma intestinal, atribuyen a la experiencia de la enfermedad y al tratamiento de cáncer de colorectal. Fueron utilizadas las referencias teóricas de la antropología médica, de la masculinidad y del método etnográfico. Participaron del estudio 16 hombres en el intervalo de edad de 40 a 79 años, residentes en Ribeirão Preto, SP, y región. La recolección de los datos fue realizada por medio de observaciones participantes y entrevistas semiestructuradas. Por medio del análisis inductivo de los datos, se seleccionó de los núcleos de significados: el reconocimiento de la gravedad de la enfermedad y el sufrimiento de tener cáncer, someterse a la cirugía y al estoma. Esos significados revelan la tensión que se desarrolla entre los estándares tradicionales de masculinidad y las nuevas formas de identidad provocadas por la experiencia. Conocer esos significados, bajo la perspectiva cultural, facilita la comunicación entre enfermero y paciente y permite planificar los cuidados adecuados a sus necesidades.

DESCRIPTORES: neoplasias colorrectales; el enfermería; la cultura; identidad de género

OS SENTIDOS DE SER HOMEM COM ESTOMA INTESTINAL POR CÁNCER COLORRETAL: UMA ABORDAGEM NA ANTROPOLOGIA DAS MASCULINIDADES

O estudo teve como objetivo analisar os sentidos que homens com estoma intestinal atribuem à experiência da doença e do tratamento do câncer colorretal. Foram utilizados os referências teóricas da antropologia médica, das masculinidades e do método etnográfico. Participaram do estudo 16 homens na faixa etária de 40 a 79 anos, moradores de Ribeirão Preto, SP, e região. A coleta dos dados foi realizada por meio de observações participantes e entrevistas semiestructuradas. Pela análise indutiva dos dados, selecionou-se dois núcleos de sentidos: o reconhecimento da gravidade da doença e o sofrimento de ter câncer, submeter-se à cirurgia e ao estoma. Esses sentidos revelam a tensão que se desenvolve entre os padrões tradicionais de masculinidade e as novas formas de identidades provocadas pela experiência. Conhecer esses sentidos, sob a perspectiva cultural, facilita a comunicação enfermeiro-paciente e permite o planejamento de cuidados adequados às suas necessidades.

DESCRIPTORES: neoplasias colorretais; enfermagem; cultura; identidade de género

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INTRODUCTION

Literature has, in recent years, admonished about the importance of men's health considering they suffer more illnesses than women and that there is a relation with the construction of masculinity and how their health is compromised. Given the important role that occupation plays in men's identity, such as being the head of the house, various problems can occur in relation to health promotion and disease intervention⁽¹⁾.

In this scenario, the Brazilian Ministry of Health, in August 2008, established the "National Policy of Integral Care to Men's Health: Principles and Guidelines" reaffirming that harm to men's health is a public health problem and its proposal aims to improve the quality of integral health care for the Brazilian male population. The document highlights the fact that tumors occupied the third place among mortality indicators and were responsible for 43.2% of deaths⁽²⁾ of men between 25 and 59 years of age in 2005. According to the National Cancer Institute (INCA), 231,860 new cancer cases in men and 234,870 in women were expected for 2008⁽³⁾.

As nurses, faculty members and researchers in the cancer field, the authors of this study are focused on the health of men with colorectal cancer (CC). This neoplasia is ranked fourth among those affecting men and mortality rates have increased. Estimates of incidence published in 2008 predict 12,490 new cases of colon cancer in men and 14,500 in women. These numbers correspond to an estimated risk of 13 new cases for each 100,000 men and 15 for each 100,000 women⁽³⁾.

Despite coloproctology advancements in the prevention and early diagnosis of CC, there are still difficulties due to the population's lack of knowledge about the risks, lateness in seeking care or lack of access to health systems and insufficient resources for diagnosis in Brazil. In general, diagnosis of the disease is performed in advanced stages, requiring prolonged hospitalizations and culminating in intestinal stomas for patients⁽⁴⁾.

Brazilian nurses have shown through interpretative studies that physical and psychosocial disorders caused by CC, surgery and stoma compromise the quality life of patients and their family members⁽⁵⁻⁶⁾.

In the face of this scenario, the process of rehabilitating these patients from a perspective of masculinity is noteworthy. It is not a very well studied aspect in Brazilian nursing.

Aiming to bridge this gap, this study analyzed the meanings attributed to the disease experience and treatment among men with intestinal stoma.

THEORETICAL METHODOLOGICAL APPROACH

Medical anthropology, masculinity in anthropology and ethnography were the theoretical-methodological approach used in this study. Medical anthropology holds that culture is a symbolic system of creation of meaning that express knowledge, beliefs, norms and values. From this perspective, the disease needs to be interpreted not as a biological, static and individual process, but as a process that demands interpretation and action in a sociocultural environment. Thus, one needs to understand the disease as an experience, as a subjective process. The individual experiencing a disease such as CC, attributes meanings to it according to common sense and acquire new knowledge in the course of treatment⁽⁷⁾.

Complementing this idea, the division of the social world into male and female expresses in all societies a different socialization. It is in this way that culture collaborates in the creation of implicit and explicit guidelines that govern life in society, in which men and women are submitted to different norms of emotion, cognition and practices. However, gender roles are not fixed; they can change under the influence of several social processes as in the experience of a disease⁽⁷⁾.

Studies carried out over decades addressed only hegemonic masculinity, which is a ideal cultural model that exerts control over men by the normalization of social practices, contrasting with the female gender's approach.

Given critiques of this model, other patterns of masculinity are considered⁽⁸⁾. Identification of these patterns permits one to understand the variations of subjectivity present in the process of becoming ill, because studying men implies seeking their singularity in the context of their group of reference.

For the process of the illness experience to be understood with individual nuances, one needs to describe the problem etiology, its physiopathology, the course of the disease, and prognosis and treatment through a method that permits close contact with patients⁽⁹⁾.

According to the noted assumptions, the ethnographic method was adopted to develop the study. This method aims to produce a "thick description" of the meanings attributed by participants to a phenomenon, expressed in language. Based on these meanings, it is the researchers' role to synthesize relevant aspects⁽¹⁰⁾.

The following selection criteria were used: being a resident in Ribeirão Preto or neighboring cities, SP, Brazil, older than 18 years, any level of education; having a temporary or permanent stoma for at least one month; being in physical and emotional condition to participate in the study, and providing consent through the free and informed consent agreement.

A total of 16 men with intestinal stoma, due to CC, registered in the Proctology Outpatient Clinic in the Hospital das Clínicas, University of Sao Paulo at Ribeirão Preto, Medical School participated in the study. Data collection was carried out between June and December 2007 after the approval of the hospital's Research Ethics Committee was obtained.

Semi-structured interviews and participant observation, which are procedures that enable intersubjectivity between researchers and participants⁽¹⁰⁾ were employed. The following guiding questions were used: tell me how your disease started and what you think about it; how was your search for treatment?; what was it like having to undergo the surgery?; what is it like to be a man with a stoma?

Data was collected in the hospital (in the outpatient clinic and in the medical office) and at the participants' homes. Interviews and observations at homes were scheduled. On average, two interviews were held for about 60 minutes with each participant in order to complement data. Participant observation aimed to identify participants' non-verbal behavior, relationships and practices in their homes and on medical visits, which is when men relate with other patients and with the team. Information about the disease and its development and treatments for patients were obtained through their medical files. Data were registered in a field diary and all obtained information was transcribed afterwards.

Inductive analysis was performed in two stages: ordination of data texts for each participant, identification of meanings given to the experience in a set of texts or in each individual text, which permitted identifying empirical categories by considering their common and distinct aspects. Based on these categories, the meanings given to the experience were interpreted considering the participants' sociocultural context⁽¹⁰⁾.

Among the 16 participants, three were between 40 and 50 years old and 13 between 51 and 79 years old; 12 had permanent and four temporary stomas; time of the intestinal stoma varied from one month to seven years. Thirteen patients were affected by rectal cancer, two by sigmoid neoplasm and one by synchronous cancer of the sigmoid colon and rectum. These characteristics confirm that rectum cancer is more frequent than colorectal cancer and more prevalent in men in the majority of populations⁽³⁾.

In relation to social characteristics, we highlight that: ten were married, six resided in Ribeirão Preto and ten in the surrounding region; eleven reported being non-practicing Catholic; professions varied: driver, farm worker, mechanic, among others. Six were retired, seven were on sick leave, two were unemployed and one of them was working. Income varied from one to five times the minimum wage, current at the time; two participants had no income and four received only minimum wage. Nine had not completed middle school, which is consistent with their occupations (before disease) and reduced salaries (or benefits from retirement). Given these characteristics, the majority of participants are considered part of the working class, characterized by workers in urban centers who live in poor financial conditions, due to reduced occupational qualification and a low level of education with consequent limited access to public services such as education and health⁽¹¹⁾.

RESULTS AND DISCUSSION

Acknowledging the severity of the disease

Among the signs and symptoms indicative of problems in the intestinal system, informants describe *diarrhea*, *bleeding*, *thinning stool* and *hemorrhoids* that lasted months. These symptoms were considered low in severity and individuals tried to solve them using lay knowledge such as *home remedies*, *much sprout*, *guava and parsley tea*. As these signs intensified, impeding them in carrying on with their daily routine, they re-evaluated the importance of these symptoms and sought solutions in the healthcare system as exemplified in the following. *I'd go to the bathroom but it'd take a lot to come out (feces), then it'd come out with a little pellet of blood. It got more frequent. After one year I went to the doctor. I was paralyzed with fear of the diagnosis. I was in pain and my*

stool was tiny just like cat's stool, there was blood. I thought it was nothing.

An interpretative⁽⁶⁾ study describes these same beliefs and practices, and there are no differences between men and women. It is known that men delay their search for primary care services because, due to hegemonic stereotypes of masculinity, they neglect caring for their health⁽¹⁻²⁾ as presented earlier.

Their search to obtain a medical diagnosis was a challenge for them; they had to go through referrals between different physicians and health institutions, deal with schedules for months ahead, had to repeat exams, to leave their jobs, to deal with a lack of financial resources to move around, among other difficulties. These hardships certainly are institutional barriers found in the access of men to health services⁽¹²⁾.

The colonoscopy and rectal exams left, in all participants, bodily and emotional marks. *The rectal exam was the first one. Then, the other (colonoscopy). This was a hard one, in a bad site, weird position... I was sweating and trembling, [...] it was embarrassing. It's a weird thing. Men were created not to be touched there (anus); [...] I felt a lot of pain. It hurts us!*

The rectal exam is designed to detect hardened masses, changes in the rectum and bleeding. Through the colonoscopy the physician can see the intestinal wall and observe any abnormality; it also permits taking a biopsy. For the professional system, these exams are effective and of low cost⁽⁴⁾. For the informants, these procedures represent an invasion of their privacy, hurting their manhood's dignity, due to the physical and emotional discomfort of being touched in a site that is not supposed to be accessed by others⁽¹³⁾.

Throughout the exams, informants reported that they started thinking about the possibility of having a serious illness. *Everything I need right now is him (doctor) saying that I have cancer.*

The diagnosis disclosure was remarkable for the informants, causing emotional distress, anxiety and perception of fragility. *He (physician) just said I had to have an urgent surgery. I expected that the bag would be for only two or three months. Now, he said I'm going to have it for life. It was difficult! I'm strong, I don't get down easy with a disease. But it was a shock... a big scare!*

After the diagnosis, the disease has a name - cancer - and the patient suffers a rupture in his life biography; his identity is altered; he is now a patient with cancer. In people's imagination, regardless of gender and social class, the representations of cancer

are of a fatal disease that causes much suffering and leads to severe limitations⁽⁵⁻⁶⁾. From this perspective, men feel vulnerable, fragile, acknowledge they will not correspond to the socially established standards of masculinity, feel marginalized and subjected to the knowledge and practices of the medical model^(8,13).

The distress of having cancer, undergoing surgery and a stoma

The diagnosis disclosure initiates a process of questioning: why have I developed this disease at this moment in my life? Among the different strategies employed, men recalled familiar cancer situations. *A woman younger than me got it in the intestine and had no chance, she's gone; I lost a cousin who had an operation and it came back (the disease).* The conception of fatality was common. *[...] all the time hearing and seeing: look, there's no cure for cancer; it's a tough disease; I thought it had no cure.* With their experiences in the healthcare context, they started to discover the medical causes of the disease and related them with their previous lives, food habits and consumption of alcohol. *I ate too much red meat, sausage. Never liked greens and fruits,* revealing their lack of knowledge about the risks of the disease.

For some, religious beliefs were reported as the cause of *the disease*, from a perspective of a profane life. *I never had anything. He (God) said: let me punish you a little. You have to suffer a little.*

A hard worker's life and exposure to natural phenomena also gave meaning to the disease onset. *I've been a suffering person since my childhood. I think that because of my hard life of cutting cane, riding in overcrowded and substandard work trucks, picking cotton, being exposed to cold, dust.*

It has been shown that there is generalization in the different western social groups, when associations are employed between the diverse elements of human life^(5-6,11). Poor work conditions are highlighted by the informants, consistent with the working class' condition.

After acknowledging the severity of CC, these men agreed to the medical therapies of surgery and colostomy because *life is at risk*. However, the decision to accept the colostomy, whether temporary or permanent, was a moment of distress and indecision. Some accepted it with resignation. *[...] you have to face it, what can you do? I got totally down in the dumps. It was very difficult!* Others initially refused, but ended up consenting. *I got sad, then I accepted it. It happened, so you have to face it and keep going on.*

Knowledge, values and beliefs were reconsidered in the process of giving meaning to the life threat and the need to have the body altered. We understand that this period was marked by the meaning of rupture in the male view of invincibility, causing a rupture with some dogmas related to masculinity and power, marked by images of a strong and resilient body. Thus, male power also echoes in their experience with CC, leading to a process of resignation with the situation, a cultural rationale characteristic of people belonging to the Brazilian working class^(5,11).

Being ready to undergo the treatment is related to life values and how life is presented. In the condition of having CC, readiness is presented from a perspective of hope in the therapeutic results, not necessarily in a cure, but in the interruption of symptoms and the chance of recovering the control of the body and life⁽¹⁴⁾.

Initial reactions when they saw the stoma and finding that they had lost sphincter control were dramatic. *When I woke up and saw that little ostomy bag at my side... Gosh! It was a shock, horrible! It was horrifying to look at a piece of intestine. A piece of me is on the outside...*

The memories of when they saw their body transformed by the colostomy were expressed in crying and with sorrow, showing that men also cry, but this is a private and not public behavior. These emotions were expressed in a sphere of male complicity with the researcher, who, in turn had to respect it.

The body is the existential base of the human being and culture. In common sense, social values attributed to the body are the result of discourse and interest that generate personal and collective attributes to what it means to be a man⁽¹⁵⁾. We believe that the symbolism given to the colostomy models the transformed body, generating conflict due to the loss of the previous life, echoing the hegemonic meanings of masculinity.

Over time, looking at the stoma is not so scary, but the participants acknowledged that its daily care requires changes in several aspects of life and can lead to embarrassing situations. [...] *when I stood up the bag got loose. I had to hurry up to the bathroom and clean it up. The other day I went to a child's birthday and then gas started to come out. Everybody looked at me: eating habits had to change, the frequency I go to the bathroom, clean it up. It's kind of uncomfortable to leave the house, it lets gas loose, makes noises.*

All participants learned how to care for their colostomy. If, at the beginning, they depended on

caregivers, over time all of them acquired confidence in self-care and they were able to overcome this stage. *I cut, wash and put it again all by myself.*

Learning to live with changes in their intestinal system and with a colostomy were processes that demanded internal and external resources that approximate characteristics related to the female gender: sensitivity, care, dependency and fragility⁽¹²⁾.

After overcoming this stage, the search for getting back control of life is a difficult task because they are concerned with sexual activity. *You're less male. You get weaker... Have no desire. I have desire, but with no erection.*

Researchers on sexuality have shown that advanced age and illness do not necessarily automatically imply an end of sexual life. For these men, sexuality is linked to their genitalia, that is, the real and physical activity of the sexual act, which is characteristic of the hegemonic masculinity values held by the working class, regardless of age range⁽⁸⁾.

Another reported difficulty was the impossibility to go back to work, especially among the seven men on sick leave and the two unemployed. *I feel tied up... depending on others. My previous life is over. As a man, I perceive myself as a failure. It's a disappointment. My main concern is to support my family. I still haven't managed to arrange sick pay.*

In the context of the working class, an occupation is a reference for the construction of the masculine identity. It is acknowledged as moral value that sustains the honor of the head of the family and enables men to have personal self-realization^(5,11). Not being able to work due to the disease leads them to financial hardships and dependence, which make them perceive themselves as a burden to the family, a marginalized man.

Magical-religious beliefs, family members and friends form a support network to help them in their uncontrolled life, which creates complicity among all of them, to deal with problems and to find solutions, resulting in perceptions of marginality being kept in the private sphere.

In the context of severe disease, the temporality of life is an important aspect and permits one to resume control. *Now, I'm getting used to it. It's normal, I'm slowly recovering.*

Getting used to the colostomy and feeling normal are images they construct about their altered bodies, which enable them to link past and present⁽¹⁵⁾. Through the image of their transformed body,

individuals project themselves into the social environment, in the expression of emotions and through their social roles. Thus, resuming life within normal standards is a desire they have in order to obtain a sense of control over social standards.

A noteworthy fact in the participants' narratives as they referred to getting back to normal life was the symbolic conception of honor that guided expectations and actions of men at home and in social life, a hegemonic masculinity standard. *Being a man is to be a person who complies with his obligations, in the role of father and husband. Being a landmark at home and at work.*

We understand that these men, who belong to the working class and survived CC with colostomy, put their *life at risk*, imposing new patterns of masculinity such as subordination, complicity and marginalization⁽⁸⁾. Over time, they create expectations of recovering their ideal, dominant and hegemonic position so that they will have the feeling of being reintegrated in the social world.

In analyzing these meanings, we believe that nursing has an essential role in acknowledging male subjectivities of men affected by CC with temporary or permanent colostomy, which are constructed in the sociocultural life. Being attentive to these patients' reactions is necessary when they perceive the same disease or treatment differently with the aim to

preserve their identities. Thus, the need for specific support during care delivery to men imposes a reflective base for professionals to plan their intervention in the process of the rehabilitation of patients with cancer at all levels of health care. In this way, the guidelines of the National Policy of Integral Care to Men's Health in the care of men with CC will be then incorporated.

FINAL CONSIDERATIONS

Aiming to analyze the meanings given to the CC and the ostomy experience among men belonging to the working class through the theoretical framework of medical anthropology, of masculinity and ethnographic method, we found that masculinity patterns become altered, assimilating rules of subordination, complicity and marginalization. However, over time, as they overcome problems, the rules of the hegemonic masculinity predominate again so men can feel they are part of their social group once more.

The analyzed meanings contribute to health professionals' reflections, especially nurses, regarding their support and care delivery to this group of clients with specific needs.

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