

POSTOPERATIVE PERIOD OF OSTOMIZED PATIENTS WITH COLORECTAL CANCER: A COMPREHENSIVE ANALYSIS

Pós-operatório de pacientes com câncer colorretal estomizados: uma análise abrangente
Post operatorio en las personas con cáncer colorrectal estomizadas: un análisis comprensivo

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ABSTRACT: Objective: To understand the feelings of ostomized patients with colorectal cancer. **Methods:** Reports of interview respondents were transcribed and analyzed under the theoretical framework of content analysis in its thematic modality. Patients interviewed were hospitalized in the coloproctology and oncology clinics of a large hospital in Belo Horizonte, Minas Gerais, Brazil. **Results:** Two categories emerged: “coping with and facing feelings related to the stoma” and “influences on the visions of sexuality and marital relationship”. These were then divided into subcategories. **Conclusion:** a change of perspective on the care of these patients is suggested, with focus on training of professionals who deal with them, so they are assisted in an integrated and humanistic way, thus minimizing difficulties faced by both the patient and the health professional.

Keywords: Colostomy. Medical oncology. Resilience, psychological. Sexuality.

RESUMO: Objetivo: Compreender os sentimentos da pessoa colostomizada devido ao câncer colorretal. **Métodos:** Os relatos dos entrevistados foram transcritos e analisados sob o referencial teórico da análise de conteúdo, na sua modalidade temática. Os pacientes entrevistados estavam internados nas clínicas de coloproctologia e oncologia dos ambulatórios de um hospital de grande porte de Belo Horizonte, Minas Gerais. **Resultados:** Emergiram duas categorias: “conviver com sentimentos relacionados ao estoma e enfrentá-los” e “influências nas concepções sobre a vivência da sexualidade e do relacionamento conjugal”, que foram divididas em subcategorias. **Conclusão:** Sugere-se uma mudança de perspectiva quanto ao cuidado dos participantes deste estudo, priorizando a capacitação de profissionais que lidam com essas pessoas, para que sejam assistidas de forma integrada e humanística, minimizando-se as dificuldades enfrentadas pelo paciente e pelos profissionais de saúde.

Palavras-chave: Colostomia. Oncologia. Resiliência psicológica. Sexualidade.

RESUMEN: Objetivo: Comprender los sentimientos de los pacientes de cáncer a convertirse en estomizado. **Métodos:** Los informes de los encuestados fueron transcritos y analizados bajo el análisis de contenido teórico, en su modalidad temática. Los pacientes entrevistados fueron hospitalizados en clínicas de cirugía colorrectal y en clínicas de oncología de un hospital en Belo Horizonte, Minas Gerais, Brasil. **Resultados:** Emergieron dos categorías, “vivir con sensaciones relacionadas con el estoma y hacerles frente” y “influencias de las concepciones de la experiencia de la sexualidad y relación matrimonial”, divididas en subcategorías. **Conclusión:** Se sugiere un cambio de perspectiva en la atención de los participantes en el estudio, dando prioridad a la formación de profesionales que se ocupan de estas personas, que pueden ser asistidos de manera totalmente paga y humanista, reduciendo al mínimo las dificultades sufridas por el paciente y por los profesionales de la salud.

Palabras clave: Colostomía. Oncología médica. Resiliencia psicológica. Sexualidad.

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Received: 20 Apr. 2016 – Approved: 24 June 2016

DOI: 10.5327/Z1414-4425201600020005

INTRODUCTION

Colorectal cancer (CRC) is the third most common type of cancer and the third leading cause of death among men and women in the United States. Almost two thirds of CRC survivors live for around five years after the diagnosis¹. In some of the developed countries, this is the second most common cancer in terms of incidence, and in many parts of the world, incidence and mortality related to this have been increasing².

Many surgical procedures aimed at eliminating cancer can result in intestinal stoma, the two most common being colostomy and ileostomy. Stomata are intended for the disposal of waste and flatus for the external environment, therefore it is known as stoma disposal³.

Being ostomized due to cancer leads to situations that are beyond cultural norms and affects the meanings people give to themselves, the disease, the treatment, and their very existence⁴. The diagnosis of cancer pushes the subject into the disease world and the treatment context; with the stoma, their bodies change along with their existence⁵. The person often starts dealing with two concurrent realities: facing a diagnosis of cancer and, depending on results and procedures related to stoma disposal. Health professionals should consider such issues while planning for their care.

When a person receives the information of the diagnosis and the need of colostomy, it is hard to face and overcome the several changes of the new phase of life, including pre-, trans- and postoperative periods⁶. There are also significant changes in social and familial dynamics. Patients who undergo colostomy often struggle to accept their new condition and become weakened⁷.

The multidisciplinary team of the hospital where this research was conducted, especially psychologists and nurses, realize that cancer patients who undergo colostomy are twice as vulnerable as all others, for they not only face cancer, a stigmatized disease, but also face colostomy as a consequence. This picture is aggravated when colostomy is permanent. Reactions vary from embarrassment, difficulty to verbalize, anxiety, guilt, and decreased self-esteem among others⁸.

Multidisciplinary assistance has rehabilitation as its purpose, which involves comprehensive assessment, taking into account the subjectivity of each person cared for. It is important to note that these patients require social, spiritual, and emotional support in addition to physical care⁹.

The fragile condition of these people demands a more steady support by the professionals involved. However, feelings experienced by a patient who faces colostomy due to cancer are not always recognized by the psychologist or the nurse in daily care, which is considered as the problem of this study. There is the need for a comprehensive approach without losing sight of subjective questions outlined from the onset of the disease and, subsequently, from the event of colostomy.

OBJECTIVE

To try to understand the feelings of patients who had been ostomized owing to CRC.

METHODS

This is a qualitative and exploratory study performed in the facilities of a private hospital of Belo Horizonte, Minas Gerais, Brazil. The institution services patients with several clinical and surgical specialties, including coloproctology, for hospitalization, intensive care, emergency, and outpatient care. People from all age groups are cared for.

The research had a convenience sample. Inclusion criteria were patients aged 18 years or older who had undergone definitive colostomy more than three months before study due to stage III CRC (when cancer affects neighboring lymph nodes, but not other body parts) or stage IV CRC (cancer can be found in a spot that is very distant from its onset site), and who were hospitalized for the treatment of the disease or stoma complications. All of them agreed to participate in the study and signed the informed consent form.

A study population was formed by 18 patients who had undergone colostomy or ileostomy, and the sample held five ostomized patients that met the inclusion criteria.

Data was collected by means of a semi-structured questionnaire, which allowed identifying subjectivity and particularities of different speeches. Three questions directed it:

1. How do you feel about using a stoma, and how do you face this experience?
2. How is the handling of the accessory?
3. Could you talk about your sexual life after being ostomized?

Interviews were conducted by one of the researchers from January 30th to March 2nd 2015 at the Oncology Psychology Unit of the hospital, thus assuring participants' privacy. In order to keep the secrecy, interviews and interviewees were named as E1, E2, E3, E4, and E5.

Few steps of content analysis in thematic modality were followed to analyze the findings, as proposed by Bardin¹⁰. The author recommends breaking up a text in units and categories, according to analogical regroupings. Among different subcategories, investigation by themes is considered effective and fast when it comes to simple and direct speech. The following steps were taken: pre-analysis, content exploring, data handling (inference and interpretation). In pre-analysis the recorded interviews were listened to, then transcribed and re-read.

This workflow allowed initial appropriation of the content, with posterior linking to most relevant matters regarding the study purposes when building the study corpus on the basis of representativeness, homogeneity, and suitability. The second phase was that of operations decomposition, which consists of exhaustive exploring of the material in order to consolidate categories; at this point, patients' speeches had words related to the aspects sought for and were highlighted. In the third and last phase, data was treated, validated, and considered significant or not.

The study project was approved by the Ethics Committee of the hospital, protocol CAAE 234853214.8.0000.5125, report 888.066, on October 29, 2014. It fully complies with Resolution 466/12 by the National Health Council.

RESULTS

Among the five patients of the sample, three were females and two were men. Four were married and one was divorced. Ages varied from 53 to 68 years, with mean age of 59 years. One of the patients was a housekeeper, one was a banker, one was a sewer, one was a psychiatrist, and one was a teacher.

Testimonials that resulted in two categories, "facing" and "sexuality," are below:

[...]I was so afraid; I could only sleep belly up, afraid to turn and something bad happen to the pouch. I was very insecure and would wake up several times every night, concerned. (E5)

I was always embarrassed, because it's something that you don't expect. You get better with time, the bad feeling about the pouch starts vanishing. (E1)

[...] I get impressed, and sad, and rebel against it, because it's out of my control. I had no idea this could ever happen to me. God forbid! [cries]. (E3)

[...] now I'm getting used to it and in fact accepting facts; I'm trying to take a normal life, or the closest possible to normal, being able to turn to both sides to rest. (E5)

Well, actually, I find it hard to handle the pouch, especially to clean it, because it must be done several times a day; my husband learned to handle it and always does the changes for me. (E5)

Change must be done twice a week, but cleanse is every four hours and my wife does that. (E4)

My sister always helps me, poor thing. She is always beside me and supports me whenever I have doubts. (E2)

I used to have a lot of leisure activities, but now I prefer to stay home; after I put the "probe" on, I became a house person; not even to my garage I would go out. (E3)

It makes it so hard to go out and do exercises, I was talking about it to the Doctor. (E7)

I just can't wait to get rid of it (the pouch), so I can return to normal activities. It totally keeps us from going out of our houses. (E5)

I find comfort reading religion magazines, or those addressing healthy habits; I try to do a little of everything. (E3)

For now, I can't work as a seamstress anymore, but, maybe one day I will be able. Nothing is impossible to God. (E3)

I thought this was other-worldly and, of course, I cried a lot. But Doctor told me I would have to use it but one day I could take it off hopefully, and I hold on to this hope. (E3)

Over time, I started going to the Health Unit to get my pouch, I was handling it myself. Sometimes they give you huge pouches, which I don't like because it gets too loose; then the girls started asking for the smaller ones, so I could feel happier. (E3)

We haven't had relations since my surgery. I'm afraid of it, but Doctor told us we could. (E4)

Since I started treatment, I haven't felt sexual desire. (E5)

I don't feel like doing anything, I don't like caresses or kisses. That's terrible, because he is very caring and loving, but I'm not. (E3)

In general it's all the same, nothing has changed. (E4)

Usually once a week. (E4)

There is desire. We kiss, hug and touch each other, but sexual intercourse itself doesn't take place. However, we find a way to finish the act, because it is something you can do. (E5)

Well, I do have desire, and he has desire. He looks for it, but in the end we get afraid. I pity him. (E2)

My husband doesn't care. He is very sweet, he is a good person. Most men would leave their wife right away if something like this happened. (E3)

Our relationship is very harmonious. My husband says he is not the kind of person who will search other women because of this; he understands what I'm going through. (E2)

DISCUSSION

From data analysis, two thematic categories emerged: "facing" and "sexuality."

Category 1: what to face

Intestinal stoma causes several changes in the lives of people, especially when it comes to gastrointestinal physiology, body image, and self-esteem. Providing information and education, multidisciplinary work and etcetera is an important strategy to help and support patients who go through colostomy. These people usually are not prepared to face such a condition. However, although they are not prepared initially, after the process of adaptation they begin to conceive life in a whole new way, particularly when the underlying disease is cancer¹¹.

Most definitive colostomy patients demand the use of a disposal pouch over the stoma to receive the effluent (feces). Those who do not use it benefit from bowel irrigation. This technique requires motor and cognitive ability, and the patient must also meet the indication criteria.

The device (pouch) handling requires emptying, avoiding overfilling, which could result in detachment of the pouch system adhesive, leakage of fecal contents and, in most cases, peristome skin damage. It is therefore crucial that patients or caregivers are clear about when and how to properly empty the collection bag¹².

Living with this device causes conflicting feelings, concerns and difficulties when dealing with this new situation, which is also mentioned in the work conducted in Northeast Brazil⁶, whose authors mention fear, shame and anguish clearly shown by respondents in their speech.

Anger and sadness were also recurring. These feelings were identified in a qualitative study about ostomized people⁴. For the authors, the state of sorrow seems to be inherent to this condition, at least in the initial stages.

Some respondents reported a hard time accepting the ostomy condition initially because of the need to deal with and handle the stoma. Its presence generates visible and significant physical change to their bodies, which causes loss of integrity, dynamism and autonomy, triggering personal and social conflicts, particularly when it comes to relationship with the outside world¹³.

The participation of the family, especially the spouse, in the care process was mentioned positively, suggesting companionship in the daily life of some respondents. The inclusion of other relatives emerged as something relevant in this process. The importance of family and friends in the rehabilitation of colostomy patients is also mentioned in a study on this subject¹⁴. However, according to the authors, it is not always easy to involve the family in the care of

patients, as there may be rejection, fear and disgust at the first contact with the situation.

Quotes about the difficulty in going out of their homes and the preference for home activities were recurrent. Regarding return to work, a research on the evaluation of education programs addressing colostomy showed uncertainty and ignorance as to coping with everyday life on the occasion of return to normal daily activities¹⁵. The authors of the study report that, when in doubt, people mentioned they prefer limiting both their social and labor activities.

Religion was a frequent theme. The belief in God and prayers emerged in some reports. Religiosity, limitations from the illness, and its role in all this are described in a qualitative study⁵ conducted with ostomized people, in which religion appears as a category. The authors discuss patients' weakness and spiritual involvement.

The issue of resilience, present in various reports, can be understood as a standard of adaptation processes in relation to current and accumulated risk throughout life. It covers a variety of psychological resources needed to overcome adversity and interpersonal control when interacting with social support¹⁶. In some statements, the factors that helped them directly or indirectly to add a new meaning to adversity were highlighted: either individual, cultural, and familial skills, or a positive view, including hope and optimism, spirituality and transcendence.

Category 2: sexuality

During interviews, participants showed difficulties in talking about sexuality. It seems that any approach related to the theme is seen by the ostomized patients as embarrassing. Speaking of sexuality in their health context seems to be complex.

Giving up on sexuality was a recurrent finding. It seems to be a natural decision among interviewees that sexual intercourse does not suit their condition.

Physical changes underlying the use of a stoma may affect people's sexual performance and behavior. Difficulties emerge from body changes or physiological dysfunctions following the surgical procedure itself. A man bearing a stoma can present reduction or total lack of sexual desire, decrease or incapacity to erection, and changes in ejaculation patterns. The most common changes among women are reduction or loss of sexual desire, and dyspareunia. Most sexual-related difficulties are psychological, mainly due to embarrassment in

front of one's partner and/or the feeling of dirtiness and repulsion, both resulting in the fear of being rejected¹⁷.

There may also be relationships that were problematic before colostomy¹⁸. In such cases, the process of illness and the change of stoma may favor or even determine distance or interruption of sexual relations under the social claim that a "ill" person must not have sexual relations, which may even be a relief for some. This issue should be addressed while approaching the topic of sexuality with these patients.

On the other hand, the maintenance of sexual life after colostomy was present in some speeches. An integrated review on the sexuality of ostomized patients¹⁹ gathered statements of people who felt no difference in sexuality, as their partners contributed to and participated in the process of adaptation.

A study with 30 women who went through colostomy showed strategies to face sexuality by changing sexual routine and handling the stoma in many ways, that is, emptying the pouch before the act, and covering it with several accessories, including towels, blouses, dresses.

Hiding the pouch is aimed at preventing accidents and putting it out of sight due to repulsion of one's partner or oneself, once there is a cultural repulsion to feces and this is totally contrary to the moment of excitement and desire. These techniques altogether characterize the ability to adapt and the creativity of these patients, but also reflect delicacy and sense of esthetics, once their body is reconfigured to sexuality²⁰.

Sexuality is beyond physiological need and is strictly related to desire. It is not limited to the genitalia, as it also involves emotions and trespasses physical definitions, becoming a more diffuse act that is present in all moments of life, and bears complex multifaceted meanings, besides holding a heavy claim of subjectivity¹⁸.

However, some participants related sexuality only to sexual act itself when referring to intimacy of the couple. Sexuality vs. genitality is addressed in a psychoanalytic article on human sexuality²¹. The author states that a purely medical view reduces sexuality to sexual intercourse only, putting it in the frame of biological units and ignoring the difference between them. He also reports that the body addressed by psychoanalysis is not biological only; it is erogenous and touched by language, and a part of cultural speeches.

Some statements suggest companionship. This is part of any individual's life and is influenced by several factors contributing to well-being. In order to face the new situation, one must also face physical and psychological changes so the routines can be resumed by the couple¹⁹.

Health professionals guide their care by aspects related to diagnosis and biomedical treatment only, that is, by the disease and the cure. More subjective aspects such as sexuality are not valued, which gives the false impression it is not part of human health²².

This study made it possible to reveal the feelings of people who went through colostomy owing to cancer, and we consider it necessary to reveal the limitations as to the specific characteristics of the participants, as well as people with stage III and IV cancer, and their realities. Another limitation of the study was being restricted to a single service unit. Therefore, results should not be generalized, and it is believed that they should be further analyzed in order to support assistance measures for this audience. Thus, it is expected that this research will encourage new questions that can increase the range of knowledge about the theme.

FINAL CONSIDERATIONS

Different forms of adaptation to the same situation were found in this study, and even though the condition addressed here were reported as something that is difficult to overcome, some key features that served as protection for some patients emerged.

This study brought more information about the subject and unveiled ways in which the ostomized patients face their condition. Also, relevant feelings and reactions were brought to light and added to the context of cancer diagnosis, dealing with stoma and care of people, and they are all very important for the planning and development of care programs aimed at this audience.

Results allow reiterating that the process of overcoming a cancer and adapting to the use of a stoma is complex and full of subjectivities and difficulties, where interaction with family, friends, and health professionals may help these people regain self-esteem.

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