

# Chapter 202

## Being a male caregiver for a wife with a colorectal cancer ostomy: Challenges and possibilities

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### **ABSTRACT**

**Objective:** Recognize the men's care livings of the wife with an ostoma by colorectal cancer (CCR). **Method:** This is an exploratory study, descriptive, qualitative, in which the wholeness care consisted of the theoretical axis, with the interview conducted by the question: "Say how is it for you to care for your wife/partner with an intestinal stoma." The database was analyzed under the theoretical reference proposed through the analysis of content inductive. **Results:** Four men participated in this study. From the testimonies, were created two categories: "The approach of the man to care" and "Living on how we can". In the first, on the illness of the woman, the spouse takes many functions, from the finances to the hedge of familiar attention, between the children, to fit on woman's needs. On the second, we learned how hard is for men to accept the role of the spouse with an ostomy from a cancer caregiver. **Conclusion:** We learned that are a lot of challenges founds by the men caregivers of a spouse with an intestinal stoma by the CCR. The support provided by the men is very important and opens a window of possibilities to the coping and treatments of a woman with CCR.

**Keywords:** Nursing, Ostomy, Colorectal Neoplasms, Caregivers

## **1 INTRODUCTION**

Projections made by the National Cancer Institute (1) point to 32,600 new cases of colorectal cancer (CRC) in Brazil in the 2014-2015 biennium, with 15,070 in men and 17,530 in women.

The CCR therapies are surgery followed or not by radiotherapy and/or chemotherapy, according to the location of the tumor and its stage, and the construction of an ostomy (2).

The term ostomy has a Greek origin and indicates the exteriorization of part of a hollow viscera, such as the intestine, through a surgical procedure that results in a hole in the abdomen for the drainage of feces and requires the continuous use of a collection device (3).

The literature points out that the person who experiences the construction of an intestinal ostomy can change their physical, psychological, social, and spiritual dimensions. The change in intestinal transit with the elimination of feces (effluents) through the abdomen and the use of collection equipment requires care with the abdominal skin; with the exchange and adaptation to the collector equipment; in the handling of the effluents that until then were eliminated through the anus. The person becomes afraid of making noise due to the involuntary elimination of intestinal gas; of detaching the collection equipment that will result in the effluent leaking into their clothes and of presenting themselves with an altered body image before society. Therefore, they may experience home confinement; problems with working, sexual and marital life, which impacts the reduction of their quality of life (4-6).

Faced with the reality presented, the person with an ostomy needs the support of the health team, especially nursing and a family caregiver to cope with the new condition. The role of women as caregivers has always been predominant in Brazilian culture, in which, historically, the care of children and household chores were attributed to them, while work and financial administration of the family were the responsibility of men, since they had by cultural determination, the function of providing the necessary resources to the family (7).

Care is essentially performed by women, while men have the role of providing the necessary resources for this (8). But, this reality began to change, as the gradual insertion of women in the labor market favored the change of social roles, establishing the role of caregiver for the partner as well (9).

In the literature, it is common to find studies that describe caregivers of children undergoing cancer treatment, elderly people with senile dementia, Alzheimer's, or other conditions that comprise these stages of life. However, the man in the role of caregiver, as a spouse, has not been the main focus of studies carried out by nurses in recent years, which reinforces the need for research in this field by the academic community.

Nursing, as a social practice committed to caring for human beings, should prioritize the person with a stoma and their caregiver, valuing their singularities, which is in line with the references of comprehensive care and not just worrying about technical issues such as the skincare training and exchange of collection equipment. Although culturally women have assumed the role of caregiver, in our clinical practice we have noticed that men have been assuming this role, facing challenges and finding possibilities, which requires support from health professionals to deal with the situation. Therefore, with this study, we sought to know the experiences of the man who cares for a woman with an intestinal ostomy due to CRC.

## **2 METHOD**

This is a qualitative, exploratory, descriptive study, in which comprehensiveness was the theoretical axis, developed from August 2014 to May 2015.

The records of the wives were obtained from a High Complexity Oncology Care Unit (Unacon) of a philanthropic hospital in Minas Gerais, Brazil. According to the survey, 30 women with intestinal ostomy

due to CRC were registered. When we started the visits to schedule the data collection, we found that of the 30, 11 were widows, 12 had no husband/partner, and 3 spouses refused to participate in the study. Thus, four male caregivers of a wife with an intestinal ostomy due to CRC who agreed to participate in the research were part of this research.

The following inclusion criteria were adopted: being over 18 years old, spouse who cares for a woman with a stoma and diagnosed with CRC registered at a Unacon; being a resident of this municipality; having good communication, and willingness to answer questions.

For data collection, carried out from March to May 2015 and at the participants' homes, an instrument was used containing sociodemographic characteristics and serial interviews, recorded in MP4, after permission, with the following guiding question: What is it like for you to care of his wife/partner with an intestinal ostomy. The data collected by the authors were immediately transcribed and analyzed in the light of the proposed theoretical framework, through inductive content analysis, which consists of valuing, understanding, and interpreting the data, to integrate them with the theoretical knowledge obtained. Thus, they were ordered, classified, and analyzed by the steps suggested by Minayo (10).

The project was assessed and approved by the Ethics Committee in Research on Human Beings of the Federal University of Alfenas UNIFAL-MG, under opinion number 975.773. Participants signed the Informed Consent Form, one copy is with the researchers and the other with each participant.

### **3 RESULTS AND DISCUSSION**

The study included four male caregivers of a wife with an intestinal ostomy due to CRC, aged between 26 and 59 years; the predominant level of education was incomplete primary education. Family income between two and three minimum wages (75%), two were retired, one engaged in paid activities and one was unemployed. Marriage time ranged from 8 to 37 years. As for religion, all participants declared themselves to be Catholics.

From the analysis of the testimonies, the categories that will be discussed below emerged:

#### **3.1 MAN'S APPROACH TO CARE**

In our Western culture, the man is responsible for work, financial resources, and activities that demand strength and confidence, while the woman, delicate and fragile, plays the role of home and family caretaker (11). The approach of men to care can be seen in the statements below:

[...] I take the bag, I take it to her, if the bag bursts, I take the towel or something, but directly like that, change it anyway, do something like that I never did (E1).

[...] I do not deal with that. She does it, and moves everything she needs, right? I don't even know what is right, I was looking for it, but I don't know how to use it. You were looking for one exam or another, right? Whatever you needed, bag and such... but it didn't move (E2).

We found in the testimonies, certain fears on the part of the caregivers about the handling of the ostomy and the collection equipment. These fears can be attributed to the change in body image, the change in the transit of feces, which are now eliminated through the abdomen, the odor, and the need to deal directly with the feces, which can represent an invasion of privacy.

We learned that men are affected by feelings of estrangement and lack of knowledge about the ostomy and the handling of the collection equipment, which can corroborate the difficulties with direct handling, which can be seen in the following statements:

[...] I'm very impressed too, you know? If I need help, I help, but she always avoids me because she knows I'm impressed. I get restless and too thoughtful. (...) it gives me shock to see (E3).

[...] I didn't even know there was this kind of thing. This surgery, right? This change in the rectum and such. I wasn't aware of anything. Didn't know (E1).

Faced with the difficulties presented by the spouse in their role as caregiver, it is up to Nursing to have a different look to raise needs, develop acceptance, and listening skills and propose appropriate interventions, constituting support in the face of adversity (12).

However, the new condition and position in the family occupied by husbands/partners who are caregivers often have to be reconciled with skills such as cooking, taking care of the house and children, and activities that were culturally performed by women and unknown to them (13).

[...] It's just that I had to divide myself, between my job, my daughters, and her, because she can no longer correspond to everything my daughters want, you know? (...) I do my jobs, I do my own thing, I work, and on the weekends I still work with sound, so I have less time with them (E3).

Faced with the wife's illness, the spouse assumes various functions, from the economic sphere to the division of attention between the children, to adapt to the wife's needs. Such situations can result in an emotional overload for the male caregiver since he has to unfold his circle's individual experiences and those in common with the couple.

### 3.2 TAKING LIFE BY LEAPS AND BOUNDS

We found that dealing with the condition of being the spouse of a woman with an intestinal ostomy due to CRC is not an easy task. They seek support through different strategies to continue life, even if it is in fits and starts:

[...] Marriage, at least for me [...] is a serious thing, you know? I got married when I was 26 to 27 years old and I think marriage is for the rest of your life. You chose someone to be with, right? It's for life. Even if it's in fits and starts, it's for a lifetime (E1).

Spirituality is one of the strategies used by men as a source of support and comfort.

[...] Without God we can't do it, right? Without Him, we can't do anything [...] we see cases around that when the guy finds out, the person finds out that his wife has cancer... I know many cases. The guy separated from the woman, left, left her alone [...] (E2).

[...] We are Catholic, even her mother is very religious and everything. So it turns out that God is very present, it helps to think that He is looking at us because she went through many difficulties. Mainly in the second surgery, she had to put the bag back on (E3).

The statements above corroborate the statement by Guerrero et. al. (14) that “faith in God is a feeling rooted in our culture and is as necessary as other ways of coping”.

Another strategy used by spouses as support is family life so that they can feel safe, and share their fears and anxieties in the face of falling ill with cancer.

In this sense, family support is of paramount importance for the adaptive process, which must also be supported by a multidisciplinary team (15) with nurses as the main articulator in the team (16).

[...] [she] was depressed, and she was hospitalized for more than a month at the hospital. I went there too much, my boys too, we didn't leave her alone! My daughter-in-law also supported her, she works there (at the hospital), and she stayed there a lot. But I was always on her side, helping with whatever she needed (E2).

Concerning the marital relationship, we also noticed, in general, unconditional support from the spouse concerning the new condition of the partner, which can even generate transformations in the couple's life and help in the development of strategies that motivate the person to live more healthy and autonomous (17).

Experiencing situations of chronic illness such as cancer and the construction of an ostomy in the wife can lead the spouse to rethink her life and values, as evidenced in the following statement:

[...] I demanded a lot from her, you know? Then, after the aggravating factor, I started to understand her side more, and then, well... I 'came to my senses', right? That we must be fragile in certain things, not only in the disease but in general [...] (E3).

We noticed that stable bonds remain even in the face of the partner's illness, while fragile ones tend to break down:

[...] our feeling itself has not changed at all. We only let go when we go to the cemetery, it's 'loco'! Our feeling since he 'married' remains the same [...] (E2).

[...] We are always together, supporting each other (...). We still like each other the way we used to be (...) I don't think you can let it go or just because she got sick I'll forget. No, it's not like that. We're still together, we're still supporting each other, right? [...] (E1)

Molina and Marconi (18) describe that previously shaken relationships can lead to family breakdown, including experiencing setbacks, such as marital betrayal by the husband and separation, while others, in the face of adversity, reach greater maturity, through dialogue and trust.

On the other hand, there was the identification of negative feelings on the part of the spouse:

[...] She and I don't have anything anymore, I don't even have much to do with her [...] (E4).

We also noticed changes regarding the couple's sexuality:

[...] Well, in the relationship... like... intimacy... sex at least, we don't have it anymore. Since she had the surgery. But we are always together, one supporting the other and that's not why I'm going to let it go, forget or abandon it. It has nothing to do with (E1).

Women affected by CRC and who have the construction of an ostomy as therapy may have their sexuality compromised by the distortion of self-image, in addition to factors inherent to the treatment itself, such as pain, fatigue, decreased libido, and emotional and physical stress (19). Nursing must act in the sexual rehabilitation of the couple, whose wife underwent an ostomy, recognizing the sexual partner as a support, and working on the difficulties encountered in this process (20-21).

Rehabilitation involves not only the sexual dimension, but, above all, the biological, psychological, social, and spiritual dimension, in which Nursing, together with the multidisciplinary team, performs actions for comprehensive care (17).

Of the four spouse caregivers in this study, only one reported having received guidance on the partner's condition, ostomy care, and collection equipment. Such statements are evidenced in the following testimonies:

[...] the people there commented... She explained everything and how it works [...] What happened to her was cancer, right? Bowel cancer, she was very depressed, right? That's why she put it... this [ostomy] (E2).

On the other hand, there were situations in which the lack of guidance and support was perceived by the study participants:

[...] I did not receive any guidance. I, as her husband, did not receive any no. Including herself to start with the bag. She had no practice, it was a learning experience. She learned on her own. Today it's two minutes she does this work there, and nobody taught her anything (E1).

B Bevans and Sternberg (22) point out that the treatment of the person with cancer should also be extended to the caregiver, using multidisciplinary in favor of the peculiar perceptions that correspond to its varied dimensions. In most cases, they remain full-time beside the sick person and participate in care both at the hospital and at home, constituting a fundamental link for providing information to the health team about the patient's situation (23).

We learned from the testimonies how difficult it is for these men to assume the role of caregiver of a wife with a cancer ostomy. The imposed situation requires another way of seeing the world and an approach with care.



## 4 CONCLUSION

The investigation of the man's experiences as a caregiver of a wife with an intestinal ostomy due to CRC allowed us to know a little more about his fears, insecurities, and approach to care.

The care promoted by the man was limited to indirect handlings such as searching for bags, monitoring and scheduling consultations and exams, with the exchange of equipment and dressings with the woman remaining.

However, the affection was notable and had a positive impact on the rehabilitation process of the wife with an intestinal ostomy due to CRC. The spouses refer to the changes that occurred after the cancer diagnosis and after the surgical intervention to establish the ostomy, as being positively significant in the couple's relationship. In the face of adversity, the spouses felt stronger in their marriage. On the other hand, we also apprehend that the treatment and care demanded by the woman with an ostomy can destabilize the marital situation. We reiterate the gaps in knowledge by the academic community about care for the husband/partner caregiver of a woman with cancer and intestinal ostomy due to CRC.

Knowing and providing guidance on care for people with an ostomy is essential for planning nursing care. Attention to the spouse should be reinforced from the preoperative period to monitoring the daily adaptation at home, in planned and multidisciplinary actions in basic health care, to comprehensive care.

We emphasize the importance of training future health professionals to care for women with an intestinal ostomy due to CRC, considering the inclusion of the husband/partner as an element in the rehabilitation process.

Developing this study allowed us to reflect on the need to include men in care. We learned that there are countless challenges faced by caregivers of a wife with an intestinal ostomy due to CRC. Support is fundamental and opens up possibilities for women to be able to face the diagnosis of CRC, and its treatments, among them, the making of an ostomy, reflecting positively on the quality of life of these people. Limitations of this study include the small number of participants and the fact that it evaluated the role of caregivers only in situations of colorectal cancer.

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