



THE REPERCUSSION OF THE COLORECTAL CANCER DIAGNOSIS FOR THE PERSON AND HIS/HER FAMILY¹

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ABSTRACT

Objective: to understand the repercussions of the colorectal cancer diagnosis in the experience of illness of the person and his/her family. **Method:** qualitative research developed from May to July 2017, with people with colorectal cancer and their relatives, totaling 23 participants, through in-depth interviewing. Data were organized and coded in the WebQDA® software and thematic analysis was performed. **Results:** three themes were organized: Colorectal cancer: repercussion of the diagnosis from the perspective of the person and family, where the relative most expressed suffering faced with the diagnosis; Previous experience and knowledge as a way to face the repercussion of the CRC diagnosis, highlighting the resilience capacity collaborating in coping; Colorectal cancer marked on body and mind, body marked by the stoma and mind by the fear of recurrence. **Conclusion:** it was possible to understand that the cancer diagnosis entails repercussions and is shared among family members, characterizing the experience as a collective event.

Keywords: Colorectal Neoplasms. Family. Nursing. Qualitative Research.

INTRODUCTION

Colorectal cancer (CRC) encompasses tumors that affect the large intestine and rectum and, according to the Brazilian estimate for the 2020-2022 triennium, there are a projection of 20,520 cases in men and 20,470 in women. In most cases, these tumors start from polyps and benign lesions, in addition to the disease being considered treatable and curable when detected early and without signs of metastases⁽¹⁾.

Nevertheless, the experience of cancer has biopsychosocial repercussions on the person's life, being a distressing and painful moment, permeated by feelings of anxiety, doubt, sadness, fear and eminence of death⁽²⁾. In addition, it is a period marked by challenges that influence social relationships and may cause limitations in productive and work capacity, thus entailing the

need to adapt to a new lifestyle⁽³⁾.

Faced with these situations where CRC results in the need to make a stoma, another important repercussion is related to the transformation of the body, which may compromise self-image, which, in some people, may cause depressive symptoms, anxiety and social isolation, given the shame that they feel due to their condition. In this context, the disease interferes not only in physical health, but also in psychological health, besides requiring this person to cultivate autonomy and self-care, as well as support from the health service and family^(4,5).

Accordingly, the nurses' knowledge enables the development of intervention strategies that minimize the stigmas and disorders arising from illness due to cancer and the construction of the stoma⁽⁵⁾. Moreover, it is important that health

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professionals allow a clear and objective dialogue with patients and their relatives. It is understood that the family is a network of complex socio-affective relationships that intertwine people's lives, a concept that goes beyond the condition of consanguinity or sharing of the living space⁽⁶⁾.

To that end, the nursing team and other health professionals need to expand their knowledge about stomas and CRC, in order to provide guidance on the care that the patient should adopt, in a comprehensive way, thus allowing him/her to clarify his/her doubts, as well as expressing his/her feelings⁽⁷⁾. In light of the foregoing, the nursing team needs to deal with the suffering and anguish of the person with cancer and their family, since the treatment can cause fear, pain, mutilations and deformities, besides compromising self-image and self-esteem, requiring them to articulate their actions to serve these patients in a humanized and qualified way⁽⁸⁾.

Faced with this issue, it is believed that understanding the experience of the repercussion of the CRC diagnosis by people and their families will significantly contribute to the promotion of a less technical care practice and with more dialogue, thus sensitizing nursing professionals about the need for a type of health care that respects the social and cultural reality of those involved. Moreover, it is noted a limited number of studies on the experience of people with CRC and family, especially with regard to the subjectivity that involves the illness process.

Such aspects justify the relevance of this study, which had the following research question: what is the repercussion of the CRC diagnosis for the person and their family? In addition, it was intended to understand the repercussion of the CRC diagnosis on the experience of illness of the person and his/her family.

METHOD

This is a qualitative research with an anthropological and theoretical framework, developed from May to July 2017, where part of the results of a Doctoral Thesis will be introduced⁽⁹⁾. It was developed between the months of May and July 2017. Its development

took place in two scenarios: the Aid Program for Stomized and Incontinent People (PAEI, as per its Portuguese acronym) of the Municipal Health Secretariat, in a municipality in the State of Rio Grande do Sul, Brazil, and the participants' homes.

The approach with the participants took place at the PAEI service, since they went there to consult or search for the material (stoma bags and adjuvants). At that moment, they were invited and, if they accepted, interviews were scheduled at home. However, in order to expand the insertion of participants, some invitations were made via telephone, and these contacts were obtained through the medical records of the patients enrolled in the service in question. Only one person refused the invitation made face-to-face; and, of the invitations made via telephone, there were five refusals.

Thus, 23 people took part in the study, being 11 people with CRC and 12 family members. The inclusion criteria were: person diagnosed with colorectal cancer and served by PAEI for at least one year (diagnosis as of May 2016), where it was decided to select people with up to one year of diagnosis in order to ensure that they had recent memory of the period of illness; family member indicated by the person who had colorectal cancer served by PAEI; being aware of the cancer diagnosis and its health condition; being over 18 years old; and, finally, be appointed by the service nurse. Accordingly, as exclusion criteria, participants who had some communication limitation, which could be due to some health problem, or even due to the advance of the cancer itself, were not eligible. It is also noteworthy that the indication of the nurse working in the aforementioned program was important due to the professional's previous knowledge about the patients' clinical history and due to the fact of ensuring promptness in the collection process. Theoretical saturation criterion was used, which happened due to the cessation of inclusion of new participants due to the repetition of information or because there was little relevant information⁽¹⁰⁾.

It is important to note that all participants signed a Free and Informed Consent Form, in two copies, and were informed about the research, the objectives, as well as possible

risks and benefits. Moreover, they were identified by fictitious names chosen by them, plus their age. If the participant was a relative, his/her position in relation to the participant with CRC was also specified, for example: (Jeremias, 61 years old; Márcia, Luciano's wife, 29 years old).

Thus, the questions that guided the in-depth interviewing technique were: Could you tell us about your illness from the beginning? What did you do to take care of your health before and after having the disease? Could you tell me about your life with the stoma? How was your participation in health care, as a family member? The questions were used to start the interview and, as needed, other questions were asked in order to know the breadth of the phenomenon.

Accordingly, the interviews lasted 2 hours and 22 minutes, the longest, and 40 minutes, the shortest, with at least two meetings/interviews with each participant. All information collected was recorded on digital media and transcribed in full in Microsoft Word® document. After transcription, the data were organized in the WebQDA® software, which allows the organization and coding of the collected data. WebQDA® is an analytical software that allows, effectively and quickly, to code, control, filter and create categories through a systematic method, with analytical transparency, which can be used for texts, videos, audios and images ⁽¹¹⁾.

It should be underlined that, during the execution of this study, the ethical precepts defined by Resolution nº 466/12 of the National Health Council (CNS, as per its Portuguese acronym), which regulates research involving human beings in force in Brazil, and Resolution nº 510/2016 of CNS, which specifically addresses social and human research, using qualitative methodologies, were respected. Thus, the study was approved by the Research Ethics Committee, under protocol number 2.063.328.

Concerning the data analysis, it was performed using Thematic Analysis ⁽¹²⁾, through the following steps: 1st step, Familiarization with the data (the transcribed material was read and re-read); 2nd step, Generation of Initial Codes (initial coding performed in the

WebQDA® software); 3rd step, Search for themes (using coded and grouped data, the search for themes started); 4th step, Review of the themes (they were refined); 5th step, Definition and naming of the themes (clear definitions and names for each theme were established); and 6th step, Final analysis report (from the set of themes, the final analysis report was prepared). Thus, with the analysis, three themes were established, which will be introduced in the results and discussions.

RESULTS AND DISCUSSIONS

Of the 11 people with CRC, eight were men and three were women, and they were aged from 31 to 82 years old. Concerning the family members, 10 were women and one man, aged from 21 to 77 years old. Of the men with CRC, most indicated the wife as a family member, while two indicated the daughter and one the sister. Of the women, two indicated their daughters and one the husband.

Regarding the location of the tumor in the participants, four had rectal neoplasia, three in the sigmoid colon, two in the rectosigmoid colon, one in the descending colon and one tumor colonic obstruction. Only one of the participants was ileostomized, the rest were colostomized. All participants with CRC underwent surgery as a form of treatment, with 10 still undergoing chemotherapy and six undergoing radiotherapy. Only one of the participants did not undergo neo-adjuvant treatment.

Three themes were prepared based on the data analysis, namely: Colorectal cancer: repercussion of the diagnosis from the perspective of the person and family; Previous experience and knowledge as a way to face the repercussion of the CRC diagnosis; Colorectal cancer marked on body and mind, which will be introduced below.

Colorectal cancer: repercussion of the diagnosis from the perspective of the person and family

The experience with CRC from the moment of its discovery causes a significant repercussion, which may be associated with

suffering, fear of death, shock, fright, dread, above all, because it is not something expected, due to the fact that the person is apparently healthy. With regard to these feelings, the study participants refer:

It was awful; I didn't expect it, because he was always a very strong man, very healthy [...]. And I'm sad because I'm afraid that he will pass away. He may suffer to die (**Gelci, Mário's wife, 77 years old**).

It was gruesome for me; it was a really big shock. I lost four kilos from one week to another. I thought of many things [...] he had to use these little bags, which was a terror there (**Pafúncia, Jeremias' wife, 63 years old**).

It's shocking! You never wait for it to happen in your family. (Aline, Vitória's daughter, 21 years old).

Here, at home, everyone got scared, it was a shock, it brought me bad things (cancer), but it fell on them (**Luciano, 34 years old**).

Sometimes, it feels like I'm not even cancerous. The body is sick; but, in my mind, I don't feel like that, you know, I don't have that thing [...] I'm down, cancerous, I'm going to die, there are people who're like that, depressed. Nonetheless, I don't! (**Jeremias, 61 years old**).

It is clear that, for the study participants, the CRC diagnosis was difficult, while they declare the repercussion of the discovery of the disease as a moment of dread, shocking, unexpected, which causes feelings of helplessness, fear of death and suffering.

In addition, it was observed that, in view of the complexity of living with the CRC, it was the family members, in this study, who more clearly expressed the repercussion of the news of the diagnosis of the disease, since, while the person with cancer shows resignation, it is the family that highlights the fear of losing its loved one.

Receiving the cancer diagnosis can be considered a difficult time for the person with the disease and their family, since it encompasses several negative feelings such as insecurity, powerlessness, sadness, vulnerability, fear, among others, due to the stigma of cancer being a painful and incurable disease⁽¹³⁻¹⁴⁾.

CRC does not generate suffering only in those who are sick, as the family demonstrates the repercussions of the illness experience

together. Moreover, in addition to the devastating CRC diagnosis, the need for care with a stoma may also be frightening, which was emphasized in the statement of Pafúncia, Jeremias' wife.

Living with a stoma initially can be difficult and cause fear, especially when it is unknown to the sick person and their family members. In this context, the family nucleus becomes crucial as a source of support in the adaptation of the stomized person, both to assist in the care of the stoma itself and to provide emotional support⁽¹⁵⁻¹⁶⁾.

As for the CRC repercussions and the accomplishment of work activities, the study participants declared:

I worked a lot. All possible times [...] not to be able to work anymore, which I liked a lot [...] sometimes, sadness comes to hit me, but what can I do? [...] We feel really useless (**Gabriel, 36 years old**).

When I get into the garage and remember I did something that I don't do today, I used to move it all around, remove a tire, do it and and make the things happen, but not now! [...] it's not the same anymore; when I deal with heavy things, I think and stop: I can't! (**Luciano, 34 years old**).

Now, I'm limited. I was always dragging one thing to one side, another thing to another, carrying weight. Now, I can't (he works at a bakery) (**Márcio, 31 years old**).

People with CRC also described the limitations arising from the disease in relation to work activities and how much this fact negatively influences the experience of illness. This rupture makes them feel even sicker, and sometimes useless. It is inferred that, for men who are at the peak of the production process, this disruption is more clear with regard to the workforce, especially the physical aspect, which may represent their vulnerability to society.

The negative repercussions emphasized due to the impossibility of work may be related to the understanding of the male gender. Moreover, in a study also with men with cancer, it was possible to show that, although there was acceptance of the disease, they understood the existence of limitations, especially physical ones, which entail the need to quit their work activities⁽¹⁷⁾.

Regarding the fear of loss, the patient's family may develop an excessive concern,

checking for the presence of breathing while the relative with cancer is asleep, according to the participant below.

That's something stronger than us, sometimes he's sleeping at night, I put my hand on him to see if he's breathing {laughs} (**Márcia, Luciano's wife, 29 years old**).

Fear of death is frequent in the CRC context. Although the participant was in a good mood to report the experience of care, tensions permeate the family's life, while, in this case, this woman feels the need to stay awake and monitor her husband's breathing during sleep. The family suffers together with the sick person, for different reasons, such as pain, the suffering of the other, fear and uncertainty of cure. However, the family member usually walks alongside and collaborates in the fight against cancer and treatment⁽¹⁸⁾.

Receiving the cancer diagnosis, especially CRC, may lead to double suffering, since the patient suffers from a stigmatized disease and also from the fact that he/she needs a bag of feces adhered to the abdomen. However, this study revealed that the family members were the ones that most showed their feelings through the illness, while the sick people highlighted the ability to cope with it.

Previous experience and knowledge as a way to face the repercussion of the CRC diagnosis

Having some previous experience of illness may facilitate acceptance of the new health condition of your family member. About this matter, the study participants point out:

I don't know if it's for life, what I have been through (lost a son with a rare disease) with these heavier things, then I am more used to deal with it. Therefore, his case is the same thing, he has cancer, I can also have it, what would we do? If he's here, I must live with him, try to progress, try to live and try to heal and move on (**Mariângela, Hugo's daughter, 50 years old**).

Look! For me, it was not so scary because I already had it, I had cancer in the eye. Maybe, if I hadn't faced it, I would have been more scared [...]. I had to accept my problem [...] I thought it was already in course, let's treat it and it did (**Maria, João's wife, 57 years old**).

The acceptance of the illness of your relative can be facilitated for those who have already

experienced similar and painful situations in life, making the experience to be faced in a less stressful way, thus collaborating for the recovery of the sick person.

People who face similar situations in life, such as having experienced cancer, may become a reference for family, friends and acquaintances, especially for the way in which they deal with problems. Knowing about positive experiences about the health problem faced may also be a hopeful way of experiencing cancer⁽¹⁹⁾.

A study involving women with breast cancer who were undergoing chemotherapy showed that they needed to face the disease and seek a cure. Facing previous experiences of suffering may strengthen people to overcome the setbacks and continue their lives, while positive experiences may help in coping with cancer⁽²⁰⁾.

Being aware of the evolution process of the disease, the problems that are going on and the fact that it can explain to people what is happening to their organisms, demonstrates awareness and realism about the illness of cancer, according to the following informant's statement:

We have a diverticulum; when it is inflamed, it is diverticulitis [...] And the polyp, which is the worst one, my tumor is the result of it. [...] mine was the one who advances, invader, because there are some that are calmer, mine was invader, that is, it would grow up quickly (**Mário, 82 years old**).

Understanding the information provided by health professionals demonstrates how much people are able to understand the illness process. It is understood that knowing the disease is necessary, as the person, having clarity about what he/she is experiencing, can express his/her feelings. To that end, it is believed that it is important for professionals to make sure what is being understood by the person and his/her family, in order to help them assimilate what is happening with their health and, consequently, understand the evolution of the disease and the importance of treatment.

For the person with cancer, the relevance of communication is uncontentious, while it is from there that there is the possibility of promoting comfort, relieving symptoms and minimizing anxieties in the search for a balance in the face

of the illness process ⁽²⁾.

Analyzing that cancer is a possible disease to be faced may also be considered a positive experience of the person with the disease, as pointed out by the following informants:

There's no use hiding, then I decided to face it and do the treatment. (**Antônio, 54 years old**).

Since the first time, the doctor told me that I was sick, I faced it very naturally. There are people who don't even like to speak the word cancer. I don't behave like them! I was very different [...] And every time they said me: "See, it moved to such a region" (referring to cancer), come on, there is so much life waiting for me (**Vitória, 53 years old**).

Facing the disease in a more pleasant way, feeling able to cope with the problem through the possibilities of treatment may be an important way to minimize the repercussion that the diagnosis causes. The fact of feeling capable of coping with the disease is permeated with individual and subjective elements, regardless of the fact that each person deals with this condition in a different way. It requires strength and resilience to face this illness experience.

Resilience consists of the person's ability to act positively in adverse conditions, and thus resignify difficult situations, in order to evolve with the experience. For the person with cancer to face the adversities of becoming ill, the family, spirituality, the will to live, the knowledge about the disease and the very treatment are important factors ⁽²¹⁾.

Moreover, the experience with cancer may represent a duality of feelings. Faced with the negative aspects arising from the diagnosis and, after the initial shock, people start to become positive and their feelings are replaced with hope, faith and optimism, thus reducing the feelings of uncertainty and fear of death ⁽¹⁴⁾.

The study participants are hopeful in their treatment, emphasizing the importance of life, regardless of the CRC diagnosis. In this sense, being aware of what is happening with your body or having already faced a serious problem can help you cope with the disease in a more positive and resilient way.

Colorectal cancer marked on body and mind

The stereotype of cancer is represented by the

physical changes that the disease causes in sick people, with loss of hair or deformity of the abdomen being the most striking points, according to the participants, as described in the statements below:

Before the surgery, the doctor asked where I wore the pants and then took a pen and made an arrow like that and a circle in my belly and said: "Your bag will stay here" [...]. It was very hurt. It was the same thing as having marked an ox, a horse! (**Gabriel, 36 years old**).

But also, she gets there and says: "You're going to have to get bald". What did you mean? [...] I have cancer! (**Sara, Cleusa's daughter, 38 years old**).

The suffering that the disease causes seems to have no end, regardless of knowing the need for treatment, as well as needing to face the illness and fighting for life, many obstacles seem to be experienced along this path, including the fact of feeling marked by the disease and the stoma.

The metaphors used to describe the experience of cancer are directly associated with difficult situations, the stigma that the disease represents, a marked body, without hair or with a bag of feces in the abdomen, in short, characteristics that nobody wants.

Cancer transforms the person's life and also brings marks to the body, which is due to the pathology and the treatment itself ⁽²²⁾. With regard to the stoma, it requires adaptations in the life of the stomized person, in order to deal with the possible limitations that it causes ⁽²³⁾. Changes in body image are highlighted by people with stomas, where shame of their own bodies becomes part of the experience, in addition to feeling deprived of beauty and mutilated, associated with dissatisfaction with restrictions on several aspects of daily life ⁽²⁴⁾.

The repercussion of cancer may also mark the person's mind with the disease due to the constant concern of recurrence or the uncertainty of cure. This is observed in the informant's speech below:

This is hard, as this disease is terrible. Thank God I went through that stage; now, I don't know if there's something more, but it can! I've always been realistic for life (**Mário, 82 years old**).

In any type of cancer, it is possible to have a recurrence of the disease, including CRC, which

causes suffering and torments the person's life, being a shadow that hangs over those who have had the experience of cancer.

The fear of recurrence is part of the cancer experience, although the therapy may have been completed, constant supervision from examinations and medical monitoring bring them closer to the context of illness, where the fear of return is a constant issue ⁽²⁵⁾.

Experiencing cancer, in the case of this study, CRC type, may cause numerous marks in the sick person. The marks on the body are related to those resulting from the treatment, such as hair loss or stoma, while the marks on the mind are focused on the insecurity of the certainty of a cure or the fear of recurrence.

In this scenario, it is understood that the support on the part of the health professional, besides the family member, is crucial, as one of the ways to favor the coping with the repercussions of the illness, and also, the treatment that may be hard, and thus leave permanent marks ⁽²¹⁾. Therefore, knowing the person's experience with CRC and his/her family is configured in a strategy that can bring subsidies for the qualification of the care practice, since the care actions will take into account the particularities of each family nucleus.

CONCLUSION

This study has allowed us to understand the repercussions of the CRC diagnosis for the person and his/her family, which was associated with suffering, fear of death, a horrible and dreadful moment, especially among family members, who were the ones who most highlighted suffering when faced with the cancer diagnosis, while people with the disease demonstrated coping capacity through the

therapeutic possibility.

Knowing what happens in your body or having experienced a complex experience in the past may be a coping strategy or a capacity for resilience that can minimize the repercussion of the disease. Moreover, the marks, the stereotypes of cancer, such as the fear of losing hair or the presence of the stoma, can directly affect the person's self-image, and thus affect his/her physical or psychological health. In addition, it should be highlighted the sadness for feeling less productive in his/her professional life.

To that end, it is necessary for the health team to act with empathy and solidarity with people with cancer and their relatives, due to the negative meanings and feelings. Moreover, it is relevant that they find strategies with those involved in the sense of promoting the ability to cope and the resilience in the face of the negative aspects experienced, with a view to ensuring the mental and physical health of those involved, as well as collaborating to make them feel useful and productive. Furthermore, with the results shown, it is hoped to contribute to the improvement of nursing care through actions that promote autonomy and self-care, in order to minimize the difficulties in the process of illness of people with colorectal cancer and their families.

As limitations of this study, it is believed in the indication of the service nurse as an inclusion criterion, added to the selection of participants, since they took place in only one service in the investigated city, which may have implied less diversity of experiences, as they experience similar care contexts. Accordingly, for future studies, it is suggested to expand this perspective, seeking participants in other regional or care services for stomized people or even in care services for people with cancer.

A REPERCUSSÃO DO DIAGNÓSTICO DE CÂNCER COLORRETAL PARA PESSOA E SUA FAMÍLIA

RESUMO

Objetivo: compreender a repercussão do diagnóstico de câncer colorretal na experiência de adoecimento da pessoa e sua família. **Método:** pesquisa qualitativa desenvolvida de maio a julho de 2017, com pessoas com câncer colorretal e seus familiares, totalizando 23 participantes, mediante a entrevista em profundidade. Os dados foram organizados e codificados no software webQDA e realizado análise temática. **Resultados:** Organizou-se três temas: Câncer colorretal: repercussão do diagnóstico na perspectiva da pessoa e da família, na qual o familiar mais expressou sofrimento diante do diagnóstico; Experiência pregressa e conhecimento como forma de enfrentar a repercussão do diagnóstico de CCR, destacando a capacidade de resiliência colaborando no enfrentamento; O câncer colorretal marcado no corpo e na mente, o corpo marcado pela estomia e mente pelo medo da recidiva. **Conclusão:** foi possível compreender que o

diagnóstico de câncer repercute é compartilhado entre os membros da família, caracterizando a experiência como um evento coletivo.

Palavras-chave: Neoplasias colorretais. Família. Enfermagem. Pesquisa qualitativa.

LA REPERCUSIÓN DEL DIAGNÓSTICO DE CÁNCER COLORRECTAL PARA LA PERSONA Y SU FAMILIA

RESUMEN

Objetivo: comprender la repercusión del diagnóstico de cáncer colorrectal en la experiencia de enfermedad de la persona y su familia. **Método:** investigación cualitativa desarrollada de mayo a julio de 2017, con personas con cáncer colorrectal y sus familiares, totalizando 23 participantes, mediante la entrevista en profundidad. Los datos fueron organizados y codificados en el *software webQDA* y realizado análisis temático. **Resultados:** se organizaron tres temas: Cáncer colorrectal: repercusión del diagnóstico en la perspectiva de la persona y de la familia, en la cual el familiar más expresó sufrimiento ante el diagnóstico; Experiencia anterior y conocimiento como forma de enfrentar la repercusión del diagnóstico de CCR, destacando la capacidad de resiliencia colaborando en el enfrentamiento; El cáncer colorrectal marcado en el cuerpo y en la mente, el cuerpo marcado por la ostomía y la mente por el miedo de la reincidencia. **Conclusión:** fue posible comprender que el diagnóstico de cáncer es compartido entre los miembros de la familia, caracterizando la experiencia como un evento colectivo.

Palabras clave: Neoplasias colorrectales. Familia. Enfermería. Investigación cualitativa.

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