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EXPERIENCES OF FAMILY CAREGIVERS WHO ACCOMPANY PEOPLE WITH STOMAS DUE TO COLORECTAL CANCER

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ABSTRACT

Objective: To analyze the experiences of family caregivers of people with colon and/or rectal cancer who use colostomy bags during the disease process. Method: This is a qualitative descriptive study, developed in a municipality in the northwest region of Rio Grande do Sul. Eight family members of people with cancer who, for this reason, use ostomys were part of the study. Data collection took place between November 2021 and August 2022, through semi-structured interviews. Ethical aspects were observed throughout the study. Results: The experiences of family caregivers involve emotional aspects related to suffering and exhaustion, changes in the daily routine of the family caregiver. Conclusion: There is a need for a careful look at those who, because they provide care to family members with a stoma due to cancer, sometimes end up unassisted in relation to self-care.

Keywords: Family. Colorectal Neoplasms. Ostomy. Patients. Nursing.

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INTRODUCTION

Bowel cancer encompasses tumors that develop in the small and large intestines, in the latter, in the colon and rectum. According to the World Health Organization's Global Cancer Observatory, colorectal cancer is the third most incident type worldwide, with a total of 1,931,590 (10%) new cases, in both sexes and in people of all ages, in 2020 (WHO, 2020).

The distribution of incidence by geographic region shows that the South and Southeast regions concentrate about 70% of the incidence, and in the Southeast Region, half of the cases are found (INCA, 2023). In the South Region, colon and rectal cancer is the third with the highest incidence rate for men and second for women, with 4,060 new cases in men and 4,090 in women, estimated for this year (INCA, 2022). For the State of Rio Grande do Sul, the estimates of new cancer cases for the year 2023 are registered at 29,810. Of these, there are 3,120 new cases of colon or rectal cancer, 1,510 in men and 1,610 in women (INCA, 2022).

In many situations, its treatment involves removing the compromised part of the intestine and diverting the exit of fecal content through an opening made in the abdominal wall, called a stoma, with the installation of a collection equipment (bag) that will store the feces, for later cleaning. An ostomy (or ostomy) is a surgical procedure that consists of externalizing part of the respiratory, digestive and urinary systems, creating an artificial opening (orifice) between internal organs and the external environment (BRASIL, 2009).

A colostomy is created by connecting a part of the colon (large intestine) with the external environment and can be temporary or permanent. The most common cases that lead to an ostomy are colorectal cancer, chronic intestinal inflammation, diverticular disease, radiation damage, or trauma (BERTI-HEARN, 2019).

From the diagnosis of colorectal cancer, there is commonly wear and tear on the sick person and their families, both physical and psychological. The care of people with ostomy must occur in a comprehensive way for their best quality of life, whose family and health professionals are appointed as the main support groups for their rehabilitation (MARECO, FARIAS, NAME, 2019)

Several aspects lead to the choice of a family caregiver, and it is essential to emphasize that, in many cases, this choice is not discussed in the family group, but imposed on a single individual. In the study in question, it is understood that the family is an open and permeable system, made up of parents, spouses, children and members that this group names as part of it (WRIGHT, LEAHEY, 2012).

The care of people with chronic diseases, especially those with cancer who are in palliation, should also extend to family caregivers (BARBOSA et al 2020). It should be taken into account that the family suffers together with the sick person and the latter, as a rule, is directly related to the care of the same, playing an essential role in their care.

It is important to involve family members, because in many situations they will be the ones who will perform the first care at home, such as changing the collection equipment and cleaning it. Thus, they also need to be able to provide them (BANDEIRA et al, 2020). From the choice of a family caregiver, changes arise in the child's daily life, which can favor the development of care skills, but can also generate overload of tasks and increase in stressors, caused by the new demands in the family scenario. When negative factors impact the caregiver's ability to understand the needs of the person with cancer, it can influence the ability to care (OLIVEIRA et al, 2021).

In palliative care situations, the presence of family caregivers becomes even more important, due to the fact that, most of the time, the person with cancer is more physically and emotionally fragile. From this perspective, it is essential that the team looks at the family caregiver in order to offer support, which favors care for the sick person (BARBOSA, et al, 2020).

When conducting a literature search regarding the productions of the last ten years, twelve articles were found that deal with the experience of family caregivers of people with ostomy due to intestinal or colorectal cancer. From the analysis of the included studies, it was found that all were produced in Brazil, by nurses, published between 2015 and 2021, with a predominance of the qualitative approach, therefore with evidence level 4. Thus, the implication of working with this theme is justified, since there is a knowledge gap associated with family caregivers of people with ostomies due to cancer.

The guiding question of this study was: what are the experiences of family caregivers of people with ostomy due to colon and/or rectal cancer during the disease process? Thus, the objective of the study is to analyze the experiences of family caregivers of people with ostomy due to colon and/or rectal cancer during the disease process.

METHODOLOGY

This is a qualitative descriptive study, carried out in a medium-sized municipality. The results presented in this study are part of the research called "Caring for a person with cancer: experiences of family caregivers". In the study under analysis, specific information was sought on the experiences of family members of people with ostomy due to colorectal cancer.

The municipality, the locus of the study, is located in the Northwest region of the State of Rio Grande do Sul/Brazil and has about 30 thousand inhabitants, according to demographic data from the Brazilian Institute of Geography and Statistics (IBGE, 2023). The health reference for hospitalization is a medium-sized hospital, which has more than 100 beds and has the following units: emergency room, adult clinical and surgical hospitalization unit, maternity, pediatrics, surgical center and adult ICU.

To meet the health demands of the citizens, at the outpatient level, there are 11 Family Health Strategies (ESFs) in urban and rural areas. In the rural area, the ESF operates in an itinerant way in four communities in the interior. It is worth mentioning that the municipality does not offer cancer treatment to users and they need to travel to cities that are a reference in this health specialty, located in the north and northwest regions of Rio Grande do Sul.

According to information received from the Municipal Health Department, in June 2023 there were twelve people using ostomies in the municipality, of these, seven are due to cancer of the intestinal or colorectal system. During the data collection period, there were eleven people who met the inclusion criteria of the study, but one of the invited family members refused to participate in the research and two possible participants could not be interviewed during the data collection period due to health issues of their sick family member.

Eight family members of people with ostomy due to colorectal cancer, identified by family members as the main caregivers, participated in the study. The inclusion criteria were to be over 18 years of age and to be the main family caregiver of the person with an ostomy due to cancer. The exclusion criteria were to be a family caregiver of the person with cancer who has already died, to be a caregiver of the person with cancer who, in the family's view, is not part of the family system or does not have cognitive conditions. Data collection took place between November 2021 and August 2022.

Personal data regarding the telephone number and address of the possible participants were obtained from the Municipal Health Department. The first contact with them was made by phone call or via whatsapp, previously explaining about the research project, inviting them to participate in the study and, after their confirmation, data collection was scheduled on a date, time and place of the participant's preference. Of all respondents, as of July 2023, five colostomy users affected by cancer died after data collection with their family member.

The interviews were held in a reserved place, respecting the participant's decision, on a previously scheduled date and time, based on their availability. To carry out the interviews, a semi-structured script was followed with guiding questions that guided the path of data collection. Initially, data regarding the sociodemographic characterization were obtained. Next, the participants were asked about their experience with the person with cancer with a stoma, guided by seven guiding questions that concern the feelings and experiences of family members, care provided by them, support network for family members and changes in daily life. To capture the data, a telephone recorder was used and each interview lasted an average of 50 minutes. Subsequently, they were transcribed, respecting the reliability of the participants' reports.

From the transcription of the collected data, they were grouped into three thematic units, according to the similarity of the information, according to the steps proposed by Minayo (MINAYO, 2014). The first is the pre-analysis, in which there was initial contact with the material obtained in the empirical field of the research, in order to categorize similar information by units of record. In the second stage, the exploration of the material, its classification and choice of theoretical categories took place. In the third stage, the data were interpreted, articulating them with the theoretical framework of the research. In the production and analysis of the data, the Consolidated Criteria for Reporting Qualitative Research (COREQ) was used to support the rigor and credibility of the research, with description of aspects related to the study design and data analysis, throughout the detailing of the research (TONG, 2007).

The research respected the ethical aspects provided for in Resolution 466/2012 (BRASIL, 2012). The anonymity of the participants was preserved and, in the presentation of the results, they were identified by the word Familiar, as it refers to the family caregiver, followed by the Arabic number (Familiar 1, Familiar 2, ...), respecting the order in which the interviews were conducted. This study was approved by the Ethics Committee of UFSM, through Consolidated Opinion No. 3,106,576.

RESULTS

CHARACTERIZATION OF THE STUDY SUBJECTS

Eight family caregivers of people with colorectal cancer and ostomy, who were playing the role of primary caregivers, participated in the study. Of these, six were female and two male. Their ages ranged from 37 to 65 years. Regarding education, half of the interviewees (four) had completed higher education, followed by incomplete elementary education (two), complete secondary education (one) and complete elementary education (one).

Seven interviewees were married and one was a widower. Regarding the degree of kinship with the sick person, four caregivers were spouses, followed by two children, a brother and a mother. With regard to the profession of family caregivers, three were retired, three were elementary school teachers and two were self-employed.

Regarding the place where care occurs, six participants reported that care takes place at the home of the sick family member and two informed that care takes place at home. The length of care ranged from 45 days to eight years. Regarding the physical condition of the person with cancer, seven interviewees reported that their family members had independence and autonomy, with the ability to deliberate on their decisions and manage their life in society. One patient was bedridden, dependent on the caregiver.

Based on the analysis of the participants' interviews, the information was grouped into three thematic units, according to their similarity.[16] The first refers to the experiences of the caregiver when following the beginning of the process of becoming ill with cancer in his relative, in addition to reports portraying the difficulties encountered in this path by the family caregiver. The second category discusses the changes and adaptations faced in daily life by the family caregiver after the diagnosis of cancer. Finally, the third category reports on the support networks that provided care to the family caregiver and the cancer patient.

EXPERIENCES OF FAMILY CAREGIVERS OF PEOPLE WITH OSTOMIES IN THE FACE OF CHALLENGES IMPOSED BY THE DIAGNOSIS AND DEMANDS OF CANCER TREATMENT

Different feelings emerged in the caregiver from the fact that his family member became ill with cancer, as well as multiple challenges faced during the illness process. The difficulty in accepting the condition of illness due to cancer of their family member and its impact, associated with the notion that the term cancer is frightening, was evidenced in the participants' statements.

> It's complicated, we don't have words to tell you, it's a rug pull. At first we don't accept it, she doesn't accept it either, to this day she doesn't accept it. Oh, at first it was terrible... We went through a bigger problem at the beginning. (Family 1)
> Cancer, just the name is scary. But in the beginning it was quite difficult because of the bags. I couldn't, it was very problematic at first. (Family 2)
> When the doctor told me like this, she has a colostomy, oh my God, I was terrified. I think that was more impactful. For me, it was the bag itself. Because I didn't know how she was going to react too. (Family 3)
> Look, it's not easy, we're not prepared for this. Let's put it this way, I never thought I'd go through this. I never imagined myself. (Family 4)
> The business of cancer, the disease, is that you receive a diagnosis and see how much there are people who suffer from it, isn't it? So, that's the biggest difficulty, then you see a business that is, you know what a fragile person is. (Family 5)

> It was a shock. We didn't expect this... It was a shock, right. We are left without ground. (Family 6)
> For the family it was a shock, a fact like this, a disease arriving at a time that we don't expect, right, it's caught off guard. (Family 7)
> For us, at first, it was a shock, which even I had never seen even on the internet... and then of course the first days are insecurity, it's my God am I doing it right or not? (Family 8)

The difficulties encountered in the process of illness by the caregiver sometimes affected the care provided to the family member affected by cancer. The discomfort with the collection equipment, the lack of support, financial difficulties, treatment and its side effects were listed by the participants. In addition, one of them portrays the overload experienced in providing the main care for her family member with cancer.

> Then we left the hospital without a bag, the worst part was this... We got home and we didn't have a bag. So this is the worst part for those who do this there, when it's time to go out, where are the bags? (Family 2)
> They could think about this emotional part (...) the mother did not adapt to that bag, and she was looking at it all the time and it affects the person's emotional state (...). Which is uncomfortable is... the colostomy bag (...) And one thing also that this also affects the financial part a lot, we spend it, because it impacts the budget, before the mother had a budget. But now there are other expenses. (Family 3)
> But it also had a cost beyond the health plan. It was not a treatment by the SUS, so we had to go where we believed. And then it had a very high cost. (Family 4)
> At first, he has to wear a colostomy bag forever, and that created another problem, you know (...) because I also have my life, I work, I travel a lot, I can't stay day and night with him. I have family. (Family 5)
> Oh the first few days it was difficult, I had to learn, quite difficult to see her in pain and I couldn't take the pain away. There was a lot of reaction to chemotherapy, a lot of pain, she lacked the appetite to eat. (Family 7)

DAILY CHANGES AND ADAPTATIONS EXPERIENCED BY THE FAMILY CAREGIVER OF A PERSON WITH AN OSTOMY DUE TO CANCER

During this study, it was possible to observe the daily changes experienced by family caregivers after the diagnosis of cancer of the sick person, with changes in daily habits, in professional life, with interruption of professional activities to perform care and maintain continuous monitoring of the person with cancer.

> Who will I send along to Passo Fundo? All the children work, they have their own lives (...) I went there and retired, so for almost two years I was only at her disposal (person with a stoma). I'm practically only at home with her here (...) either I was going to work or I was going to take care of her, so I stopped to take care of her. (...) I had never done laundry in my life, I had never done anything, nothing, you know! (Family 1)
> I was aware that from the moment he got on that stretcher to go, in my mind it was like this: Everything is going to change, a lot is going to change, a lot of things... He entered one way and came back another, very complicated. (Family 2)
> I don't even know what's worse. I had to quit work, quit my son, quit the house and do something that I never did, that I didn't know how to do. So it's a very big challenge (...) and I quit the job, got the report and stayed there with it. (Family 4)

> The biggest blow I had was at the hospital in Ijuí, when they operated on him and the doctor came to warn me that (...) he would have to use the permanent bag. Then I saw that it was going to be a very big blow for them (other family members), that I knew it was going to be complicated, because sometimes you use the bag for a while and then you can return, but his didn't work. It was a very complicated case. (Family 5)
> She worked as a maid. Then I stopped work to take care of him. (Family 6)

One of the testimonies discusses the inversion of mother-daughter roles in the care of the collection equipment.

> It's a change now, right, reversed the role... She was always the one who took care of me and she was the one who raised my son, so I was always very dependent on her, right, and when all this happened, it was actually a shock, because now it's not her who takes care of it anymore, it's me who has to go, right, go after it. (Family 8)

In the participants' statements, changes were evidenced in relation to the diet of family members affected by cancer. Many mentioned that the patient's food acceptance was altered to the detriment of oncological treatment (chemotherapy or radiotherapy), or due to adverse events related to the ostomy.

> It was never forbidden for him to eat anything, but to eat so as not to lower immunity, we have always taken care of that. Because the person who does radium and chemo needs to be always eating, if they don't eat well, immunity is low. So, what she took care of most was this, to eat well. (Family 2)
> He does not eat anything that has milk, no fruit, no vegetables, nothing he does that can make the feces even more liquid. So, the idea is to get them to be more solid. So, it's more of a constipating diet. (Family 4)
> She (patient) doesn't eat much, right, a little bit at each step, a little thing or two, she can't eat the grain, only broths, like the bean broth, right... Then the orange, only juice, cannot eat the bagasse. (Family 7)

Some participants reported changes in their daily lives, due to the specific care they need to perform for the family member with cancer. One of the changes evidenced in the interviewees' statements was the fact that they had to perform care for which they were not prepared.

> I'm the one who took it in all the chemos she did, it was only once with my son, if not, it was all the times I took it, every time I was the one who stayed in the hospital. (Family 1)
> yes, change, we have to get organized, then I have to get up earlier in the morning. Then at noon, when sometimes I lay down to rest a little, then I already have to deal with her. So we have to adjust. (Family 3)
> When he's in the hospital, it's all about giving him food. To clean it, we had to pass a probe, change a bag, empty a bag. These things I never imagined, I think. I still for myself, what was scarier, I think it was the story of the tube, because you have no idea of the limit, I think that if you put too much you will perforate the bladder. So I found this difficult. (Family 4)
> The challenge, which I never thought I would do, is to deal with this little bag, bandage, clean the bag. It's because I had never dealt with this bag and for me it's been an experience, but I'm coping. (Family 6)

As time went by, the caregivers adapted to the process of illness and accepted it. Associated with this, they realized that the family member with cancer was facing the disease and the indicated treatment, with strength and determination.

> I faced it, you know at first it's that shock, then we get used to it, I did something I had never done in my life. (Family 1)
> Accept a lot of things, right, like the colostomy for the rest of his (patient's) life, but now it's normal life (...). But it was difficult. It was like that, a very difficult phase. But it passed. (Family 2)
> And she (patient) is very strong. Sometimes he is stronger than us. Because she said to the doctor, I'm prepared, whatever I have to do, let's do it. We don't think it's easy, but it's the best for her health right now at the moment. (Family 3)
> So this is a daily struggle. Every day is a struggle, you know? It's a week it's good, a week it's bad. Then I can't go there to see him every day. It's a daily struggle. (Family 5)
> For me it's been an experience, but I'm coping, I'm doing my best. (Family 6)
> We adapt to things and we have to pay more attention to her (patient) there, you know, at this moment it's everything for her, right... She's going to get out of this, and she's going to be fine, she has to have faith, hope, she's young, she has a whole life ahead of her, she has children. (Family 7)
> I think we (family members) are calm, we didn't have many difficulties like that, in the beginning the mother (person with a stoma) had a little difficulty cleaning because it's different, you know, totally different... I think it's a matter of taking care and that's it, with affection, and just as I adapted, she adapted and we talk. (Family 8)

THE SUPPORT NETWORK EXPERIENCED BY THE FAMILY CAREGIVER OF A PERSON WITH AN OSTOMY DUE TO COLORECTAL CANCER

The third category discusses the support networks that provided care to the family caregiver and the cancer patient and that were available for any necessary support. In this study, the main support networks were children, daughters-in-law, sons-in-law, spouses and other family members. Members of the health team were also cited as supporters.

> My children, my daughter-in-law lived here, she came to do the dressing, wash it with the syringe. [...] And from time to time the girl comes here (health agent), we started to receive her bags and now we can't complain about it. (Family 1)
> The health service even came there to make dressings, even the doctor came one day, nurses came to make dressings. (Family 2)
> Then there's my husband, when I'm not here he helps. And then last week we went for chemotherapy, she had to stay there at my cousin's. My cousin and her husband helped. (Family 3)
> I contacted the health secretary, so she could find a bed. Then she arranged the bed, sent the hospitalization form by PDF. Then I contacted the health department who gave a yes and didn't take 15 minutes, the health car was already there. (...) Friends in that sense, like, now, right? Our son stayed at a friend's house and it's like that, more to take care of him. (Family 4)
> Is... The son, me, the son, the daughter-in-law and Health helped and are accompanying us, they are helping. (Family 6)
> When her girl is at home she helps me get out of bed, bathe, if not my husband helps me, he has more strength to hold her, you know that now she has little movement and doesn't get out of bed (...) Then they (SMS) are coming here to pick it up, take it, bring it back, when they need it, SAMU comes. Cancer League, give us support and we get by as we go, right, and so we go. (Family 7)

> They (brothers) help with the issue like this, for example: if there is a review, there is an appointment, there is something, I can't get a break to go, they go, and my sisters-in-law, right, more in that sense, but in the matter of dealing with the bag, neither of them has ever done it, right. One of my sisters-in-law, who is a health agent, she was the one who forwarded all this part of getting the bags, it was all her, I don't even know what she did, I don't know how she did it, because it was all up to her. (Family 8)

In view of the above, it was analyzed that all the experiences of family caregivers caused emotional, professional, financial, structural changes for the family environment and many others mentioned. As a result, there is a need to take a close look at those who, because they provide care to people with cancer and ostomy, sometimes end up unassisted in relation to their own care.

DISCUSSION

Faced with a cancer diagnosis, each person responds individually, but reactions such as fear, anxiety, denial, hopelessness, and loss of control are common. In this scenario, the experiences of family caregivers who followed the process of illness of people with ostomies due to cancer, the sudden changes that occurred in their lives and the support network that this family group belongs to and can count on were observed.

In relation to family caregivers, the study found that most are female, this fact may be associated with gender issues, since women, throughout history, in the vast totality of circumstances, are the ones who develop the role of caregiver, both in the family and in society (CELICH, BATISTELLA 2007). This data is in line with the study carried out in Havana/Cuba with caregivers of patients with head and neck cancer, which alludes that the majority of family caregivers are women (81%), who are daughters, spouses or sisters of the sick person. The study highlights that, even without specific knowledge about care, women are delegated as the main caregivers of their sick family member (MARTÍNEZ-DEBS, et al, 2020).

Receiving the diagnosis of cancer from a family member, for anyone, regardless of age or gender, makes them fragile. At the time of cancer discovery, feelings of sadness, indignation, and anguish are usually due to the meaning of cancer, as a stigmatizing disease, which brings suffering and can lead to death. During the caregiver's experience with his family member affected by cancer, feelings of discouragement, difficulty in accepting the diagnosis and concern with prognosis and impotence are observed, characteristics that are also reinforced by the literature (DE MELLO, et al, 2021).

Communicating bad news, such as the diagnosis of cancer, becomes a delicate event and, therefore, the way in which the information is passed on is essential in order to minimize the suffering attributed to this malignancy. In this sense, it is important that the multidisciplinary team has adequate communication for the moment, based on quality care, providing emotional support, guidance, help and confidence to deal with the adversities imposed by the disease. It is necessary for communication to be effective, clear, and empathetic so that people feel welcomed by professionals, especially because they are vulnerable and emotionally disorganized in the face of a serious disease, such as cancer (BARBOSA et al, 2021).

The difficulty in accepting the fact that a family member has cancer was pointed out by the participants. In some reports, the term cancer was understood as frightening and related to the moment of the end of life. It is important to mention that, in situations of terminal cancer, it usually progresses quickly, which makes it challenging for family caregivers to deal with end-of-life care for their loved ones (BARBOSA et al 2020).

People with ostomies often faced difficulties related to cleaning the stoma and handling the collecting equipment, especially in the initial period, right after surgery. Stoma care represents something new and unknown, and the skills for hygiene, emptying, and changing the device are still incipient, with the need to be improved (SILVA et al, 2022). Thus, it is understood that the family, in addition to being surprised by the presence of a disease that causes great emotional impact, is often asked to take care of and face the daily changes caused by the illness process (MORAES et al, 2019).

The impact of knowing that her family member would use a colostomy bag caused discomfort, mainly due to the lack of knowledge of the device and the need to assist in this care. It is verified that care skills are intrinsically related to overload, so the greater the knowledge, the lower the interpersonal impact resulting from the relationship of care provision. Thus, the lack of autonomy caused by the health situation of cancer patients occurs with the course of the worsening of the disease and the little information that caregivers receive about the procedures performed on the patient (SIQUEIRA et al, 2019). Thus, decision-making becomes the responsibility of the family caregiver, generating stress in the family group because they do not know the chosen measures well.

People with cancer, in general, require special care, in which information about the disease and the necessary care are important elements. In this case, family involvement in the treatment of chronic diseases such as cancer is extremely relevant (JIMÉNEZ-LUNA et al, 2020). Therefore, enabling access to information, both for the person with a stoma and for their families, is essential and can be done through discussions on topics involving colorectal cancer and ostomy, preparation for the handling of the stoma and collecting equipment, and offering space for the expression of doubts and feelings (BANDEIRA, et al, 2020). According to the same author, the implementation of health care guidelines requires professional competence, as well as knowledge, skills, and attitudes to carry out this action.

A study (SILVA et al 2022) is in line with the participants' reports regarding health guidance for self-care, which is received only in the postoperative period in which there is a specialty in the area of stomatherapy, which may favor care for this population, but the continuity of monitoring the health status of the person with a stoma in the primary health unit of reference is fragile. There is still resistance from some professionals not only to perform stoma management, but also to health education actions. Nurses are an important pillar in this care and must reflect on their practices, which go beyond technical-scientific skills (SILVA et al 2022).

The participants pointed out that the illness produces moments of difficulties and limitations, related to routine, financial issues and social life for both the patient and their family member who assumes the role of caregiver. In this scenario, the suffering of the caregiver who experiences all the phases of the disease with the sick person stands out, facing fears and insecurities, which may be linked to difficulties in the economic sphere, lack of dexterity when providing care or even lack of support from other family members. It is reaffirmed that this progressive physical and emotional deterioration during the advancement of the disease induces psychological suffering, requiring great adaptive efforts on the part of the caregiver (BARBOSA et al, 2020., DE MELLO et al, 2021).

International studies developed by medical oncologists have recorded high levels of burden in non-spouse caregivers, in those who cared for patients who had more treatment-related side effects, those who spent more hours caring, and those who cared for more than one person (LANGENBERG et al 2019., ANSUK et al, 2019). Simultaneously with this, family caregivers face their particular demands, favoring physical and mental exhaustion, corroborating the overload of activities.

There is a certain neglect in relation to the care provided to family caregivers by health teams, as mentioned in the participants' reports. Most of the time, care is provided only to the person affected by the disease, but the family caregiver also needs to be assisted by health professionals with a broader view so that they are able to care for the person with cancer and ostomy. Furthermore, the importance of the family group, as a whole, being close to the sick person and their main caregiver is ratified, with a view to contributing to the demands arising from this scenario.

The roles of each family member who experiences cancer change and the way each one faces the transformations related to the disease can affect the way they live with this scenario in the future (MORAIS et al, 2019). In the context of the study under analysis, the expenses resulting from the treatment of people with cancer with stomas ratified the increase in expenses, reducing the financial contribution of the families. This reality arises since most sick people require exclusive attention and caregivers sometimes had to be absent from their professional activities or even leave permanently, thus reducing financial resources.

A study (NACENTES et al, 2019) reveals that the primary social network of people with cancer was composed of children, siblings, spouses, and friends, who were identified as the most present people who offered support during colorectal cancer treatment and ostomy care (NACENTES et al, 2019). The secondary social network, on the other hand, was composed mainly of professionals from medium and high complexity health institutions in Oncology (NACENTES et al, 2019). In this line, studies reveal that the main support network cited by family caregivers was the health team specialized in oncology and stomatherapy, which demonstrates the importance of the intervention of the multiprofessional team to provide full support to the caregiver and facilitate their return to their normal routine (BARBOSA et al 2020., NACENTES et al, 2019).

The acts of stimulating self-esteem, encouraging social feedback, and recognizing similarities in support groups are important contributions generated by the social network in the development of care for family members with ostomies (SIMON et al 2020). Hope is what drives a person to move forward, as it has a beneficial effect, while strengthening their ability to deal with crisis situations (MORAIS et al, 2019).

The limitations of this study are related to the difficulty of collecting data, since the interviews were carried out in the caregivers' homes, several unforeseen events occurred and the interviewee chose to cancel or reschedule. The health status of cancer patients constituted a limitation to interview their family caregiver, due to the fact that they are involved in the care of the demands of the sick person. In addition, the difficulty of finding up-to-date studies on the subject leads to a knowledge gap.

CONCLUSION

This study aimed to analyze the experiences of family caregivers of people with colon and/or rectal cancer who use colostomy bags during the disease process. The feelings highlighted by the family caregivers were fear of the new, stress, anxiety and difficulty in accepting that a member of the group had been diagnosed with cancer. There was also mention in relation to the discomfort with the collection equipment, lack of support to cope with this scenario, financial difficulties, difficulty in treatment and its side effects.

Thus, it is identified that there was little attention to family caregivers, who, like cancer people, need specific care so that they take care of the sick person and also so that they do not get sick.

Similarly, there were reports highlighting changes in the daily routine, these situations generated financial overloads, in addition to psychological and social exhaustion. The actions involving care with the collection equipment, medications, dressings, and food also changed the daily lives of family caregivers. In several situations, they had little knowledge of how to perform such procedures.

Regarding the support network, family caregivers highlighted people from the family group as important allies in the process of caring for people with cancer with stomas. The role of the health team, including the nurse in the approach and care of the person with cancer with a stoma and their family caregivers, involves technical intervention, clarification of doubts and guidance regarding the necessary actions that can contribute to the treatment.

Thus, there is a need for an attentive look, which encompasses the experience of these family members after cancer diagnosis, since they go through changes in habits and routines, in addition to the suffering that all this transformation entails, in order to provide qualified listening and minimize emotional exhaustion.

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