



Experiences of the family caregiver of a person with intestinal ostomy due to colorectal cancer

Vivências do cuidador familiar de uma pessoa com estomia intestinal por câncer colorretal

Vivencias del cuidador familiar de una persona con ostomía intestinal por cáncer colorrectal

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This is a study with the objective to know the experiences of the family caregiver of a person with intestinal ostomy due to colorectal cancer. A qualitative research, grounded on the humanization referential, made in 2013, through serialized semi-structured interviews and inductive analysis. It was approved by the Ethics and Research Committee under legal opinion no. 237,771. Seven family caregivers participated in this study in a county of southern Minas Gerais state, Brazil. Three categories emerged from the data: Relation with the disease and its treatments; Impact facing treatment and rehabilitation and Nets of support. The representation of the disease associated to finitude is reaffirmed. In order to lessen anguish and suffering, the family caregivers search support, mainly in spirituality. The impact resulting from the illness and the rehabilitation process imposes a new order to the caregivers, with personal and social renouncing, which provides a closer and more dedicated relation with the patient.

Descriptors: Colorectal Neoplasms; Ostomy; Caregivers; Nursing.

Estudo realizado com o objetivo de conhecer as vivências de ser cuidador familiar de uma pessoa com estomia intestinal por câncer colorretal. Pesquisa qualitativa, fundamentada no referencial da humanização, desenvolvida em 2013, por meio de entrevistas semiestruturadas seriadas e análise indutiva. Participaram do estudo sete cuidadores familiares de um município do Sul do Estado de Minas Gerais, Brasil. Dos dados emergiram três categorias: Relação com a doença e seus tratamentos; Impacto frente ao tratamento e à reabilitação e Redes de apoio. Reafirmamos a representação da doença associada à finitude. Para amenizar as angústias e o sofrimento os cuidadores familiares buscam apoio, principalmente na espiritualidade. O impacto decorrente do processo de adoecimento e da reabilitação impõe novas ordens aos cuidadores, com abdicação pessoal e social, o que propicia uma maior aproximação e dedicação ao adoecido.

Descritores: Neoplasias Colorretais; Estomia; Cuidadores; Enfermagem.

Estudio con objetivo de conocer las vivencias de ser cuidador familiar de una persona con ostomía intestinal por cáncer colorrectal. Investigación cualitativa, basada en el marco teórico de la humanización, desarrollada en 2013, a través de entrevistas semiestruturadas seriadas y análisis inductivo. Participaron del estudio siete cuidadores familiares de una ciudad del sur de Minas Gerais, Brasil. De los datos, surgieron tres categorías: relación con la enfermedad y sus tratamientos; Impacto delante del tratamiento y rehabilitación y Redes de apoyo. Se afirma una vez más la representación de la enfermedad asociada a la finitud. Para aliviar las angustias y el sufrimiento, los cuidadores familiares buscan apoyo, principalmente en la espiritualidad. El impacto resultante de la enfermedad y rehabilitación impone nuevas órdenes a los cuidadores, con abdicación personal y social, que proporciona aproximación más cercana y dedicación al enfermo.

Descriptorios: Neoplasias Colorrectales; Estomía; Cuidadores; Enfermería.

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Introduction

The Colorectal Cancer (CC) is one of the malign neoplasias that most attack the Brazilian population, comprising colon and rectum tumors. The estimates for 2013 are 30,140 new cases⁽¹⁾.

It is a type of cancer with good prognostic when it has an early diagnosis, through rectal touch, sigmoidoscopy, colonoscopy, test of hidden blood in feces, barium enema, biopsy, tumor marker and image exams⁽²⁾.

However, despite the advancement of the coloproctology related to the prevention and early diagnosis of colorectal cancer, the Brazilian population still deals with difficulties due to the precarious socio-economic conditions, to the lack of knowledge on this type of cancer, to the delay or to the limitations of access to the health system, as well as to the diagnosis resources and to the existing prejudice against the methods of diagnosis investigation such as the rectal touch⁽³⁾. These economical, political, social and cultural factors seriously corroborate for the delayed diagnosis, increasing the risks and the prolonged hospitalizations⁽¹⁾.

The choice of the treatment will depend on the stage of the disease. The radiotherapy can be one of the therapeutical alternatives, which, associated or not to chemotherapy, has contributed to increase lifetime with quality, even in more advanced cases of the disease. Surgery is the therapy that constitutes the treatment of choice for CC, which can result in ostomy⁽⁴⁾.

Under these circumstances, the purpose of ostomy is the drainage of the intestinal content, having the need to connect a device for the collection of the effluent, a term adopted to name the drained intestinal content. Ostomy can be temporary or definitive, depending on the stage of the colorectal cancer and is named according to the exteriorized intestinal segment. If it is in the colon, it is named colostomy, in the ileum, an ileostomy. The consistence of the feces can vary according to the area where ostomy happened⁽⁵⁾.

Cancer is a disease feared by everyone, once it is intimately linked to the myth of being incurable, to pain, to suffering and even death. The impact suffered by the patient that is submitted to ostomy is double: cancer and ostomy. Ostomy jeopardizes different dimensions beyond the physiological one, which unleashes conflicting feelings. The alterations of the body image provoke great changes, significantly interfering in the identity of the patient⁽⁶⁾.

The alterations resulted from the disease and the treatment impose a new way of living and to accept this new condition, facing the process of adaptation and rehabilitation of the patient, it is necessary that the family and, especially the family caregiver, is prepared for such objective⁽⁷⁾.

The family is a key piece in the process of coping with this reality, once it is the main source of information and affective link with the patient, helping him to deal with insecurity and with several other feelings which emerge from this experience⁽⁸⁾.

Each family goes through this process in a particular way, experiencing different manners of offering support and help. Under this aspect, the health professionals, especially the nurse, have a fundamental role as a support to the patient and to the family in order to cope with the adversities resulted from this processes of the disease. Many times, the family is not ready to deal with such situation, it is important that they are stimulated and able to take care at home⁽⁹⁾.

Although the importance of the nurse with the patient and the family has been unquestionably revealed in the national and international literature, it is evident that the assistential clinical practice is distant from the humanization of the assistance, one of the principles of the public policies related to the patient with cancer.

The assistential clinical practice has prioritized the hard technology emphasizing the disease and the treatment. The small value given to the dialog, to the singularities of the human being, to the knowledge of the other, to the experience of the disease, to the rights

of the people with ostomy and to the recognition of the role of the family caregiver, has constituted barriers to implement the humanization of the assistance. The inefficiency of the system, of reference and counter-reference corroborates, as well as the biomedical unaccountability in which the truths scientifically produced feed the trend to the conversion of the patient and of the cure into elimination or control of diseases and risks⁽¹⁰⁾.

This reality which is presented in the daily activities of the practices in health led us to restlessness which brought us the following question: Which are the experiences of a family caregiver of a person with intestinal ostomy caused by colorectal cancer? In order to provide answer to our wishes, we propose to know the experiences of the family caregiver of a person with intestinal ostomy due to colorectal cancer. Throughout the clinical practice, it is observed that not always all the members of a family have emotional structure and time to have the function of a caregiver. So, the nurse must have the perspicacity to detect such situations and choose members with potentiality for the development of new abilities, able to provide support for self care and to administrate suffering.

Method

It is a qualitative study of exploratory and descriptive type, made in the homes of family caregivers of people with intestinal ostomy.

For such, the following criteria of inclusion were established: to be a family caregiver of a person with intestinal ostomy due to CC, to be older than 18 years; to be in condition to answer the questions and to participate in the study.

The study was made in a county of southern Minas Gerais, Brazil, with seven family caregivers of people with intestinal ostomy, registered in the County Center of Attention to Impaired People. The study was limited to seven participants, when it was possible to know, from the collected data, the experiences of a family caregiver of a person with ostomy due to

colorectal cancer. So, we stopped collecting when the data began to be repeated and therefore there was data saturation⁽¹¹⁾.

Data were collected by the researchers from May to June, 2013, from the following guiding question: 'How is it for you to be a caregiver of a family member with ostomy due to CC?' The technique of serialized semi-structured individual interview was adopted, aiming at providing the participants of the study more freedom to expose their individual experiences.

The interviews were held in the homes of the family caregivers and they lasted for approximately 60 minutes. The interviews were recorded in Mp3 after the permission of the participants and, afterwards, transcript and analyzed.

The inductive analysis was adopted, based on the referential of the Policy of Humanization of the Assistance⁽¹²⁾ understood as a way of care centered on the voice of the subject, on the family, regarding his autonomy, and therefore on qualified listening, on the dialog and on the satisfaction of the needs which make interactional process reframing possible. The following recommended steps were complied with: ordination of the data: organization of the collected material, in order to have a general vision; classification of the data: a step in which the researches identifies the central ideas and main common points to extract the theme nuclei afterwards; the final analyzes: this step requires dedication and perspicacity from the researcher for the analysis of all empirical material, which is the starting as well as the arrival point of comprehension and interpretation⁽¹¹⁾.

After the organization of the collected material, the process of data classification was started, describing the feelings assimilated by categories. So, three categories emerged: relation with the disease and its treatment; unawareness and impact facing ostomy, nets of support facing rehabilitation.

In order to assure ethical principles, the authorization from the County Health Development for the development of the research was asked. The subjects with ostomy were clarified concerning the

objectives of the research and signed the Permission Form. The family caregiver signed the Informed Consent Form and received fictitious names: Maria, Júlia, Suelen, Rita, José, Paty and João in order to guarantee anonymity. The project was registered at the Comissão Nacional de Ética em Pesquisa (CONEP) (the national committee of ethics in research) and approved by the Comitê de Ética e Pesquisa em Seres Humanos (the committee of ethics and research of human beings) of the Universidade Federal de Alfenas (UNIFAL-MG), under legal opinion no. 237,771.

Results

5 (five) women and 2 (two) man participated in the study; the majority was single, from 26 to 57 years old, schooling varied: 1 (one) with incomplete grade school, 3 (three) with complete high school and 3 (three) with complete university. Concerning family relation, 5 (five) caregivers were children, 1 (one) nephew and 1 (one) wife. The family income was between three and four minimum wages, from the retirement plan of the person with ostomy and/or some other member of the family, and most of them were catholic. From the analysis of the statements, three categories emerged: relation with the disease and its treatment; impact facing treatment and rehabilitation and nets of support, which will be presented below.

Discussion

Relation with the disease and its treatment

Facing the growing rates of colorectal cancer and other malign neoplasias and the stigma of death which involves cancer, it is observed that the disease becomes a synonym of pain and suffering⁽¹³⁾. The following statements make the representation of the disease evident for the participants: *Fear of losing. It was difficult. Every day I looked and thought, Will it be my last day? Because everybody who has cancer says: see, he died. Died of what? Cancer* (José). *Because cancer is a word that we say like this: Go. Go*

away (Paty). *When they mention cancer the first word that comes to our mind is death* (Suelen).

In many cases cancer provokes great physical and psychological weakness, requiring major care, so the person attacked by cancer depends each time more on a caregiver, whether or not he is a family member⁽⁶⁾. Exercising care to a sick family member is becoming each day more common among many families. The family goes through deep changes after the discovery of cancer having to deal with intense emotional conflicts and feelings of fear facing the new and unexpected experience⁽¹⁴⁾.

Coping with the disease seems to be a difficult task for the family members. Even so, some caregivers try to show strength to encourage the family member to face the problem: *I didn't have any other option, I had to face it and what was I going to do? Pass on strength and security* (Maria).

After the confirmation of the diagnosis, therapy starts, either through surgery, radiotherapy or chemotherapy. Chemotherapy and the radiotherapy can be neoadjuvants, being made before the surgery or adjuvant after the surgery⁽⁴⁾. At this stage, the caregivers seemed to be worried watching the family member present the side effects of the treatment as it is evident in the statement: *She got home she didn't eat she didn't drink. Spent the whole day lying down on the sofa. Vomited. Worst thing it was. And when I was working she was there, through, you know? But my heart would break. I thought I can't work, then I had to go home* (José).

A statement called our attention due to the courage shown by the participant in the performance of activities never before performed, in order to bring comfort and help in the recovery: *Just that because of the infection she had, and the cuts down below opened all, all, all. There was a hole of 5 centimeters and deep! And I had to do all the dressings, below. So, I never imagined that I would have the courage to do that. But like, on the spot, you don't even think! Let's do it and that is it. Then, I was the one to learn* (Suelen).

It was observed that in several occasions, the family member, by imposition of the circumstances, even without education in health, becomes the caregiver.

In a great part of the cases, these layman caregivers work full time, beside the patient, and take care both in the hospital and at home, constituting fundamental elements to provide information on the situation of his family member to the health team⁽¹⁵⁾.

The nurse must be present in the process of care through a holistic approach able to contemplate the patient in his multidimensional aspects. In this moment of suffering and anguish, it is vital that there is a relation of affection, respect and attention among the patient, family members and the health team in order to maximize the capacities and abilities of the people with ostomy⁽¹⁶⁾.

Impact facing treatment and rehabilitation

The body image, altered by ostomy, is able to provoke feelings of inferiority and anxiety in the patient which can generate feelings of pity and compassion in the family caregiver. The adoption of strategies which lessen suffering becomes essential not only to guarantee the recovery of possible psychological harm but also to bring a better quality of life to the patient⁽⁵⁾.

The statements revealed that in a general way people have little information on ostomy and its purpose and are caught by surprise when they have to deal with this new condition, as revealed in the statement : *Never new. We only knew afterwards when he came home and we knew how to treat him. The way of sanitization and everything else, that's when I knew, we had never heard of it (Júlia). Never saw in my life. Didn't even know how it was (João).*

Under the perspective of the caregiver, the difficulties to deal with the person with ostomy are not limited to the family member, but, above all with the health professionals: *Not even the hospital nurses knew how to fix it. But then I had researched everything on the internet and I managed to do it (Maria). I had a sister in law who was a nurse, not even she knew how to clean. She didn't know how to take care of this. Then we learned little by little (José).*

So, we understand that the health professionals must be able to assume their functions, providing

assistance of quality to the person with ostomy and his family members.

Despite the existence of several publishing regarding the care with the person with ostomy, it is observed that many nurses are not yet prepared to provide assistance to their patients⁽¹⁷⁾.

We are living new times, with changes in the epidemiological profile, which are characterized by the increase of the number of people with chronic diseases, showing the need of updating and improvement of the health professionals for the treatment of the person with cancer, among them, ostomy⁽¹⁾.

The statement below reveals that, facing the little guidance received by the health professionals, the patient with ostomy and his family caregiver search, through self learning, some ways of care with the equipment and with ostomy, through attempts of success and obstacles: *Then we learned little by little. Then she saw that the bag could be removed, could be washed in the toilette bowl to change. Because at the beginning there weren't enough bags (João).*

It is up to the health professional to provide care to the person with ostomy, providing knowledge on the rights granted by law and not limiting the care to the handling of equipment⁽¹⁷⁾.

We have noticed the impact of ostomy in the family context, when we observed that among those who had condition to take self care, the patients ended up developing dependence on the family caregiver maybe because they did not accept the new body image as shown in the statement: *I think that if he changed (the collecting bag)it was only one, you know! Because he is very dependent on me. Not financially, but like, psychologically, emotionally. For those things he is very dependent, understand? Then I taught him, he already changed once because I was not at home, but he doesn't like it (Maria).*

Facing this reality the family caregiver ends up quitting his job and his social life to dedicate himself fulltime to the one who needs care⁽¹⁴⁾. With this he stops seizing daily life due to the lack of free time to rest and have social activities: *Before this I would go out every day, from Monday to Monday in the neighborhood, party every*

day. It has been two years that I don't know what party is. I quit my job to take care of her. And I will wait for her to recover so that I can go back (José).

The statement shows that the family caregiver is obliged to conciliate the activities of his daily life with the care to the person with ostomy, increasing even more the overload of tasks, which makes his quality of life bad: *I stayed 4 or 5 months because of that. Because of the dressing, everything, I had to stay more at home, because there was nobody to take care of the house, I did everything, she was bedridden longer in the first month. Then I took care of everything, it was not possible to work, I just had to stay with her and take care of the house, because, whether you want it or not, there is feeding, dressings and everything. And then there is my father too. I had to take care of everything* (Suelen).

During the process of rehabilitation, the first step to be taken is the acceptance of ostomy, which must be understood as a treatment whose purpose is to save lives⁽⁶⁾. This process, however, does not happen so fast and easily, as can be observed in the statements as follows: *At first it was quite complicated for her to accept, right, that she had a bag that would be forever and there would be no return. But then we kept on talking, but now it is alright* (Paty). *He did it. He cleans until today. We received orientation from a neighboring nurse* (João).

The impact of the treatment and of the rehabilitation imposes to the family caregiver the commitment in several dimensions, whether they are psychological, physical, economical, social or spiritual, which is significantly reflected on the daily activities of the family, leading to the reduction of chances of leisure activities and to the impossibility of job out of the house⁽¹⁸⁾.

Nets of Support

The social support is characterized as an activity which allows the sharing of different experiences with religious groups, friends, family members, among others. There are three kinds of social support: emotional, material and educational. The emotional support allows people to express their

anguishes, fears, anxieties, pains and sorrow. The material support is the direct or indirect help which provides material and financial help. The educational support makes the exchange of knowledge among people possible, so that they feel more secure⁽¹⁹⁾.

It is observed that the main net of support mentioned in this study to cope with the difficulties was spirituality. Independently of the religious belief, it was evident that the faith was the most frequently support pursuit at this moment: *God is the balm, without him, no deal. For me, right. For me. I think that without God in my life I am nothing. I am just like straw, is goes back and forth. There isn't a target, understand? So, for me God is everything. God in the first place* (Paty).

The emotional support provides the family caregiver strength so that he can lessen his suffering and the other's: *in terms of support, that's what we try to do, support, talk: keep calm because it is like this, it will get better! It is more in this sense, as a family member that I think we can help, because we actually do not know* (Júlia).

Regarding financial support, it is noticed that the resources came from the retirement plan of the person with ostomy and some income from other members of the family, as it is revealed in the statement: *Only for my mother [retirement plan] and my unemployment insurance, nothing else!* (José). *From the [name of association of volunteers] Gee, they are wonderful. Everything. There was psychological support, my father received boxes with bags, any medicine he needed, vitamins. Anything he needed, the [name of association of volunteers] is very good* (Rita).

It is necessary to mention the participation of the 'University Project of Extension' developed by the authors of this study as one of the important supports once it provides the social reinsertion of the person with ostomy through the organization of meetings and exchange of experiences in the pursuit of a better quality of life.

It was observed that the nets of support promote health and exert direct effects on the welfare of the patient, improving his psycho-emotional aspects and helping in the rehabilitation facing difficult situations brought by the disease⁽⁹⁾.

In order to have a fast and effective adaptation of the person with ostomy, it is of great importance to have the support of the family caregiver who must also be backed by a multi professional team⁽²⁰⁾.

Time makes the person with ostomy overcome the feelings of not accepting the new condition turning into resignation, conforming himself with his limitations and possibilities, which has a positive reflection in the perception of the family caregiver⁽²¹⁾. So, the patient and the family caregiver start facing life with a new look, a new meaning, facing the situation with a more positive manner, and so becoming confident to go back for this daily activities.

Final Considerations

When making this study with the objective to know the experience of being the family caregiver of a person with intestinal ostomy due to CC, we testified that the representation of the disease is associated to the finitude of life. The impact resulting from the process of the disease and of the rehabilitation imposes new orders, with personal and social renouncing which provides a greater approximation and dedication to the patient. In order to lessen the anguishes and suffering they pursuit support, especially in spirituality.

Knowing the experiences of the family caregiver also allowed us to analyze the public policies regarding the patient with ostomy and to conclude that there are gaps in the process of working with health. Such gaps point at the difficulties of the health professional in dealing with the singularities of the person with ostomy and his family members. Many times his health professional, prioritizes the hard technology in detriment of light ones, with the technical procedures, maybe influenced by the advancement of science, by the technological innovation and by the inefficiency of the systems of reference and counter reference.

As a contribution of this study, we suggest the formation of health professionals in order to value not only the scientific knowledge, but above all, to understand the human being facing a process of

disease and everyone linked to him and to implement health education aimed at improving assistance.

Collaborations

Oliveira GS e Bavaresco M contributed for the conception of the work, data collection, analysis, interpretation of the data and writing of the article. Filipini CB, Rosado SR, Dázio EMR and Fava SMCL contributed for the conception of the work, analysis and interpretation of the data, writing of the article and final approval of the version to be published.

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