

# The perception of ostomized patients with colorectal cancer regarding their quality of life

Percepções de pacientes estomizados com câncer colorretal acerca da qualidade de vida

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#### ABSTRACT

Objective: to understanding the perception of ostomized patients affected by colorectal neoplasms regarding their quality of life. Methods: qualitative research, with 15 patients in outpatient treatment. Data collected through semi--structured interviews. To organize and present data, the content analysis technique was used. Data were interpreted according to the social phenomenology of Alfred Schutz. **Results:** three thematic categories emerged: Quality of life: social, psychic, and spiritual influences; Personal and environmental adaptations considering the new reality; and Complications of living with an ostomy. Conclusion: patients with ostomies resulting from colorectal cancer, in general, have variations in the way they perceive their quality of life. In the physical domain, they consider the device to be vital in the treatment, but it generated, a priori, social isolation, due to embarrassment, requiring them to adapt to the new reality as to diminish its emotional impact, which frequently presents in the form of sadness and non-acceptance. Descriptors: Colorectal Neoplasms; Ostomy; Quality of Life; Qualitative Research; Philosophy.

#### RESUMO

Objetivo: compreender as percepções de pacientes afetados por neoplasia colorretal com estomias acerca da qualidade de vida. Métodos: pesquisa qualitativa, com 15 pacientes em tratamento ambulatorial. Dados coletados por entrevista semiestruturada. Para organização e apresentação dos dados, utilizou-se da técnica de análise de conteúdo. Os dados foram interpretados de acordo com a fenomenologia social Alfred Schutz. **Resultados:** emergiram três categorias temáticas: Qualidade de vida: influências sociais, psíquicas e espirituais; Adaptações pessoais e ambientais frente à nova realidade e Complicações no viver com estomia. Conclusão: pacientes com estomias proveniente de câncer colorretal, em geral, têm variações nas percepções de qualidade de vida, de forma que, no domínio físico, consideraram o dispositivo vital no tratamento, mas que gerou, a priori, isolamento social, por vergonha, necessitando de adaptações diante da nova realidade, a fim de reduzir o impacto emocional, muito frequentemente representado em forma de tristeza e não aceitação.

**Descritores**: Neoplasias Colorretais; Estomia; Qualidade de Vida; Pesquisa Qualitativa; Filosofia.

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## Introduction

Colorectal cancer stands out among neoplasms. The incidence of this type of cancer in people under 40 years old is low. In 90.0% of cases it takes place in those above 50. One evident problem of this disease is its silent advance, which diminishes the chance of an early detection. That is why an efficient prognosis is directly tied to an early diagnostic<sup>(1)</sup>.

Worldwide, colorectal cancer is the deadliest, with nearly 900,000 deaths a year. Factors such as the aging of the population, inadequate dietary habits, obesity, absence of physical activity, and smoking, increase the risk of the disease<sup>(2)</sup>.

In Brazil, according to statistics for colorectal cancer, there were 19,603 cases in 2018, 9,608 of which were in males and 9,995 of which were females. Estimates indicate that, in 2020, there will be 41,010 new cases of colorectal cancer in the country, making it the second type of cancer with the highest estimated incidence, according to the primary location of the tumor<sup>(3)</sup>. These data show that it is relevant to study the epidemiology of this type of cancer for society.

Depending on the stage of the colorectal neoplasm, the main treatment is surgical. The most radical surgery implies in the removal of the rectum and of the large intestine, requiring an ostomy to be placed and, as a result, leading to social, physical, and psychological impacts<sup>(4)</sup>.

The word ostomy originates from the Greek word "stomia", which means "opening". Its main use is in the gastrointestinal tract and its main types have the objective of intestinal evacuation, and are known as colostomies and ileostomies<sup>(5)</sup>. This surgical procedure aims to circumvent the complications resulting from neoplasms and intestinal diseases.

Despite its benefits, ostomies bring many social, psychological, and religious changes to one's life. The individual needs to balance daily life tasks, port-operative care, self-care, and social interactions. Additionally, it is challenging to the accept one's self-

-image, the feeling of grief, and the changes in life habits caused by the stoma<sup>(6)</sup>.

Considering the impacts in the lives of the individuals who live with ostomies due to colorectal cancer, it is essential to get to know the subjectivities that permeate said alterations and impact the quality of life of these people. National and international scientific literature are still lacking in works about living with ostomies and the implications it brings to the quality of life of individuals who are not evaluated by rigid quantifiable scales, pointing to the need of recognizing the unique life experiences of these people and subsidizing unique practices of care.

In this situation, evaluating the quality of life should make it possible to understand the changes, which involve from the psychological state to the environment in which the ostomized people live<sup>(4)</sup>.

This study is justified by the importance of knowing the relation between the quality of life and living with ostomies that result from colorectal cancer, as to investigate the magnitude of the changes in the perception of health and quality of life of these people. As a result, this study aimed to understand the perception of ostomized patients affected by colorectal neoplasms regarding their quality of life

## Methods

This is a mixed method study, with a qualitative approach, carried out in a specialized center for the health care of ostomized patients in Fortaleza, Ceará, Brazil. Its participants were 15 ostomized patients with a diagnostic of colorectal cancer, attended at the institution. Inclusion criteria considered patients from 18 to 65 years old who had the ostomy for at least three months and were regulars in the institution that was the field of study. Patients who missed five or more consultations in the place of collection and those who had psychiatric disorders, or some type of cognitive deficit, were excluded. The research used a convenience sample.

The number of patients was determined by the theoretical exhaustion of data. In data collection, theoretical exhaustion is reached when adding new information does not change the understanding of the phenomenon investigated and no new elements can be found<sup>(7)</sup>. For each participant, an alpha-numeric code (E1 to E15) was used, to keep interviewees anonymous.

Data collection was carried out from October to November 2019, by a male student from the nursing course, adequately trained in the subject of ostomies. Two instruments were used for the collection. The first one was a questionnaire with socioeconomic, demographic, and clinical data, aiming to acquire information on the participants of the study. It addressed aspects such as sex, age, marital status, profession, educational level, who the participant lives with, physical activity, and leisure.

The questionnaire for the evaluation of the quality of life from the World Health Organization, known as the World Health Organization Quality of Life-Bref (WHOQOL-Bref) set the standards for the production of the questions carried out in the interviews. The instrument addresses issues related to the Physical, Psychological, Social Relations, and Environment domains<sup>(8)</sup>. The items from each of these domains were the base for the formulation of the guiding questions of the interview. The questions generated reflections and responses from the individuals that were based on life experiences, and as a result, three non-structured questions were produced: How do you perceive your quality of life? How do you evaluate your physical conditioning since you were ostomized? How do you evaluate your mental health since the ostomy was implanted?

The interviews lasted for approximately 10 minutes and were carried out privately, in a waiting room near the nursing office of the institution where the research was carried out. The only ones present were the researcher and the participant, and the interviews were recorded and transcribed in full. There

was no need to repeat any question. During the interviews, field notes were registered.

Bardin's content analysis technique was used to analyze the data. It is divided in the stages of pre--analysis, material exploration, and data treatment. In the pre-analysis stage, after the transcription of the lines, paragraphs were selected as contextual units capable of representing the ideas that were in consonance with the study subject<sup>(9)</sup>.

Later, during the exploration and treatment of the material, the units in the records that would generate the thematic categories were identified. These Record Units were sentences manually removed from the context units, highlighted using colorimetry and grouped in similar colors, according to the synthesis and congruence of the thoughts<sup>(9)</sup>.

To analyze and discuss the data, some assumptions from Alfred Schutz Social Phenomenology were used. This framework point at the fact that the world experienced by these people, which it calls social actors, is built by them. Data collected in the field are previously structured by those who pronounce them, and are filled with meanings for those who live the $re^{(10)}$ 

This research did not attempt to carry out a phenomenological analysis, merely trying to use it as a base for the point of view that would lead to the production of the corpus of the study, considering the lens of daily life, in which something is experienced and the individual is both influencer and influenced, according to the situation experienced due to the stoma. It should also be considered that the discussion was carried out in a reflexive way, based on the scientific literature on the theme.

This study followed the recommendations from Resolution 466/2012, from the National Council of Health, and was approved by the Research Ethics Committee of the Universidade Federal do Ceará, under opinion No. 3,765,607/2019 and Certificate of Submission to Ethical Appreciation No.19892819.5.0000.5054.

## Results

15 patients were interviewed. Their mean age was 55 years old, varying from 37 to 65, with a mean income of R\$ 1,630. With regards to their educational level, it varied from the second year of elementary education to complete higher education. Regarding their marital status, four participants were married, four were single, three were divorced, three were widowers, and one was in a stable union. Regarding religion, only one was evangelical, while the others were catholic.

Regarding their occupation, four participants were unemployed, three employed, three retired, two self-employed, two on health leave, and one lived on welfare. Other information was related to the time using the stoma. The patients had been using it for from three months to 10 years, while the time since their diagnostic of colorectal cancer varied from 6 months to 10 years.

Three thematic categories emerged from the statements of the interviewees: Quality of life: social, psychic, and spiritual influences; Personal and environmental adaptations considering the new reality; and Complications of living with an ostomy. The findings of this research were presented to the professionals in the health team from the institution were the research took place and to the interviewees themselves, in order to provide and receive feedback.

## Quality of life: social, psychic, and spiritual influences

In this category, there were 60 recorded units, resulting from the lines of all people who used the codifiers "normal life"; "thanking God", and "sadness". Three aspects related to the perceptions of the quality of life were found: social, emotional, and spiritual.

Regarding the social impact and the positive aspect of this condition, patients who had been ostomized for longer stated that they had normal lives after

the stoma was introduced, meaning that there were few or no significant changes in their routines or in their biopsychosocial aspects. Also, this perception varied when the individuals stated to have become used to the ostomy since the beginning: My social life? It didn't change at all, the same thing before treatment (E1). I didn't feel any differences, in regard to believing that I'm more frail, feeling weaker, no, no difference, I eat normally, you see? (E7). It was also found that the interviewees who lived with the ostomy for longer were better adapted to the condition.

Another positive feature highlighted by the interviewees with regard to the quality of life and the impact in the Physical dimension was the improvement in the clinical conditions after the stoma was implanted. They recognized the device as an essential part of the treatment and of the cure of the pathologies that afflict them: Better... because before it I was throwing up a lot, I felt stomach pains, and after the tumor was shown in the operation I had, which was sudden, I didn't know what they would do, and only after I woke up I found out about it... but the fact that I don't feel anything alone makes it better already (E13).

On the other hand, some patients become socially isolated due to not being able to adapt physically to their new reality. Many of them prefer not leaving their houses due to the fear that some accident could happen with their pouches, in addition to feeling embarrassed by the device: Oh, it's very difficult... not being able to leave, I just stay home, caring for the, there's no way I have the nerve to leave... it's aggravating (E11). Much less (going out) because I don't want to... I don't want this to be what I give to people (colostomy images), I want to give them happiness, optimism... I don't want to show it, because many people, when they know about the problem, want to treat me with compassion, with pity (E9).

With regards to the emotional influences, the negative aspects related to the quality of life are very clearly presented in the Psychic dimension, in which some of these people manifest feelings of sadness and nonacceptance: I'm really sad, thinking about it all the time (at the ostomy) (E8). I was feeling very bad, earlier, but after I had the operation... At first, I was depressed, but I was attended by the psychologist and I understood that I was feeling much better than I would if

I hadn't... Because if I hadn't done the colostomy, I wouldn't be here anymore, I would have gone away (E14). At first, I felt the impact, I didn't want to accept it (E1).

With regards to spiritual influences, it shows the perspective of improving the quality of life of these people with the support of divine entities, while other patients thank God for improvements in their quality of life or for the support they received to overcome the challenges that came after the surgery: *So, I just let God do His work, there is no reason for me to despair* (E7). Everything is done by God, so all we can do is thank Him, right... I'm fine, I eat well, thank God, I'm eating already (E6). I feel great, fighting, a lot of faith in God, wonderful (E9).

## Personal and environmental adaptations considering the new reality

This category generated 20 record units from 12 participants, with the coding change and adaptation. Many patients found it difficult to adapt to their new lives, with the presence of the ostomy pouches. The reported the need to carry out adjustments to accommodate the devices, in addition to making changes to the infrastructure of their residence.

To do so, the patients changed their homes. These changes varied from the installation of sinks to the building of new rooms in the house: *In my house, I adapted my toilet, I made a bathroom just like needed, had them install a strong shower...* (E14). *The house, I changed, I put a sink, something to clean the pouch in* (E2). *One extra compartment* (that the patient had built), *I bought a little bed for me, a single bed...* (E8).

They also, in most cases, had to use objects to overcome the problem of changing the pouch when they were not home. This situation shows the creativity and versatility of the patients, as promoted by the use of the ostomy pouch and their attempts to continue living normally: Well, I bring a plastic PET bottle in my backpack, I call it my portable douche, and then I empty it there (E1). When I go to the house of someone I know I take a bottle of water and a diaper, as if I was a baby, I have it cleaned and ironed and neatly folded so when it's time to clean, I do it myself (E14).

## Complications of living with an ostomy

This category generated 14 recorded units from 12 participants, with the codifiers: physical challenges and memory changes. In addition to the fact that the lives of the patients had to undergo many changes in adaptations, they also presented complications involving the ostomy, such as pain and fatigue, which intensify the negative feelings the patient had had since the cancer was discovered, such as sadness and denial: I believe that... when I'm dozing off under the effect of medications, when I'm in bed and I sleep on top of it, when I wake up I feel a bit of pain, but when I sleep like this, on the side... (E8). I got thinner, I'm more tired... and I lost calories (E4). I don't do any type of physical activity, and I should, I have trouble sitting down, grabbing things from the floor, I can't stay on my feet for long, nor can I sit down for long, so I have some trouble, and up here in this part of my femur, in this part of my surgery, I have some trouble (E12).

The confection of the ostomy is also permeated by memory changes: Here and there there's some missing (memories), and I'm remember something, and then, when I notice it, I don't know what's going on, it's not all the time, but I forget... I don't know (E5). My mind is very good, but now I forget everything... I don't know (if it is related to the ostomy), but it was after it that my head became like this (E11). From last year on, I'm becoming more forgetful, you know (E6).

#### Discussion

Limitations of this study included the fact that data collection took place in only one institution, the sample was small, and the methodological approach used makes it impossible to generalize the data. Therefore, later studies, with more people and diverse methodologies, can contribute and complement the information found by this research, making available new data that involve the aspects related to the quality of life, socioeconomic, and demographic characteristics of patients with colorectal cancer who have ostomies.

The collaborations brought by this research

are related to directing researches on the changes in the quality of life, the main aspects it affects, and the strategies developed by the patients to deal with this new reality, since not only their diagnostic of cancer, but also the changes in the lifestyle due to the ostomy bring challenges that they have to confront. Such design may give nurses information on the quality of life of these people, offering subsidies for them to carry out singular health care plans and directing them to the real needs of these individuals.

Understanding the patient when it comes to the procedures and the benefits of the ostomy is essential to better confront this challenge, especially as it is associated to such a destructive disease as cancer<sup>(11)</sup>. The influences imposed on the quality of life of these individuals, demanding from them changes in the arrangement of their social and psychic structures, which sometimes are held together by faith, seemed to be a simultaneous experience, in the sense that all seemed to go through the same one. It is essential to understand that the narratives are individually organized, requiring the nurse to look at each individual to outline the specific care adequate for each person.

People, as they receive hospital discharges, felt, mostly, distressed, since they were dealing with changes in their bodies and with problems that go from the specialized attention to the physical, social, and psychological impacts. That is why it is understandable that patients would not accept, at first, these changes, after the implantation of the stoma, and then would use adaptative strategies<sup>(12)</sup>.

It should be considered that two situations that change the body are juxtaposed as they are experienced by these people: the experience of a cancer, which brings changes and consumes the body internally; and the confection of the ostomy, which is attached to the dimension of the body and will expose the human excrement. That means that a body which gets sick is exposed, showing the frailty of the human and removing the false feeling of self-control.

Also, with regards to overcoming the challenges of living with an ostomy, the time with the ostomy

seems to be one of the factors that affects its confrontation and acceptance by the patient, making it possible for them to carry out daily tasks and go back to social relations<sup>(11)</sup>.

Anchoring this reality<sup>(10)</sup>, it is possible that some people have more knowledge due to the time spent living with the device, since they went through many situations, including inconveniences, adaptation of clothes, leakage, among other situations. This set of experiences become concrete and, in most cases, are elaborated to help adaptation.

Multiple experiences, permeated by the perception of the benefits, can also be noticed. The objective of the ostomy is, in addition to saving the life of the patient, reconstituting gastrointestinal functions. Therefore, despite the changes that the ostomy can bring to the life of the person, it brings them more benefits than harm. These benefits are the experiences reported in the post-op, in which there were significant clinical improvement, including the disappearance of abdominal pain<sup>(13)</sup>.

Understanding the gains with the use of the pouch was a found to be a paradoxical process, since, simultaneously, it frees the patient from pain, makes it possible to treat the cancer, and can be part of the process of achieving a cure. However, it is also a non-anatomic device, which presents in a very explicit manner the bodily secretions that people prefer to leave isolated. The nurse who is attending this type of patient must know that these doubts may surface with regards to the ostomy, and, as a result, try to guide them and their relatives in reflections about the implications of these experiences.

Among them, there are some challenges, one of which is the fear that the pouch will detach, which distresses the patients to the point of preventing them from leaving their houses. It was found that one of the greatest fears of patients is that the ostomy pouch would detach from their abdominal walls. It was inferred that incidents involving the pouch are part of the main challenge for the ostomized patients to go back to their social lives, and many of them, as a result,

restricted themselves to going to the doctor or work and coming back home<sup>(11)</sup>.

The fear that the pouch would detach is justified, since it happens frequently for many users. Many factors can lead to it, and it is possible to deal with many of them, but the event has permanent impacts in the life of these patients, which is made clear by the statements recorded in this study. Fearing this possibility, many do not follow the recommendations that indicate how long they should use the pouch, exchanging it more frequently, which damages the skin to which the pouch is attached and means that the input is wasted. Nurses must recognize this demand in its legitimacy, using their knowledge to identify the factors that make the pouch detach, and intervening to change this situation, until the patient feels safe.

Considering so many adaptations and confrontations, many patients had a better perspective to deal with the disease when they associated the experience with faith and spirituality. Having faith and practicing some religion has a good effect on people, since it functions as a pillar that gives support and strength to overcome this stage, with the consequent wellbeing<sup>(6)</sup>.

Spirituality is a strong condition for social organization. The world, in its plurality, has accepted that spirituality transcends religiosity and, as such, should be accepted by nurses as an anthropological feeling of the life experience of individuals and supported during care, especially when it enables positive adaptations in the lives of ostomized patients.

Regarding physical adaptations, the statements of the interviewees pointed to many, from the accommodation of the pouch to structural changes in the house. While searching for a new meaning for their lives, individuals start managing their own physical conditions, adapting to a new way of living<sup>(11)</sup>. This starts with changes in the use of the pouch.

With regard to the adaptations of the environment, a study pointed to the challenges ostomized people have to face when using conventional bathrooms or even bathrooms adapted for wheelchair users, showing the importance of structural adaptations

directed to the ostomized patients themselves, as to provide them with a more comfortable life $^{(14)}$ .

After the challenges are overcome or even while dealing with them, the ostomized advanced in the practice of self-care and in structural modifications in their houses, important factors in the acquisition of autonomy. Not all of them are always so creative, which, sometimes, makes it more difficult to have a more comfortable life.

To this end, the National Policy for the Health of People with Disabilities recommends that public places must be adapted for the use of ostomized people, to help them coexisting with the rest of society and become active members of it, exercising their citizenship and having equality in many aspects of daily life<sup>(11)</sup>.

Since there are not public policies subsidizing the environmental adaptation of public and private spaces, it is important to think about the political stance of the nursing workers, who, as they identify the repressed demands that originate from the ostomized people, can elaborate policies and programs that subsidize the needs of these beings.

Another aspect reported by the patients interviewed were the secondary physical complications that result from the disease and from the stoma, such as pain and fatigue, in addition to other repercussions, such as memory loss. Ostomized patients have psychological, social, and emotional fragilities that result from the changes caused by the implantation of the stoma<sup>(6)</sup>.

Embracing the feelings they experience implies that the nurse must create a bond without judging them. Ostomized people go through an experience that may be common, but which demands unique knowledge, and each one presents organic and emotional changes in a very particular way. These changes can reflect even more on the physical or psychic scope; the nurse must invest in a strong and substantiated therapeutic relationship.

In addition, problems generated by this new reality, such as the memory loss indicated in the interviews, may demand the professional aid of a psychologist, since they could be related to the ostomy. From another perspective, it should be noted that the patients who reported memory loss were older, and as a result, it was not possible to confirm whether the ostomy is the only source of the problem. Still, the nurse is not exempt from preparing this type of care, considering that these professionals must care for the person as a whole, in all their needs.

The physical problems related to the stomas, which generate complications, involve, in general, the use of low-quality pouches, the lack of knowledge about self-care, and complications regarding the patient themselves and their skin.

It was shown that focusing on self-care is the best way to avoid the surfacing of these complications<sup>(15)</sup>. This practice must be encouraged, so ostomized people manage to care for themselves, considering that the difficulties in self-care can generate additional problems associated to the ostomy, such as dermatitis, granulomas, prolapses, among others<sup>(16)</sup>.

Therefore, the participation of nurses in the empowering of patients with regards to self-care must be recognized, as it goes much beyond avoiding complications, and requires them to seek improving the quality of life of the patients, according to the context of each one.

## Conclusion

Patients with ostomies resulting from colorectal cancer, in general, have variations in the way they perceive their quality of life. In the physical domain, they consider the device to be vital in the treatment, but that it generated, *a priori*, social isolation, due to embarrassment, requiring them to adapt to the new reality as to diminish its emotional impact, which frequently presents in the form of sadness and non-acceptance. With regards to the spiritual domain, they pointed at improvements with the support from spiritual entities. Considering the above, it becomes clear that nursing workers must act directly in the many

domains of quality of life that are affected, and, if necessary, count on the support of the interdisciplinary

## **Collaborations**

Macêdo LM was responsible for data collection, analysis, and interpretation, and for the writing of the article. Cavalcante VMV collaborated through a relevant critical review of the intellectual content and the final approval of the version to be published. Coelho MMF, Ramos SLTC and Rodrigues AB took part in the writing of the article and in the relevant critical review of the intellectual content. Correia DL and Menezes TAC took part in data interpretation and analysis of data.

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