

Quality of life in colostomized colorectal cancer patients

Qualidade de vida em pacientes com câncer colorretal colostomizados

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ABSTRACT | OBJECTIVES: To evaluate the quality of life of patients with colostomy due to colorectal cancer. **MATERIALS AND METHODS:** This is a quantitative descriptive study carried out in the Programa de Pessoas Ostomizadas (Ostomized Persons Program) through the application of two questionnaires, the first to evaluate sociodemographic aspects and the second the Stoma-QoL developed to measure the quality of life of people with a stoma. Descriptive analyses of the variables were carried out, with the qualitative variables categorized and organized into absolute and relative frequencies, and for the quantitative variables, measures of central tendency (mean and median) and dispersion (minimum, maximum, and standard deviation) were calculated. **RESULTS:** There was a predominance of males, with a low level of education, low per capita income, and lack of physical activity and psychological support. Concerns about aspects involving the colostomy bag and the stoma were very present, as were tiredness and the need to rest during the day. The individuals obtained a good assessment of their quality of life. **CONCLUSION:** Although the results do not indicate a poor quality of life for the participants, there are still some peculiarities that require attention and training from health professionals aiming for an individualized and humanized assessment.

KEYWORDS: Colostomy. Quality of Life. Colorectal Neoplasms.

RESUMO | OBJETIVOS: Avaliar a qualidade de vida de pacientes com colostomia decorrente de câncer colorretal. **MATERIAIS E MÉTODOS:** Trata-se de um estudo quantitativo descritivo realizado no Programa de Pessoas Ostomizadas, através da aplicação de dois questionários, sendo o primeiro para avaliar os aspectos sociodemográficos e o segundo o Stoma-QoL desenvolvido para medir a qualidade de vida de pessoas com estoma. Foram realizadas análises descritivas das variáveis, sendo as variáveis qualitativas categorizadas e organizadas em frequências absolutas e relativas, e para as variáveis quantitativas foram calculadas as medidas de tendência central. **RESULTADOS:** Observou-se o predomínio do sexo masculino, com nível baixo de escolaridade, baixa renda per capita, ausência da prática de atividade física e de acompanhamento psicológico. As preocupações com os aspectos que envolvem a bolsa de colostomia e o estoma foram bastantes presentes, assim como o cansaço e a necessidade de descansar durante o dia. Os indivíduos obtiveram uma boa avaliação da qualidade de vida. **CONCLUSÃO:** Apesar dos resultados não pontuarem má qualidade de vida dos participantes, ainda existem algumas peculiaridades que requerem atenção e capacitação dos profissionais de saúde objetivando uma avaliação individualizada e humanizada.

PALAVRAS-CHAVE: Colostomia. Qualidade de Vida. Neoplasias.

1. Introduction

According to the Instituto Nacional de Câncer – INCA (National Cancer Institute), colorectal cancer is the second most common type of cancer.¹ In 2020, 40,990 new cases were recorded, 20,520 in men and 20,470 in women, and 20,245 deaths, 9,889 men and 10,356 women.^{2,3} For each year of the three-year period 2023-2025, 704,000 new cases of cancer are expected in Brazil, especially in the South and Southeast, which account for around 70% of the incidence.¹

Colorectal cancer has the highest annual mortality rate in the world, causing around 900,000 deaths. Intrinsic and extrinsic factors can determine the incidence of the disease, such as smoking, ageing, poor eating habits and lack of physical exercise.^{3,4}

In colorectal cancer, as well as in various pathologies such as abdominal trauma, congenital anomalies and inflammatory diseases, there may be a need for a colostomy, which is a surgical procedure designed to externalize part of the large intestine through an orifice in the abdominal wall, which can be permanent or temporary, with the aim of eliminating feces and flatus.⁵ It is necessary for colorectal cancer when the tumor partially or completely obstructs the passage of feces, preventing the elimination of body fluids. When the colostomy is temporary, intestinal activity can be re-established by resuming the continuity of intestinal transit. A definitive colostomy occurs when the final portion of the colon or rectum is compromised, making it impossible to re-establish the intestinal path.⁵⁻⁶

The various changes experienced by people who need a colostomy, be they emotional, social or physical, can result in low self-esteem and impaired quality of life, which triggers non-acceptance of self-image, social isolation, impaired sexuality, fear, feelings of mourning and worthlessness, influencing the process of coping with this new reality.⁷⁻⁸

The difficulties faced in handling the bag can also significantly interfere with the colostomized person's quality of life. Detachment of the bag can lead to leakage of fecal contents, gases and odors, stomal prolapse and fistula. In addition, the embarrassment of wearing the bag makes the user put it under their clothes, causing skin irritation.^{7,9} The fear and insecurity of colostomized patients that one of these complications will occur prevents them from living in society, leading them to become reclusive. With this distancing behavior, they even withdraw from their work environment.^{8,10}

Health professionals play a fundamental role in the process of rehabilitation and re-socialization of colostomized patients, based on guidance and health education aimed at overcoming the feelings of shame and overall difficulties, promoting independence, autonomy and understanding of the new reality, resulting in a better quality of life. It also contributes to social reintegration and the prevention of complications. Humanized care prioritizes self-care and promotes the health and well-being of ostomy patients and their families.^{8,11}

A colostomy can have a profound impact on the physical, emotional and social aspects of an individual's life. Changes in body image, adaptation to colostomy devices and the need to readjust daily routines are aspects that can affect the perception of well-being and independence. In this context, assessing the quality of life of these patients enables a more comprehensive understanding of their needs, helping health professionals to develop more effective and personalized interventions that promote not only survival but also an improved quality of life. Therefore, this study aimed to assess the quality of life of patients with a colostomy due to colorectal cancer.

2. Materials and methods

This is a descriptive and quantitative study carried out in partnership with the Programa de Pessoas Ostomizadas (Ostomized Persons Program) from the municipality of Campos dos Goytacazes, Rio de Janeiro. This program aims to promote the appreciation and development of users' potential to face their new lives and minimize the discomfort caused by illnesses. It provides assistance to patients who use tubes and catheters (for urinary incontinence) and patients who have undergone intestinal ostomies and surgical interventions with the aim of eliminating waste from the body - such as colostomies - using a stool collection bag. It also provides care to patients diagnosed with neoplasms. The unit has professionals such as a coloproctologist, a general practitioner, nursing assistants, nurses, a psychologist, a social worker and a pharmacist.¹²

The sample consisted of 30 patients, including those over the age of 18 diagnosed with colorectal cancer and using the stomatherapy service. Patients with neurocognitive disorders or any cognitive deficit were excluded. The data was collected by the researchers between November 2022 and January 2023.

Two instruments were used to collect the data. The first was a questionnaire that assessed sociodemographic aspects, with the aim of getting to know the profile of the patients taking part in the study, as well as data on the colostomy. The variables investigated were: age, place of birth, origin, gender, color/race, marital status, per capita income, schooling, physical activity and data on the colostomy, such as type, duration, time of use, time of replacement, who and how often the bag is sanitized, as well as questions regarding psychological follow-up after the colostomy, improvement in quality of life after this follow-up and how often the patient has negative feelings.

The second instrument used was the Stoma-QoL questionnaire, developed to measure the quality of life of people with a stoma and validated for Brazilian Portuguese. This instrument addresses the following questions: concerns about sleep, concerns about

intimate relationships, concerns about relationships with family and close friends and concerns about relationships with people other than family and close friends. The questionnaire consists of 20 questions and all questions are on a four-point Likert scale (never=4, rarely=3, sometimes=2 and always=1). The sum of the answers results in a total score ranging from 20 to 80 and was been converted to a scale of 0 to 100, where one score represents the highest level of quality of life, while lower scores represent low levels of quality of life.^{13,14}

After applying the questionnaires, the data was compiled in the Microsoft Office Excel program, version 2016, where the database was built, and then the data was exported to the Statistical Package for the Social Sciences (SPSS), version 20.0. Descriptive analyses of the variables were carried out, with the qualitative variables categorized and organized into absolute and relative frequencies, and for the quantitative variables, measures of central tendency (mean and median) and dispersion (minimum, maximum and standard deviation) were calculated.

The project was submitted to the Comitê de Ética em Pesquisa - CEP (Research Ethics Committee of the Institutos Superiores de Ensino do CENSA (Higher-education Institutes of CENSA) for ethical appraisal, and only began after approval under CAEE nº 64265122.7.0000.5524. The data was collected after signing the Informed Consent Form (ICF), complying with the ethical aspects of research involving human beings.¹⁵

3. Results

Of the 30 colostomized individuals, the majority were male (60.0%), white (53.3%), married (46.7%) and had elementary school education (36.7%). The average age was 56.7 years (SD=14.3 years), ranging from 26 to 86 years. Per capita income ranged from R\$242.20 to R\$2,727.25, with an average of R\$855.23 (SD=R\$582.18), as shown in table 1 below.

Table 1. Sociodemographic characteristics of colostomy patients, Campos dos Goytacazes-RJ, 2023. (n=30)

Quantitative variables	Average	Standard deviation
Age	56.7	14.3
Per capita income	855.23	582.18
Qualitative variables	n	%
Sex		
Feminine	12	40.0
Masculine	18	60.0
Color/race		
White	16	53.3
Brown	10	33.3
Black	two	6.7
Yellow	two	6.7
Marital status		
Yes, I am formally married	14	46.7
Yes, I have a common-law marriage	4	13.3
No, but I've been married or lived with someone before	10	33.3
I've never been married or lived with anyone	two	6.7
Education		
From the 1st to the 4th grade of elementary school I	7	23.3
From the 5th to the 8th grade of elementary school II	11	36.7
High school incomplete	1	3.3
Completed high school	9	30.0
Higher education completed	two	6.7

Source: the authors (2023).

Colostomy time ranged from 1 month to 276 months with an average of 43.4 months (SD=73.0 months). Regarding the number of times the bag was emptied, they said they emptied it between 1 and 10 times a day, with an average of 4.8 times (SD= 2.5 times). There was a predominance of temporary use of the bag (70.0%) and 31.0% changed it every 5 days. When asked who cleans the bag, 90.0% answered that they do it themselves. The majority did not practice physical activity (76.7%), had no psychological support after the colostomy (60.0%) and had never felt any negative symptoms (33.3%). It is worth noting that of those who had psychological support after the colostomy, most reported an improvement in their quality of life (83.3%). The score related to quality of life ranged from 43.7 to 100.0, with an average of 65.9 (SD= 14.1), characterizing a good quality of life, as shown in table 2 below.

Table 2. Clinical characteristics, care and quality of life of colostomized patients, Campos dos Goytacazes-RJ, 2023. (n=30)

Quantitative variables	Average	Standard deviation
Colostomy time	43.4	73.0
Emptying frequency	4.8	2.5
Quality of life score	65.9	14.1
Qualitative variables	n	%
Scholarship temporality	21	70.0
Temporary	9	30.0
Definitive		
Bag exchange time (days)		
2	4	13.8
3	5	17.2
4	5	17.2
5	9	31.0
7	5	17.2
10	1	3.4
Who sanitizes the bag		
Spouse	two	6.7
Myself	27	90.0
Child	1	3.3
Physical activity		
Yes	7	23.3
No	23	76.7
Psychological support		
Yes	12	40.0
No	18	60.0
Improved quality of life after psychological counseling		
Yes	10	83.3
No	two	16.7
Negative symptoms after colostomy		
Always	4	13.3
Sometimes	9	30.0
Rarely	7	23.3
Never	10	33.3

Source: the authors (2023).

In relation to the frequency of responses to the items, it was observed that the majority reported always feeling anxious when the pouch is full (36.7%), worrying about the possibility of the pouch coming loose (66.6%), feeling the need to know where the nearest toilet is when leaving (73.3%), worrying about the smell of the pouch (73.3%), worrying about noises from the stoma (33.3%), needing to rest during the day (40.0%), limiting themselves when choosing clothes (50.0%) and sometimes feeling tired during the day (46.7%). There was a predominance of patients who rarely felt sexually unattractive (36.7%) and who sometimes slept badly at night (40.0%). Half of the participants said they never worried about the bag making noise.

The majority never felt ashamed of their body because of their colostomy (46.7%), had no difficulty spending the night away from home (34.5%), didn't hide the fact that they wore a colostomy bag (70.0%), did not worry about the ostomy being a problem for people close to them (73.3%), did not avoid close contact with friends (66.7%), reported never finding it difficult to be with other people (60.0%), was never afraid of meeting new people (76.7%), never felt lonely (76.7%) and reported not feeling worried about their family feeling uncomfortable being around them (76.7%), as shown in table 3 below.

Table 3. Frequency distribution of responses to the Stoma-QoL questionnaire applied to colostomy patients, Campos dos Goytacazes-RJ, 2023. (n=30)

Questions	Always	Sometimes	Rarely	Never
	n (%)	n (%)	n (%)	n (%)
Do I get anxious when the bag is full?	11 (36.7)	7 (23.3)	3 (10.0)	9 (30.0)
Do I worry that the bag might come loose?	20 (66.6)	8 (26.7)	0 (0.0)	2 (6.7)
Do I feel the need to know where the nearest toilet is?	22 (73.3)	3 (10.0)	3 (10.0)	2 (6.7)
Am I worried that the bag might smell?	22 (73.3)	2 (6.7)	2 (6.7)	4 (13.3)
Am I worried about the noises the stoma makes?	10 (33.3)	9 (30.0)	4 (13.3)	7 (23.3)
Do I need to rest during the day?	12 (40.0)	11 (36.7)	4 (13.3)	3 (10.0)
Does the bag limit your choice of clothing?	15 (50.0)	7 (23.3)	1 (3.3)	7 (23.3)
Do I feel tired during the day?	4 (13.3)	14 (46.7)	3 (10.0)	9 (30.0)
Does the colostomy make me feel like I am not sexually attractive?	7 (23.3)	2 (6.7)	11 (36.7)	10 (33.3)
Do I sleep badly at night?	7 (23.3)	12 (40.0)	3 (10.0)	8 (26.7)
Am I worried about the bag making noises?	7 (23.3)	3 (10.0)	5 (16.7)	15 (50.0)
Do I feel ashamed of my body because of the colostomy?	8 (26.7)	5 (16.7)	3 (10.0)	14 (46.7)
Is it difficult for me to spend a night away from home?	8 (27.6)	8 (27.6)	3 (10.3)	10 (34.5)
Is it difficult to hide the fact that I wear a colostomy bag?	2 (6.7)	5 (16.7)	2 (6.7)	21 (70.0)
Am I worried that my condition will be a problem for the people close to me?	5 (16.7)	2 (6.7)	1 (3.3)	22 (73.3)
Do I avoid close physical contact with my friends?	4 (13.3)	4 (13.3)	2 (6.7)	20 (66.7)
Does the colostomy make it difficult for me to be with other people?	1 (3.3)	10 (33.3)	1 (3.3)	18 (60.0)
Am I afraid of meeting new people?	2 (6.7)	4 (13.3)	1 (3.3)	23 (76.7)
Do I feel lonely even when I am with other people?	0 (0.0)	4 (13.3)	3 (10.0)	23 (76.7)
Am I worried that my family will feel uncomfortable around me?	2 (6.7)	2 (6.7)	3 (10.0)	23 (76.7)

Source: the authors (2023).

4. Discussion

The sociodemographic characteristics such as age, color/race, and marital status showed results similar to those found in a study of ostomized patients treated at the Sergipe Health Care Center in Aracaju/SE¹⁶, in which the majority of patients with intestinal colostomies were over 50 years old, with 53.3% being white and 46.7% married.

There was a predominance of males, corroborating the study carried out in a reference center for people with disabilities in the Northeast of Brazil.¹⁷ Regarding education, the majority had completed middle school, corroborating the study carried out at the Polo da Baixada Litorânea do Serviço de Atenção Básica à Pessoa Ostomizada – Polo I (Baixada Litorânea Hub of Primary Care Service for Ostomized People - Hub I), located in the municipality of Cabo Frio/RJ¹⁸, in which the majority had completed elementary school. This may be a factor in the failure to prevent colorectal cancer, since a lower level of knowledge makes it difficult to acknowledge health problems, including those in eating habits.¹⁹

The per capita income found in this study ranged from R\$242,20 to R\$2.727,25, which presents a risk in terms of supporting the necessary treatments financially, negatively influencing quality of life due to this lack of resources for basic care such as food, housing, health and leisure.²⁰

The colostomy time variable showed an average frequency similar to that found in the study carried out in Sergipe, Aracaju/SE.¹⁶ In relation to the temporary nature of the bag, the majority reported that it was temporary, diverging from the data found in the study carried out with stoma patients treated at the stoma outpatient clinic of a hospital in Goiânia/GO, in which the majority reported that it was permanent. This influences quality of life since patients want to return to their previous condition.¹⁰

The prevalence of a sedentary lifestyle is a factor that is detrimental to the quality of life of these individuals.^{7,10,20} Psychological support has resulted in a better quality of life, with the possibility of reducing negative impacts.⁷

Concerning the items on the quality of life questionnaire, what most concerned the research subjects was the risk of the bag smelling bad and the need to know where the nearest toilet is, differing from the study carried out in Aracaju/SE¹⁶, in which the main cause of concern was the filling of the bag and the fear of the bag coming loose. The social, physical and psychological limitations that lead to embarrassment and the fear of “accidents” due to intestinal physiology result in impeding and damaging factors for the reintegration of these patients into society, leading them to social isolation.²¹

Most of the patients reported feeling tired during the day, sleeping badly at night and always needing to rest during the day, showing that there are changes in these domains and corroborating the study carried out with ostomized patients seen at the specialty clinic of the Universidade Federal do Triângulo Mineiro – UFTM (Federal University of Triângulo Mineiro), in the city of Uberaba/Minas Gerais²² which mentions insomnia and fatigue as the main physical symptoms. They also reported that they rarely felt sexually unattractive, an aspect that corroborates the study carried out at St. Paul's Hospital Millennium Medical College/Ethiopia which states that this is an impediment factor in the sexual sphere.²³

Regarding the relationships with friends and family, the majority have never felt uncomfortable, are not afraid to meet new people or feel lonely and are never worried about their new condition being a problem for people close to them. These factors were important in the general analysis of quality of life, which proved to be good, confirming the importance of the support of those closest to them and their families in this new condition of the colostomized patient's life, as described in the study carried out with patients registered with the Programa de Ostomizados da Secretaria de Saúde do Distrito Federal (Ostomized Program of the Federal District Health Department).²⁰

Negative symptoms had little effect on quality of life, reaching a low score, which helped the participants to have a good perception and acceptance of their new condition and did not prevent them from socializing. The average scores indicated a good quality of life, corroborating studies carried out with colostomized patients in Goiânia/GO¹⁰ and in non-metropolitan Australia²⁴, which identified a good quality of life in colostomized patients.

The study's limitations include its sample size and the fact that it was only carried out on a specific group. However, this study makes important contributions to health professionals, patients and society, since it highlights the need for qualified care focused on quality of life, as well as coping with bodily changes, sexuality, maintaining the colostomy bag and social interaction, reducing the negative impacts caused by the current condition.

5. Conclusion

In this study, the sample was predominantly male, with a low level of educational background and a low per capita income. Despite this, the colostomy care reported was similar to that recommended by current protocols, a fact that influences the quality of life of these patients. The absence of physical activity and psychological support were identified, and these are considered relevant risk factors.

Concerns about aspects involving the colostomy bag and the stoma were very present, as well as feelings of fatigue and the need to rest during the day. The current condition influenced their self-image, generating the perception that they did not feel sexually attractive and were ashamed of their bodies. However, social relationships were little affected.

In the general analysis, the individuals had a good quality of life assessment, including a good perception of their body image and their social interactions, as well as a favorable adaptation to the use of the collection bag. Although the results do not significantly indicate the poor quality of life of the participants, there are still some peculiarities that require attention and training from health professionals, with the aim of an individualized and humanized assessment.

It is recommended that further research be carried out on this subject to improve the quality of life of ostomised patients, preventing and reducing possible complications in terms of the clinical picture, taking into account emotional, socio-economic and environmental factors.

Author contributions

Silva SS participated in the conception of the research question, methodological design, search for research data, interpretation of results and writing of the scientific article. Manhães TSS participated in the conception of the research question, methodological design, search for research data, interpretation of results and writing of the scientific article. Ricardo EV participated in the conception of the research question, methodological design, interpretation of the results and writing of the scientific article. Silva ATMF participated in the conception of the research question, methodological design, interpretation of results and writing of the scientific article. Santos CM participated in the conception of the research question, methodological design, interpretation of results and writing of the scientific article. Palermo TAC participated in the conception of the research question, methodological design, statistical analysis of research data, interpretation of the results of the scientific article and writing of the scientific article. All authors reviewed and approved the final version and are in agreement with its publication.

Conflicts of interest

No financial, legal or political conflicts involving third parties (government, private corporations and foundations, etc.) have been declared for any aspect of the submitted work (including but not limited to grants and funding, participation in advisory boards, study design, manuscript preparation, statistical analysis, etc.).

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