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## Original article

# Quality of life analysis in ostomized colorectal cancer patients

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## ABSTRACT

**Introduction:** the oncological patient submitted to ostomy faces multiple losses which affect their quality of life.

**Objective:** assess quality of life in ostomized patients due to colorectal cancer, regarding the physical, psychological, social and environmental relationships, treated at the Ostomy Program of the Health Department of Distrito Federal, Brazil.

**Methods:** epidemiological-based, analytical, cross-sectional and descriptive study. The sample consisted of 54 patients enrolled in the Ostomy Program of the Health Department of Distrito Federal - Brazil. The WHOQOL-BREF questionnaire was used to evaluate quality of life. Data was analyzed by Microsoft Office Excel 2010 and SPSS 20.0.

**Results:** the Physical, Social and Environmental aspects were correlated to the mean score, resulting in statistical significance ( $p < 0.0001$ ). The item "Positive feelings" in the Psychological Domain was the only one that did not achieve statistical significance.

**Conclusion:** the results demonstrate that the care of cancer patients with ostomies should focus on the technical-scientific, political and socio-educational actions, to allow a multidisciplinary team to recognize health as a right for all, working to guarantee the health care process.

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## Análise da qualidade de vida de pacientes estomizados devido ao câncer colorretal

### R E S U M O

#### Palavras-chave:

Qualidade de vida  
Ostomia  
Câncer colorretal

**Introdução:** a pessoa estomizada oncológica, depara-se com o enfrentamento de várias perdas, comprometendo sua qualidade de vida.

**Objetivo:** analisar a qualidade de vida de pacientes estomizados por câncer colorretal, sob as dimensões física, psicológica, de relações sociais e do meio ambiente, atendidos pelo Programa de Estomizados da Secretaria de Saúde do Distrito Federal, Brasil.

**Métodos:** estudo de base epidemiológica, de caráter analítico, com delineamento transversal e descritivo. Amostra constituída por 54 pacientes cadastrados no Programa de Estomizados da Secretaria de Saúde do Distrito Federal – Brasil. Utilizou-se o questionário WHOQOL-bref para avaliar a qualidade de vida. Os dados foram analisados pelos programas Microsoft® Office Excel 2010 e SPSS 20.0.

**Resultados:** as facetas dos Domínios Físico, Relações Sociais e Meio Ambiente estão correlacionadas com o escore médio, resultando na significância estatística ( $p < 0,0001$ ). A faceta “Sentimentos positivos”, do Domínio Psicológico foi à única que não obteve significância estatística.

**Conclusão:** os resultados demonstram que o cuidado à pessoa estomizada oncológica, deve privilegiar as condutas técnico-científicas, políticas, e sócio educativas, de forma a permitir que a equipe multidisciplinar, reconheça a saúde como direito de todos, atuando para garantir o processo de cuidar em saúde.

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## Introduction

The World Health Organization defines quality of life as “an individual’s perception of their place in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”.<sup>1</sup>

Colorectal cancer is among the leading causes of the surgical creation of a stoma and is related to a sedentary lifestyle, obesity, smoking habits, family history, genetic predisposition and a diet rich in red meats.<sup>2-4</sup>

This type of cancer is the second most prevalent in the world, being the third most common for men and the second for women, thus becoming a serious public health problem worldwide. Colorectal cancer is considered one of the most serious types of cancer in the adult world population, with increasing incidence and mortality in most countries.<sup>5</sup>

In the context of illness, one can identify two important cultural meanings: cancer, a disease that carries the stigma of death and suffering; and stoma, a physical mutilation, which, despite the fact that is kept hidden, brings many consequences.<sup>6-7</sup>

The cancer patient submitted to ostomy faces the loss of sphincter control caused by the opening of an intestinal stoma and carries concerns about the odor, leakage and physical discomfort, which can be a factor that affects interpersonal relationships.<sup>6-9</sup>

Given these circumstances, individuals with ostomies, despite fighting the cancer, have poor body image and self-esteem, and experience anxiety of rejection. The meaning of the change in the physical body and suffering regarding the new lifestyle affect the physical and psychological aspects, as well as social relationships and environment, compromising the quality of life of ostomized patients.<sup>2,6,9-10</sup>

The aim of this study was to assess the quality of life of ostomized patients for colorectal cancer, in the physical, psychological, social relationships and environment aspects, treated by the Ostomy Program of the Health Secretariat of Distrito Federal, Brazil.

## Materials and methods

### Study methodology

This is an epidemiological-based, cross-sectional and descriptive study with an analytical approach. It is characterized by the presence of a group of individuals with ostomies due to colorectal cancer, randomly selected, which was used as a basis for result comparisons.

The observations and measurements of variables of interest were performed simultaneously, constituting a statistical picture of what occurs at a given time.<sup>11</sup>

The study was approved by the Research Ethics Foundation of Fundação de Ensino e Pesquisa em Ciências da Saúde of the State Health Secretariat of Distrito Federal (CEP/FEPECS/SES/DF), under protocol number 418/200. The individuals who agreed to participate in the study signed an informed consent form after detailed explanation of the study objectives and procedures. The confidentiality and anonymity of the study subjects, as well of all data collected were guaranteed, according to Resolution 196/96 of the National Health Council.

### Sample

The sample consisted of fifty-four patients with ostomies due to colorectal cancer, enrolled in the Ostomy Program of the

Health Department of Distrito Federal, Brazil, in the Outpatient Clinics of Gama, Samambaia and Ceilândia Regional Hospitals.

The inclusion criteria were: patients diagnosed with colorectal cancer, submitted to surgical intervention that created a stoma, aged twenty years or older; the exclusion criteria were: children, adolescents, pregnant and lactating women, bedridden individuals, patients with other disabilities and those who refused to participate.

### Data collection

Data collection was carried out using a socio-demographic and clinical questionnaire and the WHOQOL-BREF questionnaire in Portuguese, which is a summarized version of the World Health Organization Quality of Life Assessment Instrument (WHOQOL-100).

The WHOQOL-BREF consists of 26 items that represent aspects, which in turn, refer to 4 domains: Physical, Psychological, Social Relationships and Environment. The answers to all the questions of the WHOQOL-BREF are obtained through a Likert five-point scale, for which scores range from 1 to 5.<sup>12</sup>

### Statistical analysis

Statistical analysis was performed using SPSS (Statistical Package of the Social Sciences, SPSS Inc, Chicago, USA) software for Windows, release 20.0, as recommended by the World Health Organization. Statistical significance was set at 5%.

Data from the WHOQOL-BREF questionnaire was analyzed by calculating the mean, standard deviation, proportions, and inferential analysis using the following statistical procedures: a confidence interval of 95%, Student's t test, normal distribution and Pearson's linear correlation coefficient.

## Results

The mean age of ostomized patients due to colorectal cancer was  $58.72 \pm 12.56$  years, of which 49.29% (n = 25) were males and 53.70% (n = 29) were females. Regarding family life, 22.22% (n = 12) lived with a partner (a), 51.85% (n = 28) lived with a partner and children, 14.81% (n = 8) lived with children, 7.40% (n = 04) lived with a relative and 3.70% (n = 2) lived alone.

There was a predominance of the married marital status of 74.08% (n = 40), completed elementary education of 53.70% (n = 29) and 70% (n = 28) of the individuals were retired or pensioners at the National Institute of Social Security.

Regarding religion, 48.14% (n = 26) were catholics, 37.03% (n = 20) were evangelists, 9.25% (n = 05) were spiritualists, 5.55% (n = 3) belonged to other denominations and 0% (n = 0) were atheists.

Work activity showed that 12.96% of the subjects (n = 7) were active, 48.16% (n = 26) were inactive, 11.11% (n = 6) were unemployed and 27.77% (n = 15) had other type of activity, whom are affiliated to the National Institute of Social Security (INSS), with a mean household income of 2.35 minimum wages.

In the sample group, 64.82% (n = 35) of the stomata were permanent and 35.18% (n = 19) were temporary. In addition to

the surgical treatment performed (stoma), 37.03% (n = 20) of the patients did not undergo another type of follow-up and 62.97% (n = 34) underwent another type of clinical follow-up.

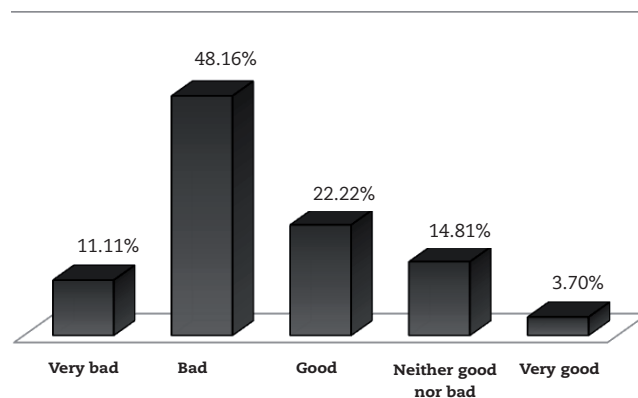
The WHOQOL-BREF questionnaire analyzes the mean scores, domains and overall quality of life. It was observed that patients rated their quality of life by classifying them as "very bad", 11.11% (n = 6), "bad", 48.16% (n = 26), "neither good nor bad", 22.22% (n = 12) "good", 14.81% (n = 8) and "very good", 3.70% (n = 2) (Fig. 1).

The correlation between each question and the mean score of the Physical Domain, showed that all facets of this domain are correlated with the mean score, and is statistically significant ( $p < 0.0001$ ). The facets "Sleep and rest", "Mobility", "Pain and discomfort", "Work capacity" and "Daily living activities" were the ones that most influenced the mean score of the Physical Domain, in this respective order (Table 1).

Regarding the mean score of the Psychological Domain, the feature "Positive feelings" was the only one who did not achieve statistical significance; that is, it did not correlate with the mean score of that domain. As for the feature "Spirituality / Religion / Personal Beliefs", it achieved a higher correlation (Table 2).

When evaluating the facets that make up the Social Relationships Domain, these were statistically significant ( $p < 0.0001$ ), so they were positively correlated with the mean score obtained in this domain (Table 3).

The facets of the Environment Domain are correlated with the mean score, resulting in statistical significance ( $p < 0.0001$ ). Therefore, the features that have the highest correlation were: "Financial Resources", "Opportunities for acquiring new information and skills", "Participation in and opportunities for recreation and leisure" and "Physical safety and protection" (Table 4).



**Fig. 1 – Analysis of the overall quality of life at the WHOQOL-bref questionnaire in ostomized patients due to colorectal cancer by the Health Secretariat of Distrito Federal, Brazil.**

**Table 1 - Correlation between each question and the mean score of the Physical Domain in ostomized patients due to colorectal cancer by the Health Secretariat of Distrito Federal, Brazil.**

Questions	Assessed feature	Cancer	
		r	p
1	Pain and discomfort	0.46	< 0.0001
2	Energy and fatigue	0.62	< 0.0001
3	Sleep and rest	-0.48	< 0.0001
9	Mobility	0.41	< 0.0001
10	Daily life activities	0.50	< 0.0001
11	Dependency on medication or treatments	0.52	< 0.0001
12	Capacity to work	0.49	< 0.0001

**Table 2 - Correlation between each question and the mean score of the Psychological Domain in ostomized patients due to colorectal cancer by the Health Secretariat of Distrito Federal, Brazil.**

Questions	Assessed feature	Cancer	
		r	p
4	Positive feelings	-0.08	0.278
5	Thinking, learning, memory and concentration	0.73	< 0.0001
6	Self-esteem	0.60	< 0.0001
7	Body image and appearance	0.58	< 0.0001
8	Negative feelings	0.59	< 0.0001
24	Spirituality/religion/ personal beliefs	0.39	< 0.0001

**Table 3 - Correlation between each question and the mean score of the Social Relationships Domain, in ostomized patients due to colorectal cancer by the Health Secretariat of Distrito Federal, Brazil.**

Question	Assessed feature	Cancer	
		r	p
13	Personal relationships	0.49	< 0.0001
14	Social support	0.39	< 0.0001
15	Sexual activity	0.43	< 0.0001

**Table 4 - Correlation between each question and the mean score of the Environment Domain, in ostomized patients due to colorectal cancer by the Health Secretariat of Distrito Federal, Brazil.**

Question	Assessed feature	Cancer	
		r	p
16	Physical safety and protection	0,57	< 0,0001
17	Home environment	0,68	< 0,0001
18	Financial resources	0,38	< 0,0001
19	Health and social care: availability and quality	0,59	< 0,0001
20	Opportunities to acquire new information and skills	0,41	< 0,0001
21	Participation in and opportunities of recreation/leisure	0.43	< 0.0001
22	Physical environment: (pollution/noise/ traffic/climate)	0.40	< 0.0001
23	Transportation	0.73	< 0.0001

**Discussion**

In the socio-demographic and clinical characterization, the mean age of ostomized patients due to colorectal cancer was 58.72 ± 12.56 years. This result supports previous studies that indicated a prevalence of colorectal cancer in the age group older than 50 years. More than 90% of colorectal cancers affect individuals older than 50 years.<sup>5-6</sup>

The analysis showed that there was a predominance of females, which is consistent with studies performed by the National Cancer Institute (INCA) in Brazil in 2012, where estimates for the same year will be valid for the year 2013 also. A total of 14,180 new cases of colorectal cancer are expected for men and 15,960 for women. The estimated number of new cases of colorectal cancer in Distrito Federal is 510, being 220 men and 290 women, with gross percentages of 16.89% and 20.50%, respectively.<sup>5</sup>

The data become relevant when family life is discussed, since the family is seen as the support system, which cares for the individual with ostomies concerning the physical and emotional distress, involving the bond of affection.<sup>13-15</sup>

Regarding marital status, it was observed that 74.08% (n = 40) of the patients were married. International studies<sup>2-3,16</sup> indicate that 60% of ostomized individuals with colorectal neoplasia are married and 95% lived with a partner; in addition, some national studies indicate that most individu-

als are married, totaling a percentage between 61.9% and 87.5%.<sup>4,6</sup>

Given the above, continuous and permanent companionship and the presence of the family constitute a crucial support for ostomized patients with cancer to help them cope with the emotional and social impacts; therefore, the quality of life is closely associated with the psychological status and social relationships.<sup>7,10,13,17</sup>

Family income and educational level were relatively low, with a mean family income of 2.35 minimum wages, and a predominant instruction of 53.70% ( $n = 29$ ) of elementary education completion. These data emphasize the importance of government assistance to these patients. The low level of schooling and family income may be a factor for the lack of prevention of colorectal cancer due to lack of information on the risk factors for this disease, including diet, which is based on the recommendation of high consumption of fruit, vegetables, cereals and fish, as well as exercise.<sup>4-5</sup>

In addition, the Chia Chum Li et al.<sup>18</sup> study depicts the association between educational level and quality of life, that is, individuals with higher educational levels tend to have a better quality of life.

There was a prevalence of 53.70% ( $n = 29$ ) of retirees and/or pensioners by the National Institute of Social Security, with the highest percentage of retired individuals among those with permanent stoma and older than 60 years, which is the reason why ostomized patients are considered special needs individuals in accordance to Decree N. 5296 of December 02, 2004.<sup>4</sup> A study has shown that the return to work among individuals with a temporary stoma range between 20 and 72%.<sup>6</sup>

The surgery for stoma creation causes a number of adaptations to life changes, resulting in a decrease in quality of life, regardless whether the stoma is temporary or permanent.<sup>4,7,10</sup>

When analyzing the overall quality of life (Fig. 1), it was considered "very bad" by 11.11% of patients ( $n = 6$ ) and "bad" by 48.16% ( $n = 26$ ). Studies indicate that the quality of life of individuals with cancer submitted to ostomies influence the changes that compromise their well-being, such as physical changes, and suffering regarding the new lifestyle, which modify the physical and psychological domains, as well as social relationships and relationship with the environment.<sup>4,6,13</sup>

The feature "Sleep and rest" achieved a higher correlation with the mean score of the Physical Domain, showing that the ostomy collector causes sleep disturbances in patients surviving colorectal cancer and in ostomized patients, significantly impairing the quality of life. Sleep disturbance is associated with the presence of the stoma, especially during the first months after surgery; and with fear about the future.<sup>19-20</sup>

Michelone & Santos<sup>6</sup> reported that the physical aspect greatly influences the quality of life of ostomized patients due to colorectal cancer, leading to increased pain and discomfort, dependence on medication or treatments, impaired sleep and rest, lack of mobility and difficulty in performing everyday activities and work capacity.

In the Psychological Domain, the feature "Spirituality/Religion/Personal Beliefs", achieved a higher correlation with

the mean score of that domain, and thus, the socio-demographic variables showed that all patients had a religion, or a belief. Studies have reported that religion can bring relief to suffering, as the spiritual welfare is associated not only with the psychological dimension, but also the cultural formation.<sup>7-8,18</sup>

A study carried out with a group of war veterans with colostomies concluded that religion/spirituality, in addition to improving the quality of spiritual life, can assist healthcare professionals in providing holistic care.<sup>21</sup>

The features "Body image and appearance", "Self Esteem", "Negative feelings" and "Thinking, learning, memory and concentration" were statistically significant. These results only confirm that cancer patients with ostomies face several losses, including better life conditions, which can cause psychological and social isolation, and moreover, lead to changes in body image and low self-esteem, based on negative feelings that affect learning relationships.<sup>6,13,17,22</sup> Furthermore, the study indicated that all features correlated with the mean score obtained in the Social Relationships Domain, showing that colorectal cancer added to the stoma affect social relationships.<sup>6</sup>

"Social support" was the feature that achieved the highest correlation. Considering that, studies show that a social support network becomes essential for individuals with ostomies.<sup>7-8,23</sup> The support should consist of individuals who are part of their lives, i.e., family, friends, health professionals and other individuals with ostomies, thus reaching the personal relationships.<sup>7,10,14</sup>

Sexual activity of individuals with ostomies is complicated due to the surgery itself, which can cause dysuria, pain during intercourse, urinary incontinence, and reduction or loss of libido.<sup>8-9,24</sup> Thus, the quality of life is significantly affected in both sexes: in females because women are more sensitive to changes in their body image, with negative feelings regarding having a part of the body externalized and by experiencing the stigma of being an individual with an ostomy; and in the male gender, the loss regarding the sexual life, as men suffer greater pressure regarding sexual performance.<sup>24-25</sup>

The items of the Environment Domain are statistically significant correlated with the mean score. The professionals who comprise the interdisciplinary team must be prepared to care for ostomized patients, where the goal is to provide all possible professional assistance in order to secure financial, health and social care, ensuring quality of life. Social, familial and work reintegration should be the goal of the follow-up of the individual with an ostomy, as well as the participation in leisure activities.<sup>4,6,10</sup>

Considering the above, the role of a multidisciplinary team is essential to investigate the quality of life of cancer patients with an ostomy, in order to support the patient, reinforce coping strategies and ensure the caring.

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## Final considerations

The analysis of quality of life in ostomized patients for colorectal cancer, in the Physical, Psychological, Social Relationships and Environment domains, treated at the Ostomy



Program of the Secretariat of Health of the Distrito Federal, Brazil, showed that the care of ostomized patients with cancer should focus on technical-scientific, political, and socio-educational conducts.

It is suggested that health professionals should be prepared for the increased occurrence of colorectal cancer and ostomized patient care, contributing more effectively to provide physical and psychological reintegration, taking into consideration the social relationships and environment of the individual, which strongly influence the quality of life improvement.

### Conflicts of interest

The authors declare no conflicts of interest.

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