



Original Article

# Perceptions of ostomized persons due to colorectal cancer on their quality of life



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## ABSTRACT

**Introduction:** The significance of the change in the physical body and suffering as the new condition of life of stoma oncological person affect the physical, psychological, social relationships and environment.

**Objective:** To know the perception of quality of life and the interpretation of the biopsychosocial reality of intestinal ostomy due to colorectal cancer clinics of the Ambulatory Care Program ostomy patients of the Health Secretariat of the Federal District, Brazil.

**Methods:** Epidemiological based study, analytical character, with cross-sectional descriptive design with quantitative and qualitative approach in the light of the content analysis. Sample consisted of convenience, included 120 participants. They used the questionnaires sociodemographic, clinical, and WHOQOL-BREF and an individual interview. Data were analyzed by Microsoft Office Excel 2010 and SPSS 20.0 software. Statistical significance was accepted at 5%.

**Results:** Physical Domains, Social Affairs and Environment are correlated with the mean score, statistically significant ( $p < 0.0001$ ), the content analysis resulted in four categories: Wellness Physical, Psychological Wellness, Wellness and Spiritual Well living Social.

**Conclusion:** Ostomy and colorectal cancer may represent suffered mutilation, loss of productive capacity resulting in the loss of quality of life.

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## Percepções das pessoas estomizadas intestinais em razão do câncer colorretal sobre a qualidade de vida

### R E S U M O

#### Palavras-chave:

Qualidade de vida

Ostomia

Neoplasias colorretais

**Introdução:** O significado da alteração no corpo físico e o sofrimento quanto à nova condição de vida da pessoa oncológica estomizada afetam os aspectos físico, psicológico, relações sociais e meio ambiente.

**Objetivo:** Conhecer a percepção da qualidade de vida e a interpretação da realidade biopsicossocial de estomizados intestinais em razão do câncer colorretal dos ambulatórios do Programa de Assistência Ambulatorial do Estomizado da Secretaria de Saúde do Distrito Federal, Brasil.

**Métodos:** Estudo de base epidemiológica, de caráter analítico, com delineamento transversal e descritivo, com abordagem quantitativa e qualitativa à luz da análise de conteúdo. Amostra foi constituída por conveniência, incluídos 120 participantes. Utilizou-se os questionários sócio demográfico, clínico, e o WHOQOL-bref e uma entrevista individual. Os dados foram analisados pelos programas Microsoft®Office Excel 2010 e SPSS 20.0. A significância estatística aceita foi de 5%.

**Resultados:** Os Domínios Físico, Relações Sociais e Meio Ambiente estão correlacionadas com o escore médio, significância estatística ( $p < 0,0001$ ), a análise de conteúdo resultou em quatro categorias: Bem Estar Físico, Bem Estar Psicológico, Bem Estar Espiritual e Bem Estar Social.

**Conclusão:** A ostomia intestinal e o câncer colorretal podem representar a mutilação sofrida, a perda da capacidade produtiva resultando no prejuízo da qualidade de vida.

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## Introduction

The World Health Organization defines quality of life as “the individual’s perception of his/her position in life in the context of the culture and value systems in which he/she lives and in relation to his/her goals, expectations, standards, and concerns”.<sup>1</sup> From this perspective, quality of life is a subjective concept that brings personal satisfaction in various aspects, especially those considered basic for the life of the individual.

The maintenance of the physical integrity is extremely vital for the person to feel good about him/herself and his/her social life. In this sense, the discontinuation of this integrity, like a surgery for a stoma due to colorectal cancer, can result in serious problems for physical, psychological, social and spiritual well-being.<sup>2,3</sup>

Thus, the ostomized person, although resisting against cancer, is faced with changes in his/her body image, with low self-esteem, a desire of rejection and changes in daily activities, which are factors that hinder the process of acceptance of a reality until then unknown, compromising the quality of life.<sup>3-5</sup>

This study aimed to acknowledge the perception of quality of life and the interpretation of biopsychosocial reality of the ostomized person due to colorectal cancer in outpatient clinics of the Ambulatory Care Program for Ostomized Patients of the Health Department, Federal District (DF), Brazil.

## Material and methods

### Study methodology

This is an analytical, cross-sectional, descriptive, epidemiological-based study with a quantitative and qualitative approach, in light of the content analysis. Participants included in the study belonged to a group of people with a stoma due to colorectal cancer. The observation and measurement of the variables of interest were carried out at the same time, constituting a statistical snapshot of what occurs at a given time.

The data obtained with the interviews were analyzed based on the Bardin Content Analysis, which is based on the phase of material description or preparation, inference or deduction, and interpretation.<sup>6</sup>

The study protocol was approved by the Research Ethics Committee of the Fundação de Ensino e Pesquisa em Ciências do Saúde, Health Department, DF, Brazil, under Protocol 418/200. People who agreed to participate in the study signed the Free and Informed Consent form after receiving detailed explanations of the proposed objectives and procedures. The confidentiality of the source of data and the anonymity of the volunteers were guaranteed, as stated in Brazilian regulations for research involving human subjects.<sup>7</sup> In order to respect the participants’ anonymity, each respondent is identified with names of flowers.

## Cases

This was a convenience sample, taking into account the spontaneous demand for participation in the study. 120 patients ostomized due to colorectal cancer and registered in the Ambulatory Care Program for Patients Ostomized of the Health Department, DF, Brazil, were included.

The inclusion criteria were: patients with a diagnosis of colorectal cancer with a surgery for creation of an ostomy, aged >20 years. Children, adolescents, pregnant women, breast-feeding mothers, bedridden individuals, people with other disabilities, and those who refused to participate in the study were excluded.

## Data collection

Data were collected from March 2010 to August 2012. Two instruments were used: a sociodemographic and clinical questionnaire, and WHOQOL-BREF, in its version validated for the Portuguese, which consists of 26 items: two questions are general and refer to the perception of quality of life and satisfaction with health. The four domains (*Physical, Psychological, Social Relationships and Environment*) were observed.<sup>8</sup>

The data collection based on the interviews was analyzed based on the Bardin Content Analysis,<sup>6</sup> which began by a study-driving question: "Tell me about what means to be an ostomized people." Following each narration, the interviews were transcribed verbatim. The reading of the speeches was held in its entirety several times and at various occasions, to make it possible to understand the speeches and to identify central ideas and keywords, with the observation of repetitions and similarities among interviews. The next stage was that of statement clipping, in order to begin the categorization.

## Statistical analysis

A descriptive statistical analysis of data obtained from the socio-demographic and clinical questionnaires was carried out, in addition to the interview. Data from the WHOQOL-bref questionnaire were analyzed by calculating the mean, standard deviation and proportions and an inferential analysis through the following statistical procedures: a confidence interval of 95%, the Student's t-test, and the linear correlation coefficient of Pearson.

The statistical analysis was performed with SPSS software (Statistical Package for the Social Sciences, SPSS Inc., Chicago, USA) for Windows version 20.0, as recommended by the World Health Organization. Statistical significance was accepted at 5%.

## Results

Among the 120 ostomized participants (due to colorectal cancer) in this study, it was observed that the mean age was  $58.72 \pm 12.56$  years, and most participants belonged to the 50–59-year age group ( $n=35$ , 29.2%). A higher prevalence of females, represented by 53.3% ( $n=64$ ), was observed.

A predominance of the Catholic religion was observed, 56.7% ( $n=68$ ); taking into account other sociodemographic

**Table 1 – Sample of ostomized persons due to colorectal cancer, according to sociodemographic and clinical characteristics. Brasilia, DF, Brazil, 2016.**

Variables	Ostomized people	
	n	%
<i>Gender</i>		
Female	64	53.3
Male	56	46.7
Total	120	100
<i>Age group</i>		
20–30	9	7.5
30–40	18	15
40–50	31	25.8
50–60	35	29.2
60–70	25	20.9
80–90	2	1.6
Total	120	100
<i>Religion</i>		
Catholics	68	56.7
Evangelicals	37	30.9
Spiritualists	11	9.1
Others	4	3.3
Total	120	100
<i>Marital status</i>		
Married	75	62.5
Stable union	13	10.8
Divorced	17	14.2
Widower	12	10
Single	3	2.5
Total	120	100
<i>Instruction</i>		
Illiterate to basic education	56	46.7
Secondary education	45	37.5
University education	19	15.8
Total	120	100
<i>Income</i>		
<1–3 minimum wages	89	74.2
4–5 MW	18	15
>6 MW	13	10.8
Total	120	100
<i>Diabetes mellitus</i>		
Yes	41	34.1
No	79	65.9
Total	120	100
<i>Hypertension</i>		
Yes	68	56.7
No	52	43.3
Total	120	100
<i>Smoker</i>		
Yes	52	43.3
No	68	56.7
Total	120	100

variables, as to marital status, married people prevailed, 62.5% ( $n=75$ ). With regard to formal education, 46.7% ( $n=56$ ) had completed elementary school. As for monthly income, the most often reported by the participants, 74.2% ( $n=89$ ), stood in the range of 1–3 minimum wages.

As to clinical aspect, in regard to comorbidities, 56.7% ( $n=68$ ) suffered from hypertension, and 34.1% ( $n=41$ ) had diabetes mellitus. Furthermore, 43.3% ( $n=52$ ) of respondents

**Table 2 – Mean scores of domains and quality of life of WHOQOL-BREF for ostomized persons due to colorectal cancer, Brasilia, DF, Brazil, 2016.**

Ostomized people due to colorectal cancer					
Domains	n	Mean	SD	CI 95%	p-Value
Physical	120	12.06	2.48	11.61–12.51	<0.0001
Psychological	120	12.40	2.94	11.87–12.93	<0.0001
Social relationships	120	12.64	2.97	12.10–13.18	<0.0001
Environment	120	12.22	2.43	11.78–12.66	<0.0001
General quality of life	120	12.26	2.28	11.85–12.67	<0.0001

were smokers. All variables of the socio-demographic and clinical questionnaire are listed in [Table 1](#).

[Table 2](#) lists the statistically significant differences in the mean scores for the domains: *Physical*, *Psychological*, *Social Relationships*, and *Environment*, and quality of life in general, with statistical significance ( $p < 0.0001$ ).

The results shown in [Table 3](#) indicate that the ostomized group due to colorectal cancer had affected subcategories, namely: negative subcategory – *physical strength* ( $p \leq 0.0001$ ), and negative subcategory – *sexual activity* ( $p \leq 0.0001$ ), as well as the category *Social Well-Being*.

[Table 4](#) lists four categories, namely: *Physical Well-Being*, *Psychological Well-Being*, *Spiritual Well-Being*, and *Social Well-Being*; positive and negative subcategories are listed in [Tables 4 and 5](#).

## Discussion

The mean age was  $58.72 \pm 12.56$  years. Studies indicate the prevalence of colorectal cancer in the age group over 50 years, noting that more than 90% of these cancers occur in individuals aged over 50.<sup>3,4</sup> In relation to gender, women prevailed, which is in line with the studies conducted by the National Cancer Institute in Brazil.<sup>9</sup>

As to religion, Catholics prevailed, 56.7% ( $n = 68$ ), followed by evangelical cults, 30.9% ( $n = 37$ ); 77.5% ( $n = 93$ ) of participants practiced some religion. Studies show that, in the presence of illness, the religious involvement may lead to spiritual growth since it induces the person to meditate on his/her fragility and proximity to human finitude.<sup>4,5</sup>

Regarding the variable “marital status,” 62.5% ( $n = 75$ ) of participants were married, and 10.8% ( $n = 13$ ) held a stable union. This result shows that, regardless of marital classification, being married is a protective factor for these people. In addition, studies indicate that married individuals enjoy higher levels of physical and psychological well-being versus unmarried, separated or divorced people.<sup>4,10–12</sup>

Regarding education and monthly family income, it was observed that the participants had little formal education, which restricts the insertion opportunities in the labor market and reflects the low wages received (mean, 2.25 minimum wages).

With regard to comorbidities, it was observed that, in most cases, the participants suffered from diabetes mellitus and hypertension. The association of these diseases contributes to the high risk of developing colorectal cancer.<sup>4,10,12</sup> In addition, 43.3% ( $n = 52$ ) of participants were smokers. Although the colon is not directly affected by the tobacco composition and by those carcinogenic substances carried by the blood stream,

this has a negative impact as regards the risk of developing colorectal cancer.<sup>3,4,13</sup>

The mean scores of the domains and for quality of life of the WHOQOL-bref, listed in [Table 2](#), give proof of statistically significant differences in mean scores for *Physical*, *Psychological*, *Social Relationships*, and *Environment* domains, and

**Table 3 – Distribution of categorizations of reports from ostomized people due to colorectal cancer, Brasilia, DF, Brazil, 2016.**

Subcategories	Ostomized people due to colorectal cancer (n = 120)
<b>Physical well-being</b>	
Negative	
Leakage, odor, and gasses	74.1% (25.9%)
Physical strength	74.5% (25.5%)
Complications with the ostomy	65% (35%)
Sleep	60% (40%)
Positive	
Family support	90.83% (9.17%)
Care process in health	51.67% (48.33%)
Psychological well-being	
Negative	
Self-concept	64% (36%)
Stigma	55% (45%)
Self-care	65% (35%)
Positive	
Family support	63% (37%)
Acceptance and adaptation	66% (34%)
<b>Social well-being</b>	
Negative	
Personal relationships	53.4% (46.6%)
Recreational/sports activities	58% (43%)
Social isolation	52% (48%)
Sexual activity	73% (27%)
Positive	
Family and friends' support	68% (32%)
Companionship	59% (41%)
<b>Spiritual well-being</b>	
Negative	
Indifference	12% (88%)
Religiousness	12% (88%)
Positive	
Religiousness	68% (32%)
Religious practice	69% (31%)

**Table 4 – Distribution of the categorizations physical and psychological well-being of ostomized people due to colorectal cancer, Brasilia, DF, Brazil, 2016.**

Ostomized people due to colorectal cancer			
Category: Physical Well-being		Category: Psychological Well-being	
Subcategory	Report	Subcategory	Report
<i>Negative</i>			
Leakage, odor and gases	“When I go out I have a concern to take a bag, because sometimes I can use it as my bag already leaked... so, imagine the smell. The gases are also very worrying [...]” (Azalea).	Self-concept	“I am a body without a part, I am not like other people [...] (cries). I have to live with it and it is hard (cry).” (Camellia).
Physical strength	“My life changed a lot after that bag, I have no strength [...] I cannot work nor do my homework services [...]” (Angelica).	Self-care	“At first it was very difficult, my wife helped me change the bag, I always depended on her, now I clean and exchange the bag, but I still feel difficult.” (Pacova).
Complications of ostomy	“I had a lot of irritation on my skin [...]” (Liz Flower).	Stigma	“This is the worst feeling that a person can feel, that is, that people do not want you around.” (Tulip).
Sleep	“I had great difficulty with sleep.” (Palm tree).	Acceptance and adaptation	“I accepted it. It is better to live with this bag than die from cancer [...]” (Orchid).
<i>Positive</i>			
Family support	“Thank God I did not have any trouble, and I had and have a great family support.” (Jacinto).	Family support	Without my wife I never could live with that bag, she helps to clean it up [...]” (Aloe).
Care process in health	“The outpatient clinic nurse guides me how to take care of the bag, and it helps me [...]” (Lavender).	Acceptance and adaptation	“I accepted it. It is better to be with this bag than die from cancer [...]” (Orchid).

in the mean score for quality of life in general. Studies on the quality of life of oncological ostomized patients indicate that the creation of the ostomy is a cause of adulteration of the physical body and of suffering as to the new lifestyle, which affects the Physical, Psychological, Social Relationships, and Environment dimensions, therefore affecting the quality of life.<sup>14,15</sup>

In analyzing the results of Table 3, the study participants reported that, proportionally, the subcategory *physical strength* from the category *Physical Well-Being*, and the subcategory *sexual activity* from the category *Social Well-Being* are negatively compromised, especially for female subjects aged between 40 and 60 years. These findings were confirmed in another

**Table 5 – Distribution of categorizations Spiritual Well-being and Social Well-being of ostomized people due to colorectal cancer, Brasilia, DF, Brazil, 2016.**

Ostomized people due to colorectal cancer			
Category: Spiritual Well-being		Category: Social Well-being	
Subcategory	Report	Subcategory	Report
<i>Negative</i>			
Indifference	“I’m still the same person.” (Violet)	Personal relationships	“I feel very ashamed of family and friends, the colostomy bag, do not leave me at ease.” (Ipe).
Religiosity	“God will heal me, I’m sure I will not need the ostomy treatment.” (Acacia).	Social, recreational and sports activities	“I cannot travel by bus because of the bag. I am very concerned about the bag.” (Begonia).
		Social isolation	“I had many difficulties, and the worse it was the change in my life, now I do not like to go out.” (Narcissus).
		Sexual activity	“My sexual life changed a lot [...] I feel that my husband touches me and looks at me differently.” (Jasmine).
<i>Positive</i>			
Religiosity	“My faith strengthened, I’m always saying that if it were not for God, I would not be here.” (Giant water lily).	Family and friends’ support	“My relationship with family and friends is very good. I have a wonderful support, and this brings me confidence [...]” (Hortensia).
Religious practice	“I started (sic) to attend the church more often.” (Three Marias).		“Thank God I have a partner who accepts me and loves me, this makes me (sic) feel better and safe [...]” (Pansy)

study, which describes the impairment of physical force in 30 stomized women, who were colorectal cancer survivors.<sup>16</sup> A study on sexual activity indicated that in older women the sexual pleasure (i.e., sexual activity) is affected.<sup>2</sup>

The analysis of Tables 4 and 5 shows that the obstacles faced by our participants significantly affect their physical, psychological, social and spiritual well-being. Thus, through the content analysis, we could observe that a greater number of negative versus positive subcategories occurred, which is confirmed below by the mentioned analysis.

In the *Physical Well-Being* category, reports of participants described in the negative subcategory – leakage, odor and gasses – were identified. Studies have been published that discuss the meaning of physical body change and of suffering with respect to the new lifestyle of the ostomized person; thus, the physical well-being is greatly affected, because of his/her concern with gasses, odors, fecal elimination, and leakage, resulting in physical discomfort.<sup>14,17,18</sup>

In terms of physical strength, the participants stressed that their quality of life is impaired. It is worth noting that the difficulty about physical strength with respect to daily activities was mainly identified by women, who report a decrease in household chores; this finding was also described in one study.<sup>19</sup>

Sleep was considered a negative subcategory. Studies report that the collector equipment causes sleep disturbances, impairing considerably the quality of life. It was also noted that the sleep disturbance is related to the presence of the ostomy, especially in the first months after surgery, and to the fear about the future.<sup>3,17</sup>

Education in health is critical and fundamental to the process of caring for health, resulting in a quality care. Health professionals should recognize that the family is a care/help unit for these people, and thus it should be included in health care practices.<sup>14,20</sup>

Regarding *Psychological Well-Being* category, the reports showed how the change in self-concept, i.e., changes in body image and self-esteem, influences psychological well-being. Participants reported that, among their difficulties, stands the self-care. The correct guidance on the technique of collector equipment changes, as well as on the inspection of the stoma during the change, shows the importance of the health professional in helping to prevent complications, and in making more easier the life with the ostomy.<sup>5,14</sup>

Moreover, it was also observed in the reports of the participants that often the colostomy incorporates a social stigma, i.e., the ostomized people feels different toward his family and society, thus hindering their own acceptance and process of adaptation, which leads to changes in social life. This causes the ostomized person feel different, excluded, and experiencing a sense of rejection.<sup>14,18,20</sup>

On the other hand, a very striking aspect was the acceptance perceived in the reports. Many participants accepted the ostomy for lack of choice, emphasizing that if it is difficult to live with the collector equipment, at least they are alive and no longer feel sick, in pain or with the possibility of an imminent death.<sup>5</sup>

In the category *Spiritual Well-Being*, the reports showed that religiosity can produce a negative impact. Religious faith can

also influence negatively in the patient's recovery, especially when, for example, the individual attributes to God all responsibility for his/her future, failing to carry out the treatment or to care him/herself and fight for life.<sup>21</sup>

From the evidence given, it appears that religion is the spiritual support sought most often by ostomized people. This factor functions as a reference to their general conceptions, and underlies the meanings of intellectual, emotional and moral experience, both for the individual and for the group.<sup>22</sup> Furthermore, the practice of religion may appear as an element that helps in coping with the disease, allowing a better adherence to treatment, a decrease of stress and anxiety, seeking a meaning to the new situation.<sup>14,20</sup>

Regarding the category *Social Well-Being*, it was confirmed that the man is a social being; but for the person to feel good with him and with others, the presence of physical and psychological integrity is indispensable.<sup>5</sup>

For stomized people, activities like traveling and practicing some kind of sport, are uncommon, which leads to idleness. The reasons for these restrictions relate to the uncertainty derived from the quality of the collector equipment, physical problems, difficulty to sanitizing the equipment, shame, and fear of gastrointestinal problems.<sup>5,14</sup>

Reports of sexual activities show that this practice is affected, by being closely related to the notion of self-concept and the consequent change in body image, and to a decreased self-esteem and perception of sexual attraction.

Also regarding sexual activity, companionship was considered a positive subcategory; thus, sexuality is a broad function that covers biological, psychological and social aspects. In addition, the sexual partnership is an essential part of sexuality, and can be a positive or a negative element in strengthening the relation and in the complicity of the couple's well-being.<sup>18,23</sup>

Family support becomes essential, because the ostomized people present a medical condition affected by the underlying pathology and by the major surgery, besides the need of specific care for the equipment. Both the family and friends of the ostomized person constitute his/her social protection, which admittedly has a fundamental role in the process of constitution, development, crisis and resolution of health problems.<sup>5,24</sup>

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## Conclusions

The study shows the interfaces of ostomized persons due to colorectal cancer with the challenges faced from the moment of discovery of the diagnosis, when they will undergo an ostomy, till their adaptation to a new lifestyle. These challenges can be understood as bodily changes that influence their self-concept, self-care, and relationships in social life – i.e., *Physical, Psychological, Social Relations and Environment* domains.

Moreover, the use of a collector equipment can represent the mutilation suffered, relating directly to the loss of productive capacity of the person; furthermore, it also means a telltale factor in his/her lack of control in relation to physiological body elimination, physical beauty and health, compromising the quality of life.

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## Conflicts of interest

The authors declare no conflicts of interest.

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