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#### REFERÊNCIA

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## Original Article

# Quality of life in stomized oncological patients: an approach of integrality from Brazilian Unified Health System



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## ABSTRACT

**Introduction:** Integrality is considered an essential constitutional doctrinal principle of SUS, being considered as a major challenge in health in Brazil. This involves practicing focusing on the quality of life of oncological stomized people.

**Objective:** To analyze quality of life of oncological stomized people from the Health Department, the Federal District, Brazil, from the perspective of integrality of the Unified Health System in Brazil.

**Methods:** Cross-sectional, exploratory and descriptive study with a quantitative and qualitative approach in the light of a content analysis. This was a convenience sample, including 120 patients registered in the Stomized People Program of the Health Department, the Federal District, Brazil. In this study, sociodemographic, clinical, and WHOQOL-bref questionnaires and an individual interview were used. Data were analyzed by Microsoft® Office Excel 2010 program and SPSS 20.0 software. Statistical significance was accepted at 5%.

**Results:** Physical, Social Affairs, and Environment domains are correlated with the mean score, with statistically significant results ( $p < 0.0001$ ), the content analysis resulted in three categories: complications with the stoma, self-care, and Comprehensive health care.

**Conclusion:** Our results highlight the need to realize the integrality as a principle at various levels of discussion and of the practice of health care for stomized oncological people.

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## Qualidade de vida de estomizados oncológicos: uma abordagem da integralidade do SUS do Brasil

## RESUMO

**Introdução:** A integralidade é considerada um princípio doutrinário constitucional e essencial do SUS, e é apreciada como um grande desafio no âmbito da saúde no Brasil. Isto implica práticas voltadas para a qualidade de vida das pessoas oncológicas estomizadas.

## Palavras-chave:

Qualidade de vida

Ostomia

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Neoplasias colorretais  
Integralidade de saúde  
Sistema Único de Saúde

**Objetivo:** Analisar a qualidade de vida de pessoas oncológicas estomizadas da Secretaria de Saúde do Distrito Federal, Brasil, sob a perspectiva da integralidade do Sistema Único de Saúde do Brasil.

**Métodos:** Estudo transversal, exploratório-descritivo com abordagem quantitativa e qualitativa à luz da análise de conteúdo. A amostra foi constituída por conveniência, com inclusão de 120 pacientes cadastrados no Programa de Estomizados da Secretaria de Saúde do Distrito Federal, Brasil. O estudo utilizou 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 correlacionados com o escore médio, com significância estatística ( $p < 0,0001$ ), e a análise de conteúdo resultou em três categorias: Complicações com a estomia, Autocuidado e Assistência integral à saúde.

**Conclusão:** Fica evidenciada a necessidade de se perceber a integralidade como princípio em vários níveis de discussões e de prática do cuidado em saúde para pessoas oncológicas estomizadas.

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## Introduction

The concept of integrality allows for the identification of the subject in its entirety, even if not reachable in its fullness, considering the whole universe of possible dimensions amenable to intervention, through the access allowed by themselves.<sup>1</sup>

Thus, integrality suggests the addition and enhancement of care in the health professions, not being defined only as a basic guideline of the Unified Health System (SUS). That is, integrality can be understood as a conjugate of relevant notions to an expanded assistance, with coordination of the actions of the professionals involved in a comprehensive perspective of the human being endowed with feelings, desires, anxieties and rationalities.<sup>2</sup>

Integrality is considered an essential constitutional and a doctrinal principle of SUS; therefore, it is appreciated as a major challenge in health in Brazil, in the construction, deployment and implementation process of a care model that has its foundation and its guidelines based on the promotion, prevention, cure and rehabilitation. This implies practices focused on people's quality of life.<sup>2</sup>

In this sense, we are faced with a major challenge for a comprehensive health care of stoma oncology people, since the stomized patients' quality of life implies the maximum achievement of well-being and autonomy.<sup>3,4</sup>

Colorectal cancer is one of the leading causes for the making of a stoma. Among the risk factors for this type of cancer, there is a direct link to the dietary pattern, represented by vices and bad eating habits that promote bacterial growth and the consequent degradation of bile acids, resulting in production of carcinogens.<sup>3-5</sup> Colorectal cancer is the second most prevalent cancer in the world, ranking third in terms of incidence for men and in second place for women, which makes this neoplasm in serious worldwide public health problem. It is considered one of the most important cancers in the adult population, with increasing incidence and mortality in most countries.<sup>4-8</sup>

Furthermore, stomized oncological people, although resisting against cancer, find themselves with decreased body

image and self-esteem, and with desires of rejection. The significance of the change in their physical body and the suffering in the face of the new living condition affect their physical and psychological aspects, as well as those of their social and environmental relations, and the result is an impairment of their quality of life.<sup>4,5</sup>

It is essential, however, to implement health education actions in the perspective of integrality, establishing comprehensive care to the stomized oncological person, so that, in general, health professionals involved with this universe of patients have a broader vision with respect to the emergent feelings in the face of disease, the making of a bowel ostomy, its sequels, and of rehabilitation, in order to ensure a comprehensive health care that will contribute to improving the quality of life of stomized oncological people.

Based on this notion, the aim of this study was to assess the quality of life of stomized oncological people from the Health Department, the Federal District, Brazil, from the perspective of integrality of the Unified Health System in Brazil.

## Material and methods

### Study methodology

This is a cross-sectional, exploratory and descriptive study with quantitative and qualitative approach, in light of the content analysis. Participants included in it belonged to a group of intestinal stomized people due to colorectal cancer. The observation and measurement of the variables of interest were made simultaneously, and worked as a statistical snapshot of what occurs at any given time.

The interview data collection was analyzed in light of Bardin Content Analysis, which is founded upon the phase of description or preparation of material, inference or deduction, and interpretation.<sup>9</sup>

The study protocol was approved by the Research Ethics Committee of the Teaching and Research in Health Sciences Foundation, Health Department, the Federal District, Brazil, under Protocol 418/200. People who agreed to participate in

the study signed a Free and Informed Term of Consent, after receiving detailed explanations on proposed objectives and procedures. Participants had assured the guarantee of secrecy about the origin of the data and also about the anonymity of volunteers, as stated in Brazilian regulations for research involving human beings.<sup>10</sup>

In this sense, to respect the anonymity of volunteers, each interview is marked with the letter "I" (individual) and a number indicating the order of its realization.

### Cases studied

Ours was a convenience sample, considering the spontaneous demand for participation in the study. The sample included 120 subjects with bowel ostomy due to colorectal cancer and registered in the Outpatient Care Program for Stomized People of the Health Department, Brasilia, the Federal District, Brazil.

The inclusion criteria were: patients diagnosed with colorectal cancer who underwent a stoma surgery and aged  $\geq 20$  years. Children, adolescents, pregnant women, nursing mothers, bedridden subjects, people with other disabilities, and people who refused to participate in the survey were excluded.

### Data collection

Data was collected from March 2010 to August 2012. For data collection, two instruments were applied: a socio-demographic and clinical questionnaire and the WHOQOL-bref version validated for the Portuguese. This latter instrument consists of 26 items: two general questions which refer to the perception of quality of life and satisfaction with health. WHOQOL-bref is composed of four domains (Physical, Psychological, Social and Environmental Affairs).<sup>11</sup>

Following each report collection, the interviews were transcribed verbatim. Reading the speeches was held several times and at various times in their entirety, to make it possible to understand the speeches, identifying main ideas and key words, and observing repetitions and similarities between interviews. The next stage was the phase of interview cutouts, to begin the categorization.

### Statistical analysis

In addition to the interview, a descriptive statistical analysis of the socio-demographic and clinical questionnaire was carried out. Data from the WHOQOL-bref questionnaire were analyzed by calculating the mean, standard deviation and proportions, and by inferential analysis through the following statistical procedures: confidence interval 95%, Student's t test with a normal distribution, and Mann-Whitney test without normal distribution, and Pearson's correlation coefficient.

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. The statistical significance accepted was 5%.

**Table 1 – Stomized oncological people's sample, according to sociodemographic characteristics (Brasilia, the Federal District, Brazil, 2015).**

Variables	Stomized oncological 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>		
Catholic	68	56.7
Evangelicals	37	30.9
Spiritualists	11	9.1
Other	4	3.3
Total	120	100
<i>Religion</i>		
Yes	93	77.5
No	27	22.5
Total	120	100
<i>Marital status</i>		
Married	75	62.5
Stable union	13	10.8
Divorced	17	14.2
Widow(er)	12	10
Single	3	2.5
Total	120	100
<i>Schooling</i>		
None to primary education	56	46.7
High school	45	37.5
Higher education	19	15.8
Total	120	100
<i>Income</i>		
<1–3 MW	89	74.2
4–5 MW	18	15
>6 MW	13	10.8
Total	120	100

## Results

Table 1 lists the sociodemographic characterization. The mean age of participants was  $58.72 \pm 12.56$  years; most volunteers were included in the age group between 50 and 69 years ( $n=66$ ). A higher prevalence of females was noted, 53.3% ( $n=64$ ).

Catholic religion is the predominant faith, 56.7% ( $n=68$ ), followed by evangelical cults, 30.9% ( $n=37$ ); and 77.5% ( $n=93$ ) of participants reported being practitioners of a religion and 22.5% ( $n=27$ ) mentioned not being linked to any religious group.

Regarding the variable "marital status," there was a predominance of married people, 62.5% ( $n=75$ ). With regard to formal education, 46.7% ( $n=56$ ) had completed elementary

**Table 2 – Stomized oncological people's sample, according to clinical characteristics (Brasilia, the Federal District, Brazil, 2015).**

Variables	Stomized oncological people	
	N	%
<b>Ostomy time (months)</b>		
≤12 months	24	20
>12 and ≤60 months	40	33.3
>60 months	56	46.7
Total	120	100
<b>Character of bowel ostomy</b>		
Definitive	81	67.5
Temporary	39	32.5
Total	120	100
<b>Diabetes mellitus</b>		
Yes	41	34.1
No	79	65.9
Total	120	100
<b>Blood hypertension</b>		
Yes	68	56.7
No	52	43.3
Total	120	100
<b>Smoking</b>		
Yes	52	43.3
No	68	56.7
Total	120	100
<b>Outpatient follow-up</b>		
Yes	119	99.1
No	1	0.9
Total		
<b>Receipt of equipment</b>		
Yes	112	93.3
No	8	6.7
Total	120	100

school. As for employment status, the majority of the group, 65.8% (n = 79), consisted of retirees. The monthly income most related by the participants, 74.2% (n = 89), stood in the range of 1-3 times the minimum wage.

Table 2 illustrates an overview of the clinical aspects of volunteers. The variable “intestinal ostomy time due to colorectal cancer” indicated a predominance in the range of >60 months, corresponding to 46.7% (n = 56) of participants, followed by participants in the range from >12 to ≤60 months (33.3%, n = 40). Regarding the character of the intestinal stoma, 67.5% (n = 81), had a definitive ostomy. With regard to comorbidities, 56.7% (n = 68) suffered from hypertension and 34.1% (n = 41) of diabetes mellitus. In addition, 43.3% (n = 52) of the respondents were smokers. With regard to outpatient monitoring and receipt of equipment, 99.1% (n = 119) are monitored and 93.3% (n = 112) are receiving equipment.

The results in Table 3 showed a statistically significant difference in mean scores for the domains: physical, psychological, social relationships and environment, and for the quality of life in general, with statistical significance (p < 0.0001).

The results of the interviews have created three categories, namely: Complications with the stoma, Self-care and Comprehensive health care, whose presentation is in Table 4.

**Table 3 – Mean scores of domains and quality of life of WHOQOL-bref of stomized oncological people (Brasilia, the Federal District, Brazil, 2015).**

Domains	Stomized oncological group				
	n	Mean	SD	CI 95%	P
Physical	120	12.06	2.48	11.61-12.5	<0.0001
Psychological	120	12.40	2.94	11.87-12.93	<0.0001
Social relationship	120	12.64	2.97	12.10-13.18	<0.0001
Environment	120	12.22	2.43	11.78-12.66	<0.0001
General QV	120	12.26	2.28	11.85-12.67	<0.0001

## Discussion

The mean age was 58.72 ± 12.56 years. This result is comparable to those found in other studies indicating prevalence of colorectal cancer in those aged over 50, noting that more than 90% of these cancers occur in people aged over 50 years.<sup>4,5</sup>

The results pointed to a predominance of females, which agrees with studies conducted by the National Cancer Institute in Brazil in 2014, being also considered valid for the year 2015. This report pointed to the emergence of 14,180 new cases of colorectal cancer in men and 15,960 new cases in women.<sup>12</sup>

It was observed that the prevailing religions were the Catholic profession, 56.7% (n = 68), followed by evangelical cults, 30.9% (n = 37). This finding is a reflection of Brazilian religiosity, as Brazil is the largest Catholic country in the world. Religious practice in the presence of disease may lead to spiritual growth, as it brings to the persons' mind their fragility and the proximity to human finitude.<sup>5,13</sup>

Regarding the variable “marital status,” our study showed that 62.5% (n = 75) of patients were married and 10.8% (n = 13)

**Table 4 – Categorization of interviews of stomized oncological people (Brasilia, the Federal District, Brazil, 2015).**

### Complications with the stoma

“I had a lot of irritation on my skin [...]” (I1).

“Oh my God, now with the hernia, the stoma is more to the side [...] do you understand? (sic), it is more prominent.” (I2).

“I have always dermatitis in my stoma.” (I3).

“My stoma is almost always full with complications [...]” (I4)

### Self-care

“It's very complicated to handle this bag [...]” (I5)

“At first it was very difficult, my wife helped me to change the bag, I always depended on her; now I clean and exchange the bag, but still feel some difficulty.” [...] “ (I6)

“When I had to exchange the bag, I found myself unclean, felt sick, angry, the smell made me sick, I cried a lot [...]” (I7) (I7)

### Comprehensive health care

“The outpatient nurse guides me how to take care of the bag, and it helps me [...]” (I8)

“No doubt (sic), the monitoring by a professional would make me more confident to handle the bag.” (I9)

“I don't have a different medical appointment, I'm just going to the outpatient clinic to pick up the bags” (I10)

“I felt a lot of pain at the beginning and a lot of doubts with the bag, and I did not have a professional to help me [...]” (I11)

“After the nurse explained to my wife how to stick the bag in the right way, I had no more trouble [...]” (I2)



were in stable relationships. International and Brazilian studies which included stomized persons due to colorectal neoplasia, suggest that most people were married or living with a partner.<sup>3-5,14,15</sup> This knowledge is important because, regardless of marital classification, the status of being married is a protective factor for people, since married people enjoy higher levels of physical and psychological well-being versus single individuals, or separated or divorced people.<sup>5,16,17</sup>

Regarding education and family income, it was observed that the group consisted of people with low formal education: 46.7% ( $n=56$ ) had only complete or incomplete elementary school education, which restricts their opportunities of insertion in the work market and reflects the low wages received (mean, 2.25 minimum wages). This situation emphasizes the importance of government assistance to this population of patients and may also represent impediments for the prevention of colorectal cancer. In addition, the level of schooling interferes with quality of life.<sup>4,5</sup>

With respect to the variable "Situation in the face of work," there was a prevalence of 65.8% ( $n=79$ ) of retirees and of 17.5% ( $n=21$ ) of subjects withdrawn from the labor market by the National Institute of Social Insurance, Brazil. A higher percentage of retirees among people with permanent ostomy and older than 60 years was noted, since that stomized people are considered as having special needs, according to Decree No. 5296 of December 2, 2004.<sup>4,5</sup>

With regard to the variable "character of the ostomy," a preponderance of permanent ostomy, 67.5% ( $n=81$ ) was noted. Thus, the bowel ostomy surgery due to a colorectal cancer causes a number of adaptations as a result of the changes in the patient's life, with interference his/her quality of life in different dimensions – physical, psychological, social relations, and the environment – regardless of the temporary or permanent character of the stoma.<sup>3,5,18</sup>

Regarding comorbidities, the results indicated that 34.1% ( $n=41$ ) of respondents had diabetes type II, which is an important risk factor for colorectal cancer, because of the state of hyperinsulinemia that characterizes the early stages of this neoplasm. In the case of high blood pressure, it was found that 56.7% ( $n=68$ ) of participants were hypertensive. The association of these diseases contributes to the high risk of developing colorectal cancer.<sup>5,19-21</sup>

The results indicated that 43.3% ( $n=52$ ) of respondents were smokers. Although the colon environment is not directly affected by the tobacco composition, the carcinogenic substances carried by the bloodstream have a negative impact with respect to the risk of developing a colorectal cancer.<sup>5,22</sup>

Despite the high number of participants with outpatient follow-up, 99.1% ( $n=119$ ), and of those receiving equipment, 93.3% ( $n=112$ ), in our sample, this study revealed that a contingent of stomized oncological people does not enjoy the benefits of a comprehensive health care.

The mean scores for domains and quality of life of the WHOQOL-bref (Table 3) enable the verification of statistically significant differences in mean scores for physical, psychological, social relations, and environment domains, as well as for quality of life in general. Thus, studies have reported on the quality of life in stomized oncological patients, showing that the making of an ostomy results in changes of the physical body; and that the suffering in the face of the new lifestyle

affects the physical and psychological aspects, as well as the social relations and the environment, compromising the quality of life of these individuals.<sup>3,5,6</sup>

In the "Complications with the stoma" category, reports were identified from participants concerning complications with the stoma. Living with a bowel ostomy requires that its user adopt several measures of adaptation and adjustment to daily activities, including learning care actions targeted to his/her ostomy and to the peristomal skin, as well as the handling of the collector equipment, in order to avoid future complications with the intestinal stoma.<sup>4,23</sup>

The literature states that the care for cleaning and replacement of the collector equipment are very important, as a way to ensure the integrity of the skin and prevent the occurrence of infection. To ensure that these measures are carried out properly, it is critical that the stomized person is guided by health professionals, so that he/she can assume the self-care.<sup>4,23</sup> Furthermore, dermatitis are considered the most common complication of an intestinal Ostomy, as generally its occurrence is the result of an inappropriate use of the collector device.<sup>4</sup>

In the "Self-care" category, stomized oncological subjects reported that, among the difficulties, lies the self-care. Considering this aspect, a comprehensive health assistance is vitally important, particularly in relation to ostomy self-care. The correct orientation on the exchange technique of the collector equipment, as well as on the observation of ostomy during the exchange, highlights the importance of the health professional in helping to prevent complications, and also to make more manageable the life with the stoma.<sup>4,24</sup>

Finally, in the "Integral health assistance" category, several testimonies of the stomized subjects revealed the lack of a comprehensive care. With that in mind, the comprehensive care goes beyond the hierarchical and regionalized organizational framework of health care, that is, it extends through the real quality of an individual and collective attention, afforded to all users of the health system, and reinforces the commitment to the continuous learning and to the multidisciplinary practice.<sup>1,5</sup>

However, the activities of the multidisciplinary team should be based on the holistic assessment of the individual, so that the patient receives a comprehensive, individualized and systematized care, also focused on the subjective aspects related to the social representation of their new lifestyle.<sup>5</sup>

Thus, it is understood that, to achieve the integrality in the care of stomized oncological people, the user must be regarded as a historical, social and political subject, articulated to his/her family context, to the environment and to the society in which he/she is inserted.

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## Conclusions

Stomized oncological people are faced with various issues related to the drastic changes in their everyday aspects, which constitute a challenge to their adaptation to this new reality; thus, for these people, the comprehensive health care is an imperative target, aiming their most ready rehabilitation, as well as promoting improvements in their quality of life, and also providing emotional support for affective difficulties

that they may have to face throughout this difficult adaptive process.

Therefore, it is evident the need to realize the integrality as a principle at various levels of discussion and practice of care, based on a new paradigm, with professionals ready to listen and understand and, from there on, to accept the demands and needs of stomized oncological people.

### Conflicts of interest

The authors declare no conflicts of interest.

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