

## Quality of Life of People with Definitive Intestinal Ostomies: an Integrative Review

### Qualidade de Vida de Pessoas com Estomias Intestinais Definitivos: uma Revisão Integrativa

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**Abstract**

Colorectal cancer is the third most common malignant neoplasm in men and the second in women. Its specific treatment should be the surgical resection of the affected place and an ostomy, which interferes in the quality of life (QoL), and affects the biopsychosocial-spiritual dimensions. The objective of this study was to describe the scientific evidence about people with definitive intestinal ostomy due to colorectal cancer and the repercussions for the QoL of these people. Methods: integrative review with five databases, with a temporal cut between 2012 and 2017. From the analysis of the collected data, three categories emerged that greatly compromise the QoL: physical well-being and self-image, difficulty with self-care, and sexual function. Conclusion: patients with definitive stoma presented a moderate to good QoL, even though they knew about the numerous alterations found and the need for a readaptation in their life. Therefore, some suggestions were found to help improve QoL, such as pre, trans and post-operative health education, irrigation, group activities.

**Key words:** quality of life, stomies, colostomy, ileostomy, colorectal neoplasm.

**Resumo**

O objetivo deste estudo foi descrever as evidências científicas sobre pessoas com estomia intestinal definitivo decorrente de câncer colorretal, e as repercussões para a qualidade de vida (QV) dessas pessoas. Trata-se de uma revisão integrativa feita em cinco bases de dados, com recorte temporal entre 2012 a 2017. A partir da análise do material captado, emergiram três categorias que comprometem sobremaneira a QV: bem-estar físico e autoimagem; dificuldade para o autocuidado, e função sexual. Os pacientes com estoma definitivo apresentaram uma QV de moderada a boa, mesmo sabendo das inúmeras alterações encontradas e da necessidade de uma readaptação em sua vida. Portanto, algumas sugestões foram encontradas para ajudar a melhorar a QV, como educação em saúde no pré, trans e pós-operatório, irrigação, e atividades em grupo.

**Palavras-chave:** Qualidade de Vida; Estomia; Colostomia; Ileostomia; Neoplasias Colorretais.

**Introduction**

Chronic diseases such as cancer are a major health problem worldwide. They are responsible for more than 6 million deaths each year and for most hospitalizations. The prevalence of chronic diseases and their aggravations have a direct impact on social determinants, especially the difficulties of access to information and public goods and services, low level of schooling, poor housing conditions, inadequate eating habits, among other aspects that weaken health and expose the subject to vulnerability<sup>1,2</sup>.

Colorectal neoplasms are the third most frequent cause of neoplasia in men and the second in women. The exact cause of colorectal neoplasms is unknown, but some risk factors are strongly related to its appearance. For example, age above 50 years old, family history of colorectal neoplasms, previous personal history of ovarian, endometrial and breast cancer, high fat diet, low intake of fruits, vegetables and cereals, sedentary lifestyle,

excessive alcohol consumption, smoking, inflammatory colonic diseases (ulcerative colitis), some hereditary conditions such as familial adenomatous polyposis and colorectal cancer without polyposis<sup>3-4</sup>.

The treatment for colorectal neoplasia consists of surgical procedure, chemotherapy and radiotherapy, the last two being therapies associated with the surgery. The surgical removal of the affected place and having a definitive or temporary ostomy is the most effective therapy for most of patients diagnosed with colorectal neoplasia.

An ostomy means an opening or orifice, that in the surgical point of view it is alluded to the exteriorization of an organ on the patient's skin. Thus, the exteriorization of the intestinal colon in the abdomen (denominated colostomy) can be cited as an example, as well as the exteriorization of the trachea on the neck (tracheostomy)<sup>(5)</sup>. An ostomy can be temporary or definitive, depending



on the characteristics and the extension of the disease. However, regardless of the amount of time, the ostomy is an extremely invasive procedure that can bring psychosocial, physical and spiritual embarrassment, which causes issues in social and familial relationships<sup>6</sup>.

In addition, it is emphasized that due to the excessive appreciation of physical beauty that is actively present in modern society, something that affects body image is determining to impact the quality of life of a person with an ostomy. This situation also reflects the facts of mutilation and deconstruction of a body that is considered normal, as well as to the problematic use of collector equipment and its adjuvants. In this sense, people who are submitted to this procedure have their perspective of life altered, and consequently their quality of life (QoL)<sup>7</sup>.

In the case of people with intestinal stoma, there's a change in the elimination patterns, because the individual gets incontinent. It's also evidenced that there were alterations in the eating habits, in the way they perform corporal hygiene and the clothing, which results in a low self-esteem, sexual changes and, frequently, social isolation. Social isolation can occur as a consequence to factors that many times are related to the lack of daily activities and to idleness, because patients with stoma feel insecure to resume their lives, work and have social interactions, which drastically alters their QoL<sup>6-7</sup>.

The group of studies of QoL of the World Health Organization (WHOOOL Group) defined quality of life as "the individual's perception of their position in life, in the cultural context and system of values in which he lives and in relation to their objectives, expectations, patterns and worries"<sup>8</sup>. In the health area, we use the term health-related quality of life (HRQoL), which implies the aspects most directly related to diseases or health interventions<sup>8-9</sup>.

The increase in people living with colorectal cancer - elimination ostomy - has considerably increased the interest in the health-related quality

of life (HRQoL) of such a population. This is due to the loss of health because of cancer and the consequence of treatment that results in physical and functional impairment and social and family interactions, which directly affect the quality of life<sup>10</sup>.

The contribution of the present study is anchored in the fact that there will be more and more people with ostomies to treat this disease. Therefore, nursing needs to deepen the discussions and the knowledge on such problematic in order to provide quality care. The presence of a stoma is a complex and multifaceted phenomenon, so it is not a simple task to care for these people, and the compilation of data on quality of life and people with stomas is relevant in professional practice.

Considering the initial contextualization on the problem of the person with ostomy due to colorectal cancer, the aim of this study was to describe the scientific evidence about people with definitive intestinal ostomy due to colorectal cancer, and the repercussions for the QoL of these people.

## Method

This study is descriptive and integrative literature review type (RIL). This type of research uses standardized and systematic methods, guaranteeing the necessary rigor to scientific research in order to legitimize evidence, integrating them into professional practice, which allows reflection on a certain phenomenon<sup>11</sup>.

RIL determines the development of six steps for its methodology, which are characterized as: 1 - identification of the theme and selection of the research question; 2 - establishment of the criteria for inclusion and exclusion; 3 - definition of the information to be extracted from the selected studies; 4- evaluation of included studies / categorization; 5- interpretation of results; 6- presentation of the review / synthesis of knowledge<sup>11</sup>.

It is worth noting that in addition to adopting the aforementioned sequence of RIL research, the recommendations of the Joanna Briggs Institute were also used, applying the PICO method <sup>(12)</sup>. Each PICO strategy parameter contributed to the selection of the studies to be included and corresponded to the following elements: P (population) - people with colorectal neoplasia; I (intervention) - applying the stoma; C (comparison) - instrument not used; O (outcome) - identify how the performance of a stoma affects the quality of life of people with colorectal neoplasia. This strategy allows to limit the question or problem to be investigated in a specific and scientific way <sup>12,13,14</sup>.

In this sense, the adopted research question was: How does definitive stoma affect the quality of life of patients with definitive intestinal neoplasia?

In order to elaborate the second stage of RIL, criteria were established for the use of bibliographic material in the study, which were characterized as: public domain articles, fully available in Portuguese, English and Spanish, which approached the quality of life of people with colorectal neoplasia and with definitive stoma. It was established as an exclusion criterion: integrative review articles, monographies, dissertations and theses, and publications that addressed quality of life in other pathologies other than colorectal neoplasms.

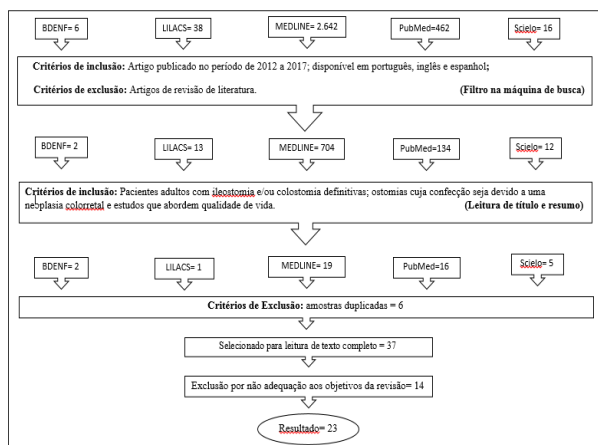
The search for articles ran in the following databases: Latin American and Caribbean Literature in Health Sciences (LILACS), US National Library of Medicine (MEDLINE), Science Electronic Library Online (SCIELO), Nursing Database BDNF, and National Library of Medicine (PUBMED). This search was carried out through the portal of the Commission for the Improvement of Higher Education Personnel - (CAPES). The descriptors of Health Sciences (Decs) for LILACS, BDNF, MEDLINE, SCIELO and the terms of the Medical Subject Headings (MESH) to PUBMED.

Data were collected in November 2017. The descriptors were: quality of life, colorectal neoplasia, ostomy, colostomy and ileostomy. For advanced research, we used the Boolean operator (AND and OR) in the following sequence: quality of life AND colorectal neoplasms AND ostomies OR colostomy OR ileostomy. The choice of these descriptors was based on the purpose of the study. The time frame established was from 2012 to 2017.

Evidence-based practice (EBP) advocates evidence classification systems characterized hierarchically, depending on the methodological approach adopted, which is based on the study design. Considering the levels of recommendation from the research focus, it is stratified into: "Level I" - Meta-analysis of multiple controlled studies; "Level II" - Individual experimental studies (randomized clinical trial); "Level III" - Near-experimental studies (non-randomized trial, single pre- and post-test group, time series or case-control); "Level IV" - Non-experimental studies (descriptive, correlational and comparative research, qualitative research and case studies); "Level V" - Program evaluation data and systematically obtained data; "Level VI" - Expert opinions, reports of experiences, consensus, regulations and legislation <sup>12-14</sup>.

The third step is to select the scientific papers to be used in the study. Thus, the following procedure was used to select the material: I) analysis of the titles of the publications, that is, checking to see if they contained a relation with the subject investigated; II) reading the abstract, paying attention to the objectives of the publications; III) publications that met the inclusion criteria previously outlined. This path is shown in Figure 1.

**Figure 1:** Research flowchart in databases. Niterói, RJ, Brazil, 2018.



Source: research data

The fourth step consists of the review with critical analysis of the selected articles. They were read in full by the three researchers to complete the fifth step on the interpretation and discussion of the results, highlighting those that emphasize the quality of life of people with colorectal neoplasia and with definitive stoma.

The sixth and final stage deals with the review and synthesis of the selected studies, and from these, in order to respond to the objectives, three categories emerged.

**Results**

We included in the study articles that could contemplate the research question. We selected 43 articles: 19 in MEDLINE, 1 in LILACS, 2 in BDEF, 16 in PUBMED and 5 in SCIELO. Of this total, 20 articles were excluded: revisions, protocols, duplicates. Only 23 were selected for complete reading that responded to this research’s objective.

**Table 1.** Selected articles for the Integrative Review. Niterói, RJ, Brazil, 2018.

Title / Journal	Year	Country	Type of study	Evidence Level
Oncology ostomized patients perception regarding sexual relationship as an important dimension in quality of life/ J Coloproctal (Rio Janeiro) <sup>(14)</sup>	2017	Brazil	Cross-sectional study	IV
Quality of life of people with intestinal stomas / Acta Paul Enferm <sup>(15)</sup>	2017	Brazil	Cross-sectional study	IV
Self-esteem and health-related quality of life in ostomized patients/ Rev Bras Enferm <sup>(16)</sup>	2017	Brazil	Cross-sectional study	IV
Perceptions of ostomized persons due to colorectal cancer on their quality of life/ J Coloproctal (Rio Janeiro)	2017	Brazil	Cross-sectional study	IV
Quality of life in stomized oncological patients: an approach of integrality from Brazilian Unified Health System/ J Coloproctal (Rio Janeiro)	2016	Brazil	Cross-sectional study	IV
Quality of life of older rectal cancer patients is not impaired by a permanent stoma/ The journal of cancer surgery	2013	The Netherlands	Cross-sectional study	IV
Gastrointestinal ostomies and sexual outcomes: a comparison of colorectal cancer patients by ostomy status/ Support Care cancer	2014	USA	Cross-sectional study	IV
From diagnosis through survivorship: health-care experiences of colorectal cancer survivors with ostomies/ Support Care cancer	2014	USA	Mixed method study (quali-quant)	IV
Quality of life in rectal cancer patients with permanent colostomy in Xi’an/ African Health sciences	2014	Africa	Cross-sectional study	IV
Quality of Life and Timing of	2016	Germany	Cross-sectional	IV

Stoma Closure in Patients With Rectal Cancer Undergoing Low Anterior Resection With Diverting Stoma: A Multicenter Longitudinal Observational Study/ Diseases of the Colon & Rectum			study	
Quality of life in patients with a permanent stoma after rectal cancer surgery/ Qual Life Res	2017	Sweden	Cross-sectional study	IV
Self-reported wellbeing and body image after abdominoperineal excision for rectal cancer/ Int J Colorectal Dis	2016	Sweden	Mixed method study (quant-qual)	IV
The impact of an ostomy on older colorectal cancer patients: a cross-sectional survey/ Dis Colon Rectum	2017	The Netherlands	Cross-sectional study	IV
The colostomy impact score: development and validation of a patient reported outcome measure for rectal cancer patients with a permanent colostomy. A population-based study	2017	Denmark	Cross-sectional study	IV
Long term quality of life of patients with permanent end ileostomy: results of a nationwide cross-sectional survey/ Colorectal disease	2017		Cross-sectional study	IV
The role group education on quality of life in patients with a stoma/ European Journal of cancer care	2012	Peru	Cross-sectional study	IV
Surviving colorectal cancer: long-term, persistent ostomy-specific concerns and adaptations / J wound Ostomy Continence Nurs	2013	USA	Qualitative study	IV
Spiritual well-being long-term cancer survivors with ostomies/ Psychooncology	2013	USA	Cross-sectional study	IV

Quality of life and psychological well-being of colorectal cancer survivor in Jordan/ Asian Pac J Cancer Prev	2014	Jordan	Cross-sectional study	IV
Health-Related Quality of Life After Colorectal Cancer in England: A Patient-Reported Outcomes Study of Individuals 12 to 36 Months After Diagnosis/ J Clin Oncol	2015	United Kingdom	Pilot study	III
A mixed-method study on the generic and ostomy-specific quality of life of cancer and non-cancer ostomy patients/ Support care cancer	2015	USA	Cohort study	III
Association of sociodemographic and clinical factors to the quality of life of people with ostomy/ Rev. Latino-Am. Enfermagem	2012	Brazil	Cross-sectional study	IV
Quality of Life Related to the Health of the Patient with Secondary Intestinal Stomach to Colon-Retal Cancer / Rev Iberam Educ Invest Enferm	2014	Brazil	Cross-sectional study	IV

Source: research data.

### Discussion

Most of the publications found in this study were international and most of them used the cross-sectional study as a method, which is consistent with the objective proposed in this study.

In this section, the predominate subjects in the articles selected according to the inclusion and exclusion criteria will be discussed. Among the found instruments of quality of life were: whoqol-bref (generic instrument of quality of life of the World Health Organization-WHO), EORTC QLQ-C30 (European Organization for Research in the Treatment of Cancer Quality of life Questionnaire), Stoma qol (de Pietro et al), SF-36 (WHO generic instrument).

Studies indicate that people who've had an ostomy for less than one year present more social activity, personal development and accomplishment than those who've had it for more than one year, since most of the patients were submitted to stomatal confection at a late stage, with metastases and for palliative purposes<sup>15</sup>.



One study compared a group of patients with cancer and esophageal stoma who did not have cancer as a cause and concluded that the type of symptoms, restrictions, and adaptations that influence the life of both groups is very similar, although patients with stoma with cancer evidenced a greater complaint of fatigue, leakage, pain, physical function<sup>16-17</sup>.

They were divided into three categories according to the dimensions of quality of life committed with the purpose of facilitating the dynamics, understanding and problematization of the ideas of this study.

### **Category 1. Physical well-being and self-image**

In the investigated subjects, body image is impaired, resulting in changes in the physical body due to the mutilation. There is a change in the abdomen, aggravated by the use of the collector equipment and adjuvants.

Dissatisfaction with self-image related to the stoma and the suffering they experience affect the psychological sphere, culminating in low social acceptance, suicidal ideas, and depression, resulting in a deficiency in their quality of life<sup>15-26</sup>.

The functioning of the physical function is also impaired, as the quality of life assessment instruments show. A 2017 study supports the idea that health-related quality of life is reduced in stoma patients and worsens when associated with complications<sup>15-16-24</sup>.

Physical well-being is greatly affected by the stoma, because of a preoccupation with the noticeable stoma, concern with gases, odors, fecal elimination and leakage, resulting in physical discomfort. Changes in appearance and lifestyle make the patients feel ashamed, being excluded by family and society<sup>17,29</sup>.

Studies have reported that the presence of postoperative complications, such as fistulas, skin irritations and protrusion of the stomach may also result in lower quality of life because they interfere with self-care and self-image<sup>18</sup>.

The prevalence of early complications of the stoma is very pronounced and there are several approaches to reduce them, such as support and counseling<sup>19</sup>.

### **Category 2. Acceptance and Self Care**

In a study by Bukley et al,<sup>(19)</sup> the study participants report the difficulty of dealing with the challenges related to acceptance and self-care. They reported the difficulty of adapting to the new life, which involves taking care of their stoma.

The intestinal stoma alters the role of the individual in the family and in society, since after the surgery the individual will need family support, even if temporarily, in addition to suffering from socially-imposed disabilities and leaving the attributes of efficiency, independence and productivity that will affect in other spheres<sup>20</sup>.

This is a process that is both subjective, collective and social, and deeply reflexive about coexistence with intestinal stoma, which can affect the physical and psychological spheres, as well as social relations and the environment, impairing their quality of life<sup>16</sup>.

### **Category 3. Compromised Sexual Function**

Sexuality is, therefore, the set of emotions, feelings, fantasies, desires and interpretations that human beings experience during life. Sexuality is an integral part of the human personality, associating personal and emotional experiences, sociocultural knowledge, beliefs, and values constructed throughout history<sup>22</sup>.

In this sense, patients with an edematous undergo changes in their bodies and self-image, as explained above, affecting the quality of life. The reports of sexual activities in studies show that this practice is affected, being closely related to the notion of self-concept, the consequent change in body image, and the reduction of self-esteem and perception of sexual attraction<sup>17,22,31</sup>.

Studies show that sexual dysfunction affects both men and women due to changes in body image, fecal incontinence, and marital

imbalance due to the self-image associated with behavioral changes, which will lead to psychological imbalance<sup>22,30,32</sup>.

### Conclusion

Quality of life studies lead us to understand the individuality of each client and to help them make the best decision regarding their treatment options. Finding the best and most suitable instrument for assessing the quality of life of the stomized client is an arduous task, since many questionnaires are available, but few are specialized and focused on clients with colorectal cancer and who have a stoma. Most of them have many restrictions for this type of customer.

The quality of life of these clients depends on several factors, such as psychological adaptation to change, self-image, self-esteem, complications of the stoma, adaptation to the collecting equipment, among others, which makes qualified professionals a necessity to support them.

Most studies indicate that the quality of life in patients with an esophageal cancer who had colorectal cancer appears to be moderate to good. Regardless of the gender, they show that the longer the patients have had the stoma time, the more adapted they are<sup>(22,23,28)</sup>. Another study points out that the HRQoL in patients with definitive stoma is inferior to patients with a temporary stoma after colorectal cancer<sup>(24)</sup>.

Therefore, this new condition of having an ostomy and living or having experienced colorectal cancer puts health professionals in the goal of seeking to achieve a level of satisfaction in the life of each client that makes them feel healthier, always with a family and multiprofessional approach.

Studying the quality of life of these patients who have colorectal cancer and who have an ostomy reminds nurses of the importance of thinking about strategies for health actions beyond the focus of the disease, which may create means to help them make decisions, verbalize feelings and

help them cope with changes in their body image for the sake of survival<sup>27</sup>.

A study of 42 colorectal cancer patients showed that education in how to care for the stoma can shorten hospitalization time, complications and cost.

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