

Associations among socio-demographic and clinical factors and the quality of life of ostomized patients

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This study identifies the socio-demographic and clinical factors of patients with irreversible colostomy secondary to colorectal cancer and correlates them with quality of life (QOL). It is a cross-sectional study. Socio-demographic and clinical data were collected through interviews and the WHOQOL-bref to assess QOL. The sample comprised 60 patients. Most of the patients were male, elderly individuals, half were married and half did not have a sexual partner, with complete primary education, receiving up to two times the minimum wage, carried a stoma for three months on average, were instructed they would carry a stoma, but did not have their stoma marked prior to surgery. The average QOL score was 75.500, while the psychological, social and physical domains were the most affected. No statistically significant differences were found in QOL in relation to the following socio-demographic and clinical factors: female gender, low income, no sexual partners, and lack of instruction. The patients with an intestinal stoma presented a satisfactory QOL.

Descriptors: Quality of Life; Colorectal Neoplasms; Nursing Care; Surgical Stomas.

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Associação dos fatores sociodemográficos e clínicos à qualidade de vida dos estomizados

Os objetivos deste estudo foram identificar os fatores sociodemográficos e clínicos dos pacientes com estoma intestinal definitivo, secundário ao câncer colorretal, e correlacioná-los à qualidade de vida (QV). Como métodos usaram-se o estudo transversal, utilizando a entrevista como instrumento de coleta de dados sociodemográficos e clínicos, e, para avaliação da QV, o WHOQOL-bref. A amostra foi composta por 60 pacientes. Como resultados tem-se que a maioria dos pacientes era do sexo masculino, idoso, casado, sem parceiro sexual, com ensino fundamental completo, recebia até dois salários-mínimos, tempo médio de estoma de três meses, foram orientados que portariam um estoma, mas não foi demarcado para a cirurgia. A média da QV foi de 75,00, sendo que os domínios psicológico, social e físico foram os mais afetados. Os fatores sociodemográficos e clínicos: sexo feminino, baixa renda, não ter parceiros sexuais e falta de orientação apresentaram diferenças estatísticas significantes na QV. Conclui-se que os pacientes portadores de estoma intestinal demonstraram QV satisfatória.

Descritores: Qualidade de Vida; Câncer Colorretal; Cuidados de Enfermagem; Estomas Cirúrgicos.

Asociación de los factores sociodemográficos y clínicos a la calidad de vida de los ostomizados

El artículo tuvo por objetivo identificar los factores sociodemográficos y clínicos de pacientes con estoma intestinal definitivo secundario al cáncer colorrectal y correlacionarlos a la calidad de vida (CV). Se trata de un estudio transversal, que utilizó, para recolectar datos sociodemográficos y clínicos, la entrevista y para evaluar la CV el cuestionario WHOQOL-bref. La muestra abarcó 60 pacientes. La mayoría de los pacientes era del sexo masculino, anciano, casado, sin pareja sexual, con educación fundamental completa, recibía hasta dos salarios mínimos, con tiempo promedio de estoma de tres meses, informado que portaría una estoma, pero no programado para la cirugía. El promedio de CV fue 75,00, siendo que los dominios psicológico, social y físico fueron los más afectados. Los factores sociodemográficos y clínicos: sexo femenino, baja renta, no tener pareja sexual y falta de orientación, mostraron diferencias estadísticas significativas en la CV. Se concluye que los pacientes portadores de estoma intestinal demostraron una CV satisfactoria.

Descriptores: Calidad de Vida; Neoplasias Colorrectales; Atención de Enfermeira; Estomas Quirúrgicos.

Introduction

Colorectal cancer affects people worldwide and is the third most frequent cause of death due to cancer among female and male individuals and the second cause in developed countries⁽¹⁾. The census conducted by the Brazilian National Cancer Institute (INCA) estimated that 28,110 cases of colorectal cancer were diagnosed in Brazil in 2010: 13,310 of these were men and 14,800 were women⁽²⁾.

Patients with colorectal cancer present various physical problems after the surgical treatment, such as altered sexual performance and urinary and intestinal functions, which significantly affect one's quality of life (QOL), especially when the surgery results in an intestinal stoma⁽³⁾.

Given such an outcome, ostomized individuals face many losses that may be real or symbolic, such as

loss of control over the elimination of feces and gases, which results in psychological and social isolation. These individuals are faced with changed body image and self-esteem, with feelings of disgust toward themselves, feel a lack of prestige in the face of society, and have difficulties coping with their situation⁽³⁾. QOL has been considered crucial for the evaluation of clinical results after surgical treatment since it takes into account the perspective of the patient for the decision-making process⁽⁴⁾.

Given the complex context faced by individuals with stomas, this study evaluates the QOL, socio-demographic and clinical factors of patients with irreversible colostomy caused by colorectal cancer.

Method

This cross-sectional study identified socio-demographic and clinical factors and the QOL of patients with irreversible colostomy secondary to colorectal cancer. A total of 60 (67%) patients among the 90 patients with irreversible colostomy (ICD-20) registered in the Gestational Care Center in São José do Rio Preto, SP, Brazil who met the inclusion criteria and consented to participate in the study were included in the study. The inclusion criteria were being an adult 18 years old or older; without mental impairment; residents of São José do Rio Preto or the surrounding region, who agreed to participate in the study in the data collection period.

Data were collected through interviews privately held in the patients' homes from July to December 2010. The instrument addressing socio-demographic data was composed of the following variables: gender, age, marital status, occupational profile, family income and schooling. Clinical data included the period since the stoma was performed, history of metastasis, whether the stoma was marked and patients were informed of it prior to the surgery.

The WHOQOL-bref was used to evaluate QOL. It is composed of 26 items that refer to four domains: physical, psychological, social relations, and environment. The answers to all the WHOQOL-bref were obtained with a Likert scale on which the possible scores ranged from 1 to 5. Additionally, two questions addressing overall quality of life were computed together and generated a single score, independent of the remaining scores.

This questionnaire is a Portuguese version of the World Health Organization's original version, validated in Brazil by Fleck at the University of Rio Grande do

Sul⁽⁵⁾. Cronbach's alpha, an internal consistency test, was performed to check the instrument's reliability. Descriptive statistics were used to meet the proposed objectives, namely: average, median, standard deviation, and non-parametric statistical tests, such as the Mann-Whitney and Kruskal-Wallis tests, were performed. The level of significance was fixed at 5%.

Guidelines regulating research involving human subjects were complied with and the Ethics Research Committee approved the project (protocol No. 5572/2009). The participants signed free and informed consent forms.

Results

The results obtained are presented starting with the socio-demographic and clinical characterization of patients with irreversible colostomy followed by an evaluation of their QOL according to the WHOQOL-bref.

Of the 60 patients with irreversible colostomy secondary to colorectal cancer who participated in this study: 34 (56.67%) were men, with average age of 65.66 ±14.14 years old; 24 (40.0%) had completed primary school; 32 (55.17%) were married; 30 (51.27%) did not have sexual partners; 25 (43.86%) were retired; and 15 (31.25%) received from one to two times the minimum wage. Clinical data included: 46 (82.14%) patients did not report history of metastasis; 36 (66.45%) did not have their stoma marked before surgery; 40 (68.97%) were informed that they would have a stoma before surgery, and the average time carrying the stoma was 87.50±90.7 days.

The QOL domains according to the WHOQOL-bref presented similar average scores, between 61.94 and 68.69. The overall domain presented the highest score (75.00) and the physical domain the lowest score (64.29), though no statistically significant differences ($p=0.664$) were found in the analyzed domains among patients (Table 1).

Table 1 – Average scores of the WHOQOL-bref domains among patients with irreversible colostomies. São José do Rio Preto, SP, Brazil, 2010

Domains	n	$\bar{x} \pm s$	Average	CI (95%)	Valor P
Overall	60	64.58±22.57	75.00	(61.63;75.00)	
Physical	60	64.33±22.92	64.29	(57.14;75.00)	
Psychological	60	68.69±18.98	68.75	(62.50;75.00)	0.664
Social	60	61.94±23.49	66.67	(66.09;67.24)	
Environmental	60	65.07±15.60	65.63	(59.37;65.84)	

The comparison between QOL and socio-demographic and clinical factors revealed that there were no statistically significant differences in relation to the variables of age, time carrying the stoma, schooling, marital status and occupational status.

Similarities were observed among the following domains in the relationship between the variable age and QOL: overall ($p=0.266$), physical ($p=0.296$), psychological ($p=0.347$), social ($p=0.315$), and environmental ($p=0.160$).

QOL related to time of stoma, schooling, marital status, and occupational profile did not present statistically significant differences in relation to the patients' average scores when analyzed by domains ($p>0.05$). In relation to the variable 'occupational profile', working patients presented the highest average scores (above 68) in all the domains when compared to non-working patients (below 62). Such an analysis indicates that being professionally active leads patients to evaluate their QOL higher. The variable 'gender' presented a statistically significant difference when related to the psychological domain $p=0.007$ (Table 2).

Table 2 – Average scores of the WHOQOL-bref domains among patients with irreversible colostomy according to gender. São José do Rio Preto, SP, Brazil, 2010

Domain	Gender	N	$\bar{x} \pm s$	Average	P-value
Overall	Female	26	59.62±20.71	62.50	0.119
	Male	34	68.38±23.48	75.00	
Physical	Female	26	61.22±24.30	60.71	0.464
	Male	34	66.70±21.87	67.86	
Psychological	Female	26	61.82±19.06	60.42	0.007
	Male	34	73.92±17.43	75.00	
Social	Female	26	59.62±21.69	66.67	0.420
	Male	34	63.73±24.95	66.67	
Environmental	Female	26	63.46±15.58	62.50	0.627
	Male	34	66.31±15.73	65.63	

The average scores of the variable 'family income' presented a statistically significant difference when compared to the psychological domain ($p=0.024$); the median values are discrepant, especially in those patients with family income up to one times the minimum wage. It indicates that the lower the patient's income, the lower his/her scores in relation to the psychological domain.

The median score for patients who reported metastasis is below that observed among patients without metastasis. Hence, a statistically significant

difference ($p=0.017$) is observed among patients in relation to the social domain (Table 3).

Table 3 – Average scores of the WHOQOL-bref among patients with irreversible colostomy according to the report of metastasis. São José do Rio Preto, SP, Brazil, 2010

Domain	Metastasis	N	$\bar{x} \pm s$	Average	P-value
Overall	Yes	10	57.50±28.99	56.25	0.346
	No	46	66.58±20.42	75.00	
Physical	Yes	10	65.00±23.62	66.07	0.923
	No	46	65.73±22.32	67.86	
Psychological	Yes	10	66.67±18.53	66.67	0.676
	No	46	70.49±18.26	70.83	
Social	Yes	10	47.50±21.53	45.83	0.017
	No	46	65.40±22.50	66.67	
Environmental	Yes	10	60.94±18.12	59.38	0.199
	No	46	67.08±14.49	65.63	

Statistically significant differences were observed in relation to the average scores of patients in the physical ($p=0.022$) and social ($p=0.031$) domains when related to the status of not having a sexual partner (Table 4).

Table 4 – Average scores of the WHOQOL-bref domains among patients with irreversible colostomy according to the existence of sexual partners. São José do Rio Preto, SP, Brazil, 2010

Domain	Sexual partner	N	$\bar{x} \pm s$	Average	P-value
Overall	Yes	28	69.20±21.65	75.00	0.116
	No	30	59.58±23.14	62.50	
Physical	Yes	28	71.43±20.85	76.79	0.022
	No	30	56.87±23.38	57.14	
Psychological	Yes	28	71.16±17.40	70.83	0.474
	No	30	66.25±20.92	66.67	
Social	Yes	28	68.75±23.53	75.00	0.031
	No	30	56.39±22.71	66.67	
Environmental	Yes	28	66.45±15.93	65.63	0.618
	No	30	63.96±15.95	62.50	

The average QOL scores of the studied patients were similar among those who had their stomas marked prior to surgery and those who did not ($p>0.05$).

Data presented in Table 5 present statistically significant differences in the physical ($p=0.023$) and psychological ($p=0.012$) domains among patients who were informed about the stoma before surgery.

Table 5 – Average scores of the WHOQOL-bref domains among patients with irreversible colostomy according to knowledge concerning the stoma procedure before surgery. São José do Rio Preto. SP. Brazil. 2010

Domain	Instruction	N	$\bar{x} \pm s$	Average	P-value
Overall	Yes	40	67.50±21.15	75.00	0.155
	No	18	56.94±25.45	56.25	
Physical	Yes	40	69.17±20.98	73.21	0.023
	No	18	52.78±24.21	57.14	
Psychological	Yes	40	72.83±17.36	72.92	0.012
	No	18	58.33±19.60	62.50	
Social	Yes	40	64.38±23.19	66.67	0.141
	No	18	54.63±23.95	66.67	
Environmental	Yes	40	67.73±14.11	65.63	0.062
	No	18	58.23±17.30	58.48	

Discussion

The socio-demographic characterization of patients showed a predominance of male elderly patients with an average age of 65.66±14.14 years old. Such a result is in consonance with the results of another study whose patients with colorectal cancer were male and were 60 to 70 years old⁽⁶⁾.

The evaluation of the average QOL scores obtained in the diverse domains (Table 1) revealed that most patients presented higher scores in the overall domain, while half of them obtained scores between 64.29 and 100.0 in the physical domain. This result is similar to that found in another study, which did not report statistically significant differences between the average scores related to QOL in patients with colorectal cancer, whether in adjuvant or palliative treatment⁽⁷⁾. Studies verified that the overall emotional and physical health of patients improves significantly the third month after surgery for colorectal cancer and continues to improve gradually over the first year after the surgery⁽⁸⁻⁹⁾.

Researchers analyzed changes in the QOL of the ostomized patients three and six months after colorectal surgery using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 items (EORTC-QLQ-C-30) and verified that though the patients' social, private and financial lives are compromised, their QOL improves over time⁽¹⁰⁾. The QOL of patients with ostomy in the United States was evaluated through the Ostomy Quality of Life Questionnaire (OQLQ), which showed that most presented a satisfactory QOL despite the presence of an ostomy⁽¹¹⁾.

The comparison of the QOL domains in relation to gender (Table 2) did not present a significant difference, except for the psychological domain ($p=0.007$), in which women presented a median score of 60.4 compared to 75.0 obtained by men. These findings are similar to those found in a study conducted in Ribeirão Preto, SP, Brazil with ostomized patients, which showed that the psychological domain was significantly affected in both genders ($p=0.04$). Such an effect is likely more evident among female patients because women are more sensitive to their body image and become ashamed for having part of their intestine "exposed" and also because of the stigma imposed by the disease, driving people away from social events⁽⁶⁾. Another study conducted in Germany showed that women were more affected in the physical and overall health domains while men had their QOL more affected in sexual terms; they suffer greater pressure to perform sexually⁽⁸⁾.

Similarities were found among age groups in relation to the QOL domains, in contrast to what was found in a study addressing the impact of QOL in patients with colorectal cancer, which reported statistically significant differences in the physical and functional domains. Patients 69 years old or younger presented better scores in the physical domain than patients 70 years old or older, especially in relation to pain and fatigue⁽¹²⁾. Another study reported that younger male patients presented lower scores in sexual terms, which were related to a difficulty ejaculating⁽¹³⁾. Younger patients, especially male patients, perceive and give weight to sexual impairment more than elderly patients, who value physical aspects, and when these are compromised, their perception concerning QOL is worsened.

The low educational level found in this study was similar to the results found in other studies^(10,14-15); the patients' educational level ranged from illiterate to completed primary school. Such information reveals the patients' educational level, but this is not a characteristic of those using public services only, where data were collected for this study, but is in fact the Brazilian educational profile. The low educational level found in this study directly reflects on the patients' financial condition: 44% of the patients received up to two times the minimum wage and 53% were professionally inactive. Another study verified that 20% to 90% of the ostomized patients have their ability to work affected not because of the stoma or the disease *per se* but due to their advanced age⁽¹⁵⁾.

Another important piece of information is that the active patients obtained higher scores in the physical and psychological domains compared to the inactive individuals (Table 5). Such results corroborate the findings of a study using the QOL SF-36V2 instrument (veteran's version) to analyze the relationship between being employed and the psychological wellbeing of patients who underwent large bowel surgeries with or without ostomy. Employed patients reported better psychological wellbeing compared to the unemployed and those working full time reported even higher scores of psychological wellbeing compared to those working part-time⁽¹⁶⁾.

In relation to the patients' marital status, 55.17% were married and 51.27% reported no sexual partners. Some studies report that most ostomized patients are either married or have a partner but do not report whether they are sexually active^(6,10). Mile's surgery often causes erectile dysfunction because vessels and nerve endings, responsible for the erectile function in men, are cut during the surgery. In women, because the vagina is very close to the rectum, the removal of a tumor from the colon or rectum causes shortening of the vagina, leading to disparemia and loss of libido. In addition to these issues, which by themselves lead patients to cease any sexual activity when not properly instructed by a health worker, there are also psycho-emotional consequences individuals have to face due to carrying a stoma, such as embarrassment, isolation and a lack of sexual interest⁽¹⁷⁾. No statistically significant differences were found in relation to the QOL domains and marital status even though the findings in the literature are that single, widowed, and separated individuals carrying a stoma face a greater difficulty in revealing their changed body image to a potential sexual partner and in becoming involved in extra marital relationships after the surgery; their spouses are the only people who accept physical contact⁽¹⁸⁾. These data are in agreement with a study that observed that patients with a recent stoma have their sexuality affected when they do not have a fixed partner; they feel insecure, ashamed, and afraid of not being accepted by partners⁽¹⁹⁾.

Most interviewees did not mention metastasis (82.14%), which is explained by more assertive treatments and early diagnosis, which prevents metastasis⁽¹⁹⁾. When comparing the domains of QOL with the existence of metastasis, the social domain was statistically significant ($p=0.017$), especially in relation to personal relationships with friends and sexual partners. This effect on social domain was

reported by a study that showed statistically significant changes in the physical and social domains in patients at the beginning of adjuvant and palliative treatment of colorectal cancer⁽²⁰⁾. Another study addressing patients in the active phase of an intestinal inflammatory disease indicated QOL is compromised. Physical aspects, vitality, and emotional aspects are the domains mostly affected by the symptoms presented by patients, which can greatly impact their behavior in emotional, physical and social terms⁽²¹⁾. Another study addressing patients with extensive and metastatic colorectal cancer observed deterioration in the patients' physical functioning⁽²²⁾.

A total of 60% of the ostomized patients did not have their stomas marked prior to their surgery. No statistically significant differences were found when comparing the QOL domains of patients who had their stomas marked prior to surgery (Table 5). Marking the stoma prior to surgery is essential and should be done by the nurse responsible for providing care to the ostomized patient or preferably by a stoma therapist because it is important for the rehabilitation process and directly reflects on the patient's QOL after surgery. Moreover, marking the stoma at a site that ensures adherence to the device and its use is easily visualized by the patient as a strategy to prevent important complications⁽²³⁾.

In contrast, the physical and psychological domains were significantly ($p=0.023$) affected in patients who were not instructed prior to surgery. Preoperative instructions concerning the likelihood of patients carrying a stoma were received by 68.97% of the studied patients.

Studies concerning the QOL of ostomized patients show the importance of marking the stoma prior to surgery and of nurses providing guidance concerning physical, psychological, economic, social, family and sexual aspects and instructing the patient in self-care through the entire perioperative period, supporting the patient's coping abilities in regard to his/her new situation⁽²⁴⁻²⁵⁾.

No statistically significant differences were found in this study when the QOL domains were compared to the stoma's duration. This is in agreement with a study that analyzed the QOL of patients with colorectal cancer with and without an ostomy, though it observed that patients who had the stoma less than one year were more socially active and presented greater personal development than those with a ostomy for more than one year⁽¹⁴⁾. A study conducted in Taiwan using the Acceptance of Disability Scale for patients with colorectal cancer verified that those with less time having the disease and lower

stoma duration presented lower levels of accepting their condition⁽²⁶⁾.

This study enabled greater understanding of the QOL of ostomized patients and provided indications that nurses should devise health action strategies beyond the focus of the disease, promoting the means to help patients make decisions, verbalize their feelings, and cope with changes in their body image toward improved survival.

Conclusions

This study revealed that most patients with an irreversible ostomy secondary to colorectal cancer were elderly men, half were married and half had no sexual partners, with complete primary school, received up to two times the minimum wage, carried the stoma for an average of three months, had their stoma marked and were instructed about the procedure prior to surgery.

The average QOL obtained by the studied sample was 75.00, which is considered to be satisfactory. The most affected domains were psychological, social and physical. The psychological domain was more affected among women, individuals with lower incomes, and those who were not informed about the procedure prior to the surgery. The social domain was more affected among those without sexual partners and who presented metastasis. The physical domain was more affected among those who did not receive instruction about their stoma before surgery and did not have sexual partners.

This study's limitations include: the sample size of 60 patients, that is, 67% of the 90 patients with irreversible colostomy registered in the Gestational Care Center in São José do Rio Preto, SP, Brazil; difficulties in collecting data in the patients' houses; and the limited number of studies addressing QOL in this population. We observed that the stoma and cancer do not negatively impact the lives of the studied patients as long as they are cared for in a humanized and systematized manner by nurses.

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