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## Original article

# Quality of life in patients with ileal pouch for ulcerative colitis

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## ABSTRACT

**Introduction:** proctocolectomy with ileal pouch-anal anastomosis (IPAA) is the standard surgical procedure for the treatment of ulcerative colitis (UC) and is associated with the prospect of cure. Experience gained over the years has demonstrated the occurrence of a high number of complications as well as bowel disorders that can compromise quality of life (QoL).

**Objective:** evaluate QoL in patients with IPAA for ulcerative colitis.

**Patients and methods:** the Inflammatory Bowel Disease Questionnaire (IBDQ) was used to assess QoL in patients with IPAA after its validation in Portuguese.

**Results:** thirty-one patients submitted to IPAA by the same group of professionals were evaluated. QoL was classified as regular in all domains evaluated (intestinal and systemic symptoms and emotional and social aspects). There were no differences in relation to gender, type of pouch or postoperative time. However, elderly patients showed a tendency toward lower scores. Having a professional activity was associated with higher scores in systemic symptoms and social aspects ( $p < 0.05$ ). Patients with ileostomy showed lower values in the domains of systemic symptoms, emotional and social aspects ( $p < 0.05$ ).

**Conclusion:** in all domains assessed, patients with IPAA for UC had QoL classified as regular. Ileostomy and lack of professional activity negatively influenced QoL.

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## Qualidade de vida em portadores de reservatório ileal por retocolite ulcerativa

### RESUMO

Retoclectomia com reservatório ileal (RI) é o procedimento cirúrgico padrão para o tratamento da Retocolite Ulcerativa (RCUI) e está associada a perspectiva de cura. A experiência adquirida ao longo dos anos evidenciou a ocorrência de elevado número de complicações assim como distúrbios evacuatórios que podem comprometer a qualidade de vida (QoL).

**Objetivo:** Avaliar a qualidade de vida em portadores de RI por RCUI.

**Pacientes e métodos:** Foi empregado IBDQ, validado em português na avaliação da QoL em portadores de RI.

### Palavras-chave:

Qualidade de vida

Reservatório ileal

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**Resultados:** Foram avaliados 31 pacientes submetidos a RI pelo mesmo grupo. QoL foi classificada como regular em todos os domínios avaliados (sintomas intestinais e sistêmicos e aspectos emocionais e sociais). Não houve diferenças em relação ao sexo, tipo de reservatório ou tempo de pós-operatório. Entretanto, pacientes idosos apresentaram uma tendência a escores mais baixos. Atividade profissional relacionou-se com escores mais altos em sintomas sistêmicos e aspectos sociais ( $p < 0,05$ ). Portadores de ileostomia apresentaram valores mais baixos nos domínios sintomas sistêmicos, aspectos emocionais e sociais ( $p < 0,05$ ). **Conclusão:** Em todos os domínios avaliados, portadores de RI por RCUI apresentaram QoL classificada como regular. Ileostomia e inatividade profissional influenciaram negativamente a QoL.

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## Introduction

Ulcerative Colitis (UC) is an inflammatory bowel disease of unknown etiology, characterized by lesions in the colon and rectum mucosa and submucosa. Drug treatment is preferred; however, cases that do not respond to medical therapy or that developed complications such as toxic megacolon or dysplasia/cancer may require surgical treatment.

Parks & Nicholls<sup>1</sup> proposed as a surgical option in UC the proctocolectomy with ileal pouch-anal anastomosis (IPAA). This procedure was associated for many years with a prospect of cure at a time when treatment options were scarcer and less effective. Thus, many patients were submitted to this surgery in the 1980's and 1990's. Currently, IPAA is still the standard procedure in UC, but the experience gained over the years demonstrated the occurrence of high morbidity, bowel disorders and pouch inflammation (pouchitis), which can negatively influence the quality of life (QoL) and oppose the initial expectations.<sup>2</sup>

Thus, it is justified to currently assess the perception and QoL of patients after IPAA in relation to surgical or other therapeutic options. The information obtained may establish parameters for the indication of the procedure, as well as provide subsidies for the better understanding of the expected results by patients. The objective of this study was to evaluate the QoL in patients with IPAA for UC after at least one year postoperatively.

## Patients and methods

Patients with IPAA for UC of both genders and aged 18 and older, operated by the Coloproctology Group (DMAD-FCM-UNICAMP) were included in the study. Patients with a postoperative diagnosis of Crohn's disease and postoperative time of less than one year were excluded.

The Inflammatory Bowel Disease Questionnaire (IBDQ), validated in Portuguese,<sup>3</sup> was used to assess QoL; it consists of 32 questions in four domains: intestinal and systemic symptoms, social and emotional aspects. Each question has seven scored answers, with the worst being scored as one and the best as seven. The sum of all domains results in the total score for each patient.

Scores between five and seven were classified as satisfactory; a score of four was classified as regular and scores

between one and three were classified as unsatisfactory. Percentages with the minimum and maximum values for each domain were evaluated. For the qualitative analysis, the intervals between the minimum and maximum values of each domain were stratified into three intervals (Table 1).

The chi-square, Fisher exact, Mann-Whitney and Kruskal-Wallis tests and Spearman's correlation coefficient were used for the statistical analysis.

All participants were informed on the study objectives, the questionnaire application form and disclosure of the data. All participants signed an informed consent form. The study was approved by the local Research Ethics Committee (FCM/UNICAMP, N. 447/2008).

## Results

The medical records of 77 patients submitted to IPAA for UC were assessed, of which 47 met the inclusion criteria. As 16 patients did not answer the request, the number of participants was 31, with a mean age of 46.4 (27-76) years old, of which 16 were females.

Postoperative time was greater than 10 years in 22 patients (71.0%); 23 (74.2%) were married and 19 (61.3%) were working at the time of the interview (Table 2).

### Postoperative morbidity and functional aspects

According to information provided by the patients, 83.9% of them had some type of postoperative complication and reoperation rate was 9.7%. Presence of ileostomy was 29.0%, pouchitis in 16.3% and 16.1% had intestinal obstruction. High frequency of bowel movements was reported by 16.1%, with the occurrence of nocturnal bowel movements in 12.9%; 54.8% had fecal incontinence and nocturnal incontinence was 6.5% (Table 3).

**Table 1 – Qualitative analysis with intervals of minimum and maximum values of each domain in three intervals.**

	Satisfactory	Regular	Unsatisfactory
Physical symptoms	63 - 70	55 - 62.99	46 - 54.99
Systemic symptoms	27 - 35	18 - 26.99	8 - 17.99
Social aspects	26.68 - 35	18.34 - 26.67	10 - 18.33
Emotional aspects	63.33 - 84	42.67 - 63.32	22 - 42.66

Regarding postoperative results, 93.6% reported being satisfied with the surgery and 96.8% would recommend it to other patients (Table 4).

**Inflammatory Bowel Disease Questionnaire (IBDQ)**

**Intestinal Symptoms**

Regarding the frequency of bowel movements, 42.0% of the patients reported it as satisfactory and 45.2% reported no episodes of fecal incontinence. The lowest score in this area was

related to the frequency of bowel movements and the highest to the occurrence of rectal bleeding.

**Systemic symptoms**

The feeling of fatigue was reported by 74.2% of participants. The lowest score in this domain was related to problems related to sleep and difficulty in maintaining adequate weight.

**Social aspects**

No problem regarding school or work attendance caused by bowel disorders was reported by 58.1% of patients, whereas 64.5% said they were never late nor had to cancel a social engagement for the same reasons. The incapacity to play sports or perform pleasurable activities was reported by 59.1% of them.

The lowest score in this domain was associated with the fact that patients avoided going to places without toilets nearby and the highest with the need to cancel or postpone appointments due to bowel disorders.

**Emotional aspects**

With respect to personal satisfaction, 41.9% of respondents reported being extremely satisfied with the procedure. The lowest score in this domain was related to frustration, impatience and restlessness (32.3%) and the highest (57.7%) with the feelings of happiness and gratitude.

**Overall analysis**

The mean score for intestinal symptoms was 55.1 (46-70), 23.4 for systemic symptoms (8-35). The mean total score was 164.19 (73-224). Thus, it was qualitatively observed that QoL was regular in all evaluated areas (Table 5).

The comparison of scores by gender and type of pouch showed no difference ( $p = 0.984$ ,  $p = 0.742$ ).

Individuals that had a professional activity showed higher scores in the physical symptom and social activities domains and had a higher total score when compared to individuals who did not work ( $p = 0.011$ ,  $p = 0.007$ ,  $p = 0.022$ ) (Table 6).

Results showed a significant worsening in QoL in patients with ileostomy in the systemic ( $p = 0.021$ ), social ( $p = 0.010$ )

Table 2 – Sample characterization.		
	n	%
Gender		
Male	15	48.4
Female	16	15.6
Age (years)		
< 40	12	38.7
≥ 40	19	61.3
Marital status		
Married	23	74.2
Single	08	25.8
Professional activity		
With professional activity	19	61.3
No professional activity	12	38.7
Time of diagnosis (years)		
≤10	09	29.0
> 10	22	71.0
Postoperative time (years)		
≤ 10	17	54.8
> 10	14	45.2
Type of pouch		
“Two-chamber”	5	16.1
“S”	5	16.1
“J”	21	67.7

Table 3 – Postoperative complications and functional results.		
	n	%
Complications		
Yes	26	83.9
No	5	16.1
Presence of ileostomy		
Yes	9	29.0
No	22	71.0
Intestinal obstruction		
Yes	5	16.1
No	26	83.9
High number of bowel movements		
Yes	5	16.1
No	26	83.9
Pouchitis		
Yes	5	16.1
No	26	83.9
Nocturnal bowel movement		
Yes	4	12.9
No	27	87.1
Nocturnal incontinence		
Yes	2	6.5
No	29	93.5
Reoperation		
Yes	3	9.7
No	28	90.3

Table 4 – Surgical outcome satisfaction		
	n	%
Satisfied		
Yes	29	93.5
No	2	6.5
Would recommend the surgery		
Yes	30	96.8
No	1	3.2

Table 5 – IBDQ score.			
Domain	Total	Reference value	Qualitative analysis
Intestinal	55.1	46-70	Regular
Systemic	23.4	8-35	Regular
Social	25.7	10-35	Regular
Emotional	60.0	22-84	Regular

**Table 6 – Quality of life and professional activity.**

	Domain	n	Mean	SD	Min	Max	p
No professional activity	Intestinal	12	47.6	13.4	26.0	70.0	p = 0.011
	Systemic	12	20.5	8.2	8.0	35.0	p = 0.92
	Social	12	19.5	8.6	10.0	35.0	p = 0.007
	Emotional	12	52.3	21.2	24.0	84.0	p = 0.138
	Total	12	140.0	44.3	73.0	224.0	p = 0.022
With professional activity	Intestinal	19	59.8	8.4	37.0	69.0	
	Systemic	19	25.3	6.4	12.0	34.0	
	Social	19	29.6	6.5	13.0	35.0	
	Emotional	19	64.8	16.7	22.0	84.0	
	Total	19	179.5	32.8	105.0	215.0	

and emotional ( $p = 0.003$ ) domains and in the total score ( $p = 0.013$ ) (Table 7).

In the social domain, there was a correlation between age and lower QoL scores ( $r = -0.366$ ,  $p = 0.043$ ). In other areas, there was a tendency to lower scores in elderly individuals.

## Discussion

IPAA is the most often indicated surgical treatment for UC, but it has high morbidity, which makes the surgical indication difficult.<sup>3,4,5,6,7,8</sup>

Achieving the cure is not the objective in patients with chronic diseases, and therapeutic care aims at clinical remission and improved quality of life. The use of validated tools to assess QoL may contribute to therapeutic decision-making, particularly surgery. These tools are useful to identify different aspects related to the disease and the impact of therapy on routine activities. In Brazil, the IBDQ questionnaire has been validated for use in patients with inflammatory bowel disease. The analysis of the postoperative quality of life becomes important, although it can be difficult, as it assesses several aspects from the patient's viewpoint.

In the present study, it is noteworthy the fact that the permanence of ileostomy negatively influenced QoL. Similar results were observed by Leoward et al.<sup>9</sup> As postoperative complications lead to permanent intestinal diversion in a significant numbers of patients, they should be advised at the time of surgical indication about how the ileostomy may have an impact on their daily activities. Thus, surgeons and patients must take this possibility into account when an important decision such as surgical treatment and creation of an IPAA is made.

In this sample, the qualitative analysis of IBDQ scores showed regular QoL in all assessed domains. A similar analysis<sup>10</sup> with the same tool found that 38.9% of the patients had QoL classified as regular or poor. A systematic review by Heinkes et al.<sup>11</sup> comprising 33 articles demonstrated that QoL after IPAA for UC was classified as regular in 23, poor in seven and high in three.

The present study identified a tendency towards reduced QoL in the elderly, as did the work by Meyer et al.<sup>10</sup> Perhaps this fact is related to the occurrence of disorders such as fecal incontinence, more frequent in this age group, as well as the situation of the elderly in our country, who are not prepared for the aging process.

Professional activity was associated with higher scores on the physical and social domains. The data is comparable to the study by Leoward et al.,<sup>9</sup> who demonstrated a significantly lower QoL in individuals without professional activity. These authors considered that the possibility of performing professional activities becomes an important aspect to be considered in patients with chronic diseases and that they should be encouraged to return to work.

In our culture, the professional activity has a central and important role, related to personal identity, self-esteem and well-being. As UC primarily affects young individuals, in its severe forms the prospect of returning to work after a surgical procedure may be encouraging. However IPAA is associated with complications and especially the increased number of bowel movements and fecal incontinence, which may hinder the return to work and also worsened QoL in this sample. Although this study did not aim to compare pre- and postoperative QoL, the occurrence of symptoms caused by the proctocolectomy may be acceptable in patients with severe UC.

**Table 7 – Quality of life and permanence of ileostomy.**

	Domain	n	Mean	SD	Min	Max	p-value
No	Intestinal	22	56.6	11.0	35.0	70.0	p = 0.306
	Systemic	22	25.2	6.7	13.0	35.0	p = 0.021
	Social	22	28.2	8.1	13.0	35.0	p = 0.010
	Emotional	22	66.5	15.8	35.0	84.0	p = 0.003
	Total	22	176.6	37.6	105.0	224.0	p = 0.013
Yes	Intestinal	9	51.3	14.3	26.0	66.0	
	Systemic	9	19.0	7.4	8.0	28.0	
	Social	9	19.6	7.5	10.0	29.0	
	Emotional	9	43.9	17.9	22.0	67.0	
	Total	9	133.8	36.9	73.0	186.0	

The highest scores were associated with the possibility of not cancelling social engagements (74.20% - satisfied) and feelings of gratitude and happiness with life (57.7% - satisfied).

The question related to the procedure showed a high degree of satisfaction with the surgery, as well as the recommendation of the surgery to other patients in 96.8%. Similar results were reported by Wuthrich,<sup>12</sup> with 70% satisfaction with the surgery, and Meyer et al.<sup>10</sup> with 85%. In a study that analyzed the results from the patients' viewpoint, Neumann et al.<sup>3</sup> observed that 53% of patients felt that the surgery should have been performed earlier, especially due to the postoperative clinical improvement.

This study showed a discrepancy between the above-mentioned data and those obtained by the IBDQ. Discomfort was observed in some patients when filling out the item "satisfied with the surgery". Some patients said they would indicate the surgery, but at the right time or that they were pleased because it did not get any worse, but they would rather take the medications than undergo surgery. Thus, comparative studies about the pre and postoperative manifestations can bring additional information to facilitate understanding regarding the current state, i.e., the postoperative effects in contrast to the symptoms and the condition of being sick.

The present study provides objective data on the influence of IPAA on QoL in patients with UC, and the surgeon as well as the patient can assess the expected results with greater confidence and, if necessary, change the therapeutic indication, either by maintaining the clinical treatment or indicating IPAA or another surgical procedure. The doctor-patient relationship has great influence on treatment success as well as the reassurance transmitted to patients based on real data and understandable information including the description of the most common outcomes.

Considering that, IPAA is still the most common surgical procedure for UC, indicated for clinical intractability or complications, one must consider that it exposes patients to a state of anxiety about the pre- and postoperative periods. The attending physician must clarify to the patient, in addition to all the benefits, aspects related to the presence of ileostomy and body image, functional aspects that can interfere with the functional and professional routine.

Preoperative data are usually provided by the surgeon, but do not necessarily offer complete information. Perhaps the development of a guiding protocol for complex procedures such as IPAA, developed in conjunction with doctors and applied by a psychologist before and after surgery could minimize the contradictions regarding personal expectations, unknown aspects and outcomes, facilitating the acceptance of the post-operative status with better QoL.

The use of the IBDQ showed that patients with IPAA for ulcerative rectocolitis had QoL classified as regular in all as-

sessed domains. The presence of ileostomy permanence and professional inactivity negatively influenced QoL.

## Conflicts of interest

The authors declare no conflicts of interest.

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