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Quality of life in ulcerative colitis patients treated medically versus patients undergoing surgery

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Abstract. – OBJECTIVES: Approximately one third of patients with ulcerative colitis (UC) require surgery.

AIM: Aim of this study was to assess the quality of life (QoL) of UC patients who have undergone surgery with ileorectal anastomosis (IRA) or ileal pouch-anal anastomosis (IPAA) compared to UC patients not operated.

PATIENTS AND METHODS: Fifty consecutive UC patients for each group observed between 1988-2010 were included. To all patients was administered a self completed questionnaire with four different scores: intestinal symptoms (IS), systemic symptoms (SS), emotional function (EF), social function (SF) and an overall QoL score.

RESULTS: Overall QoL score and three dimensions (SS, EF, SF) resulted not significantly different in the three groups, except for IS that resulted worst in the IRA-Group. According to the activity of disease it appeared that UC and IRA patients with mild activity had an overall QoL score similar to patients with complicated IPAA. A higher statistically different score of overall QoL was observed in patients with UC and IRA with moderate/severe disease.

CONCLUSIONS: Results of the study demonstrate that overall QoL score is poorer in patients with UC and IRA with mild activity and in patients with complicated IPAA and is worst in patients with UC and IRA with moderate/severe activity.

Key Words:
Quality of life, Ulcerative colitis, Ileal pouch-anal anastomosis, Ileorectal anastomosis.

Introduction

Approximately one third of patients with ulcerative colitis (UC) will require surgery for medical intractability, hemorrahage, perforation, dysplasia or cancer[1].

Over the past decades, total colectomy with ileorectal anastomosis (IRA) was usually performed. Nowadays, the ileal pouch-anal anastomosis (IPAA) has become widely accepted as the procedure of choice for the majority of these patients[2]. This procedure consists of an abdominal colectomy, rectal mucosectomy and construction of an ileal pouch that is anastomosed to the anus. Since the first reports by Sir Alan Parks and John Nicholls in 1978[3] several modifications of this procedure have been made. Pouch configuration with either two (J), three (S), or four (W) loops of the ileum has been performed and the J pouch has become the most commonly used configuration[4].

Currently, the management of UC patients has available both medical that surgical options. Generally, the patients with UC who become refractory to medical management are referred for surgical evaluation as the final step. The situation becomes more complex in patients who are currently in remission, but due to repeated flares, they need frequent hospital admissions. The decision to choose one operation rather than another is highly individualized, and it is based on the extensive evaluation of the risks and benefits as well as expected changes in quality of life (QoL).

Both surgical procedures (IRA and IPAA), as well as the presence of the disease itself, can affect the patient's QoL, even in the absence of complications. The World Health Organization defines QoL as "the perception of the individual of his/her position in life in the cultural context and the value system in which he/she lives in relation to his/her objectives, expectations, standards, and concerns"[5]. According to this definition, the concept of QoL, that is subjective, can include elements of both positive and negative impact.

The aim of the present retrospective study was to assess the quality of life of UC patients who have undergone proctocolectomy with IPAA or total colectomy with IRA compared to a control group of UC patients not operated.

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Patients and Methods

Patients

From a computerized database, we selected retrospectively 150 patients (50 for each group) with a proven diagnosis of UC disease consecutively seen at our GI Unit from 1988 to 2010 and regularly followed-up for at least 1 year (range: 1-21 years).

Three groups of patients were identified: patients with UC not operated (UC- Group), patients with IRA (IRA-Group) and patients with IPAA (IPAA-Group).

For each patient, factors such as gender, age at diagnosis, activity of disease, therapy and need of surgery were analysed.

Disease activity was measured with Disease Activity Index for UC and IRA[6].

Questionnaires

The patients were interviewed during their regular visits for post-operative follow-up or for periodical clinical assessment (UC-Group).

The QoL survey that was used was a self-completed 29-question instruments covering several broad aspects of health[7].

It considers 4 areas (or dimensions): Intestinal symptoms (IS) (evacuation frequency, abdominal pain and/or cramps, degree of continence, and evacuation urgency), systemic symptoms (SS) (nausea, fatigue, insomnia, and weight loss), emotional function (EF) (behaviour changes, irritability, anger, melancholy, and degree of satisfaction in relation to the surgery) and social function (SF) (working ability and social and leisure activities).

The validated questionnaire was multiple choice. The range of final scores, which results from adding the value of each answer, varied from 0 to 87, with the higher scores being an indicator of a worse QoL.

Statistical Analysis

Kruskal-Wallis test (with Dunn's Multiple Comparison Test) and Mann-Whitney test were used to verify if there were differences in the QoL scoring among the three groups in relation to the proportions. Probability values and confidence intervals (CI) were calculated at the 95 per cent level. Differences were considered significant when $p \leq 0.05$.

Results

Clinical and demographic characteristics of the patients enrolled are outlined in Table I.

Among the patients selected 19 were unable or unwilling to complete the questionnaire. Therefore, the IRA-Group included 41 patients (15 F, 26 M), the IPAA-Group 48 (20 F, 28 M) and UC-Group 42 (16 F, 26 M).

The UC-Group consisted of 42 patients (16 F, 26 M), with a mean age at diagnosis of 48.4 ± 16.7 years and a mean disease duration of 183.9 ± 117.8 months.

Twenty-seven patients with UC were in remission, 7 had a mild disease activity, and 8 had a moderate-severe activity. Patients were under treatment with 5-aminosalicylate or salazopyrin or with corticosteroids or with immunosuppressants according to their clinical condition.

The IRA-Group included 41 patients (15 F, 26 M), with a mean age at diagnosis of 32 ± 12.2 years and a mean disease duration of 310.2 ± 84.6 months.

Twenty-seven patients were in remission, 8 had a mild disease activity and 6 had a moderate-severe activity. All of them were treated with oral and/or topic mesalazine and the 6 patients with a moderate-severe disease with topical corticosteroids.

The IPAA-Group consisted of 48 patients (20 F, 28 M), with a mean age at diagnosis of 40.2 ± 15 years and a mean disease duration of 103.1 ± 70.4 months. IPAA was performed in all cases with the creation of a J-pouch reservoir after a temporary ileostomy.

Table I. Clinical and demographic characteristics of patients.

	UC (n = 42)	IRA (n = 41)	IPAA (n = 48)
Age at diagnosis (mean ± SD)	48.4 ± 16.7	32 ± 12.2	40.2 ± 15
Males/females	26/16	26/15	28/20
Activity			
Remission	27	27	
Mild	7	8	
Moderate-severe	8	6	

Table II. Different Dimensions and Overall Quality-of-Life Scores between the three groups of patients.

Variable	UC-group (n = 42) mean ± SD	IRA-group (n = 41) mean ± SD	IPAA-group (n = 48) mean ± SD	*p* value < 0.05
Intestinal symptoms (IS)	3.4 ± 3.6	5.1 ± 3.9	4.9 ± 3.8	= 0.02
Systemic symptoms (SS)	4.8 ± 3.9	5.2 ± 4.1	4.2 ± 3.2	= 0.61
Emotional function (EF)	6.2 ± 4.9	5.5 ± 6.4	5.3 ± 4.1	= 0.35
Social function (SF)	1.2 ± 1.5	1.4 ± 2.7	1.4 ± 2.8	= 0.55
Total	15.6 ± 12	18.2 ± 15.2	15.3 ± 10.1	= 0.93

Twenty-three patients (47.9%) complained complications. Five had early complications: 3 pouch-fistulization and 2 small intestinal occlusion. Eighteen had late complications: 5 stenosis of the ileo-anal anastomosis, 2 difficult emptying of the pouch, 10 recurrent pouchitis and 1 pouch-vaginal fistulisation.

All patients were treated with topical mesalazine and 4 patients (8.3%) also with corticosteroids and immunosuppressants. All complications were managed conservatively.

By applying the Kruskal-Wallis test for comparison of QoL score in these groups of patients, only the IS mean value resulted statistically worst in the IRA-Group.

The other different dimensions (SS, EF, SF) as well as the overall QoL score were similar in the three groups of patients (Table II).

Using the Kruskal-Wallis test to the comparison of disease activity in patients of UC-Group, all the QoL mean values of the four dimension as well as the overall QoL mean value were significantly lower in patients in remission than in patients with moderate/severe disease (Table III).

In particular, by applying Dunn's Multiple Comparison Test the results were the following: the IS mean value resulted significantly lower in the remission disease versus moderate/severe disease ($p < 0.05$); the SS mean value resulted extremely statistically significant in the remission disease versus moderate/severe disease ($p < 0.0001$); the EF mean value resulted statistically significant in the remission disease versus moderate/severe disease ($p < 0.05$); the SF mean value resulted statistically significant in the remission disease versus moderate/severe disease ($p < 0.05$); the overall QoL mean value resulted statistically significant in the remission disease versus moderate/severe disease ($p < 0.001$).

Using the Kruskal-Wallis test for comparison of patients in the IRA Group according to the disease activity, all the QoL mean values of the four dimension as well as the overall QoL mean value were significantly lower in patients in remission than in patients with moderate/severe disease (Table IV).

In particular, by applying Dunn's Multiple Comparison Test the results were the following: the IS mean value resulted statistically significant in the remission disease versus moderate/severe disease ($p < 0.05$); the EF mean value resulted statistically significant in the remission disease versus moderate/severe disease ($p < 0.05$); the SF mean value resulted importantly statistically significant in the remission disease versus moderate/severe disease ($p < 0.001$) and mild disease versus moderate/severe disease ($p < 0.05$); the overall QoL mean value resulted statistically significant in the remission disease versus moderate/severe disease ($p < 0.001$).

Using the Mann-Whitney test for comparison of patients in the IPAA-Group according to complications of disease, only the IS mean value resulted significantly lower in patients without

Table III. QoL (mean ± SD) according to different activity of disease in UC-Group.

Variable	Remission (n = 27) mean ± SD	Mild (n = 7) mean ± SD	Moderate/severe (n = 8) mean ± SD	*p* value < 0.05
Intestinal symptoms (IS)	2.1 ± 2.4	4 ± 2.9	6.9 ± 5.2	= 0.013
Systemic symptoms (SS)	2.9 ± 2.8	6.1 ± 4.3	9.2 ± 4.3	= 0.0004
Emotional function (EF)	4.7 ± 4.4	8.3 ± 4.3	9.7 ± 4.8	= 0.0119
Social function (SF)	0.8 ± 1.3	1 ± 1.1	2.5 ± 2	= 0.0276
Total	10.6 ± 8.6	20.1 ± 11.5	28.4 ± 12.5	= 0.007

Table IV. QoL (mean ± SD) according to different activity of disease in IRA-Group.

Variable	Remission (n = 27) mean ± SD	Mild (n = 8) mean ± SD	Moderate/severe (n = 6) mean ± SD	*p* value < 0.05
Intestinal symptoms (IS)	5.4 ± 7.9	5.6 ± 4.5	9.2 ± 3.8	= 0.03
Systemic symptoms (SS)	4.4 ± 4.3	5.9 ± 3.9	8.2 ± 0.7	= 0.04
Emotional function (EF)	3.7 ± 4.6	6 ± 5	13 ± 9.7	= 0.02
Social function (SF)	1 ± 1.6	1.7 ± 2.2	9.3 ± 4.3	= 0.0008
Total	13.1 ± 12.2	19.2 ± 14.6	39.7 ± 9.7	= 0.005

complications than in patients with complications of disease. The other different dimensions (SS, EF, SF) and overall QoL score were similar between the two groups of patients and were no statistically significant (Table V).

According to the activity of the disease it appeared that patients with UC and IRA in remission showed an overall QoL score not different to that of patients with not complicated IPAA, while the same two groups of patients with a mild clinical activity had an overall QoL score similar to patients with complicated IPAA (Table VI).

By applying the Mann-Whitney test for comparison of UC and IRA patients with moderate or severe disease, the overall QoL mean value resulted statistically higher in IRA patients (p = 0.03).

Discussion

Nowadays, measurement of QoL is clearly a mandatory component in evaluating interventions and management of medical and surgical diseases.

Many inflammatory bowel disease (IBD) patients require surgery at some point in their disease course and it is nearly mandatory to establish the consequent effects on QoL.

Proctocolectomy is considered the standard treatment for patients suffering from UC when medical therapy fails or when complications such as dysplasia or malignancy occurs. IPAA is considered the treatment of choice for patients requiring surgery for UC. Fazio et al[8] observed excellent or good QoL in 93% of the 645 patients studied after 40 months post-operation and the presence of a temporary ileostomy doesn't seem to influence the QoL. As regards this observation, Berndtsson and Oresland[9], in a prospective study, evaluated HRQOL before and after restorative proctectomy. The patients were subdivided upon the presence or absence of ileostomy prior to IPAA. The General QoL according to Kajang (GQL) instrument, the Visual Analogue Scale (VAS), and a modified disease specific Olbrisch adjustment scale (OAS), were used for the analysis of the results. The Authors concluded that a different surgical approach did not influence the general QoL.

An adequate evaluation of the results after the surgery or after the closure of the ileostomy, is possible only after necessary 8-12 months[8].

Many studies on the contrary investigated overall early postoperative QoL. A relatively recent clinical review of clinical trials evaluating QoL after restorative proctocolectomy revealed that only 3 smaller studies compared pre-to post-operative scores[10].

Our patients were regularly followed up for at least 1 year with a range of 1 to 21 years. In our study, we observed complications in 47.9% patients with IPAA. It is well known that long-term patients, 10 years or more after-operation may develop several complications such as fistulas or pouchitis[11].

Table V. QoL (mean ± SD) according to complicated and not complicated disease in IPAA-Group.

Variable	pts without complications (n = 25) mean ± SD	pts with complications (n = 23) mean ± SD)	*p* value < 0.05
Intestinal symptoms (IS)	3.5 ± 2	5.2 ± 2.9	= 0.04
Systemic symptoms (SS)	3.3 ± 2.5	5.1 ± 3.5	= 0.07
Emotional function (EF)	4.4 ± 3.3	6.2 ± 4.6	= 0.15
Social function (SF)	1.1 ± 2	2 ± 3.3	= 0.14
Total	12.3 ± 7.1	18.6 ± 11.8	= 0.58

Table VI. Total QoL (mean ± SD) according to different activity of disease.

	Remission	Mild	Moderate/severe)
UC	10.6 ± 8.6	20.1 ± 11.5	28.4 ± 12.5
IRA	13.1 ± 12.2	19.2 ± 14.6	39.7 ± 9.7
IPAA not complicated	12.3 ± 7.1		
IPAA complicated		18.6 ± 11.8	
p value < 0.05	= 0.46	= 0.89	= 0.03

Lichtenstein et al[10] have observed that the QoL for IBD patients after the creation of an ileal pouch was similar to that of the general population. This data is confirmed by the study of Wuthrich et al[12].

Some studies[13,14] demonstrated that QoL after surgery is comparable or not significantly lower to that of healthy controls. On the other hand, other studies[15-17] underlined that patients who undergo surgery have long-term QoL similar to that of UC patients in remission or with mild disease activity due to long-term complications of the pouch, the frequency of daily stools, the urgency or incontinence and the continuous need of medical therapy.

Total colectomy with IRA was a common operation for UC before the development of IPAA and it was mainly performed for patients who were not willing to have a permanent ileostomy. Recently, Da Luz Moreira et al[18] reviewed their experience about IRA and IPAA performed in UC. Seventy four UC patients after an IRA were matched with 66 patients who underwent IPAA. The patients were contacted by telephone to evaluate functional outcomes and HRQOL, that was determined by Cleveland Clinic Global Quality of Life (CGQOL) score. Patients with IRA had significantly more dietary and work restrictions, although the HRQOL was similar between groups. The authors concluded that while IRA is not the definitive operation for patients with UC, a significant number of patients were able to keep their rectum after 10 years with an acceptable functional outcome and QoL.

Conclusions

The results of the present study demonstrated that patients in remission with not operated UC, with IRA and with not complicated IPAA have a better and similar overall QoL.

On the other hand, the overall QoL is poorer in patients with UC and IRA with mild activity and in patients with complicated IPAA and is worst in patients with UC and IRA with moderate or severe activity.

Conflict of Interest

The Authors declare that they have no conflict of interests.

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