

Quality of Life After Proctocolectomy and Ileo-Anal Anastomosis for Severe Ulcerative Colitis

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Objective: Impaired quality of life (QOL) in patients with ulcerative colitis (UC) may be a prominent feature of the disease, and in some cases, may become an indication for surgical treatment. The objective of this study was to assess QOL in patients who underwent proctocolectomy with ileo-anal anastomosis with a J pouch for severe UC and to compare it with patients with UC of different severity who were under medical treatment. **Methods:** We used a validated, disease-specific research instrument (a 29 item, self-administered questionnaire) that examines the following four functions: intestinal (score 0–24) and systemic symptoms (0–21), and emotional (0–27) and Social Function (0–15). High scores indicate an impairment of the function examined and the sum of the four scores (maximal total score = 87) reflects the patient's QOL. We studied 29 operated patients (22 men, mean age 35 yr, mean time after intervention 3.8 yr) and compared their scores with those of 57 UC patients (39 men, mean age 36 yr) with different degrees of disease activity, and with those of 72 healthy controls (38 men, mean age 31 yr). **Results:** In UC, scores were significantly higher than in controls, increasing with the severity of the disease. Even patients in remission had higher scores than controls in the "systemic" (4.6 vs. 2.0) and emotional (5.6 vs. 2.5) functions. Patients who underwent surgical treatment had much better scores than patients with severe disease (total score 20.1 vs. 38.2), with values comparable to those of patients in remission or with mild disease activity. There was no significant gender difference, either for UC and ileo-anal anastomosis patients, or in healthy controls. **Conclusion:** In patients with UC, even in remission, there is a measurable impairment of QOL, which increases with the severity of disease. Operated patients have a QOL that is comparable to that of patients in remission or with mild disease, and proctocolectomy with ileo-anal anastomosis may restore an acceptable QOL in patients with moderate/severe UC. (Am J Gastroenterol 1998;93:166–169. © 1998 by Am. Coll. of Gastroenterology)

INTRODUCTION

Ulcerative colitis (UC) is a chronic inflammatory disease characterized by periods of remission and relapse, which is sometimes severe and may impair patients' quality of life (QOL) (1–9). The aims of treatment of UC include not only induction of remission, control of symptoms, decrease of complication rate, but also improvement of QOL. During severe relapses of the disease, medical treatment may fail to induce a satisfactory remission. This may be an indication for surgery, although many physicians may have reservations about advising a surgical solution because of the accompanying morbidity and postoperative problems.

Proctocolectomy with definitive ileostomy, or colectomy with ileo-rectal anastomosis, have now been superseded by proctocolectomy and ileo-anal anastomosis (IAA) with ileal pouch, which allows the preservation of the anal sphincter function, thereby improving patients' acceptance and eliminating the problems of definitive ileostomy or of the persistent inflammation of the rectal stump (10–11).

In spite of abundant literature on QOL in patients with medically treated UC, evaluation of patients' QOL after surgical treatment has received relatively little attention. The main aims of most studies have been to evaluate the postoperative morbidity and the functional results after pouch construction in comparison with other surgical procedures (12–15).

The aim of our study was to evaluate the QOL in patients who underwent proctocolectomy with IAA with J pouch, using a measurement instrument specific for inflammatory bowel disease (IBD), and to compare the results among patients with UC in various phases of disease (remission, mild, moderate/severe).

MATERIALS AND METHODS

We used an assessment instrument for QOL assessment of IBD patients developed by our group, details of which are described elsewhere (8). The instrument was validated for reproducibility in healthy controls (15% variation) and in stable IBD patients (15% variation). Responsiveness was assessed in unstable IBD patients, in whom it showed a sensitivity of 100%. Although the questionnaire was not specially designed for IAA patients, the great similarity of

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TABLE I
Controls and Patients' Characteristics

	Controls	Ulcerative Colitis	Ileo-Anal Anastomosis
Number	72	57	29
Sex	38 M 34 F	39 M 18 F	22 M 7 F
Mean age	31	36	35
Disease localization		35 LC, 22 PC	
Activity: remission		31	
mild		17	
moderate/severe		9	

M = male; F = female; LC = left-side colitis; PC = pancolitis.

clinical manifestations in operated and nonoperated UC patients makes, in our view, the use of the questionnaire acceptable.

Briefly, the questionnaire consists of 29 questions and explores the following functions: a) intestinal symptoms (IS), including 8 questions, maximal score 24; b) systemic symptoms (SS), 7 questions, maximal score 21; c) emotional function (EF), 9 questions, maximal score 27; and d) social function (SF), 5 questions, maximal score 15. The possible answers for each question (on a 4 point scale: never or hardly ever, sometimes, often, always or nearly always) give a total maximal score of 87. The higher the score, the more compromised the function examined, and a higher total score therefore indicates a worse QOL. The diagnosis was based on clinical symptoms, laboratory tests of inflammation, and endoscopic and histologic findings.

On the basis of the Truelove and Witts index for UC (16), disease activity was graded as remission, mild, or moderate/severe. In particular, a moderate/severe disease was defined as presence of six or more bowel motions a day, with blood in stools, fever > 37.5 , tachycardia, anemia, and ESR > 30 . Mild disease was defined as mild diarrhea (< 4 motions a day) with absence or only small amounts of blood and no systemic symptoms. Patients in remission had no intestinal or systemic symptoms.

Patients

The questionnaire was administered to 29 patients who had been treated with proctocolectomy with ileo-anal anastomosis and J pouch (22 men, 7 women; mean age 35 yr, mean time after intervention 3.8 yr, range 1–12 yr). All patients who were asked agreed to answer the questionnaire, while waiting for their routine medical examination.

The indication for surgery was the failure of medical treatment in patients with moderate/severe disease. None of these patients complained of fecal incontinence or had clinically significant pouchitis at the time of the study. We also studied, for comparison, 72 healthy controls with no symptoms of irritable bowel disease (38 men and 34 women; mean age 31 yr) and 57 UC patients (39 men, 18 women; mean age 36 yr) whose clinical features are summarized in Table I. Thirteen patients with UC were receiving cortico-

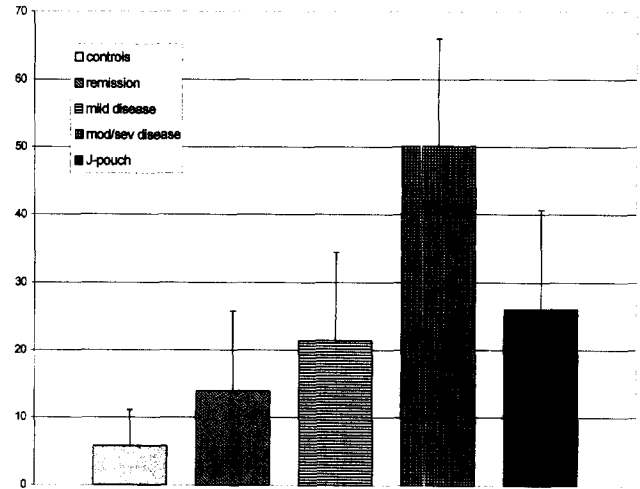


FIG. 1. Total score: sum of scores obtained in each function.

steroids (prednisone 25–50 mg/day), and all were receiving oral mesalazine.

Data are presented as mean \pm standard deviation (SD), and the Mann-Whitney *U* test was used for statistical analysis of the results. A level of $p < 0.01$ was considered significant.

RESULTS

Figure 1 summarizes the results of QOL assessment as the total score (*i.e.*, the sum of scores obtained in each function) of the patients studied. The patients who underwent surgical treatment had a QOL (total score) that was similar to those in remission or with mild disease activity and that was significantly better than for those with a moderate or severe disease ($p < 0.01$). Table 2 illustrates the scores of all functions studied in controls, UC patients, and patients with UC who had been operated.

In UC patients, the scores were significantly higher than in healthy controls ($p < 0.01$), increasing progressively with the severity of the disease. With the increasing severity of the disease, apart from the expected increase in the intestinal symptoms score there was a significant increase also of the “systemic” symptoms including fatigue, nausea, lack of well-being, sleep disorders, and the emotional function (which includes fear of relapse, of surgery or of neoplastic degeneration). However, patients in clinical remission also had higher scores than controls. The most disturbed functions were the systemic symptoms and the emotional function; as could be expected, intestinal symptoms were very mild.

In operated patients, scores for intestinal symptoms, systemic symptoms, and social function were not significantly different from those of patients with mild disease. It is apparent also that the score in the emotional function was significantly better than in patients with moderate/severe disease, and similar to that of patients in remission or with mild disease. There was no significant gender difference in

TABLE 2
Quality of Life in Ulcerative Colitis: Scores in the Four Areas Studied

	Ulcerative Colitis				
	Controls (n = 72)	Remission (n = 31)	Mild (n = 17)	Mod/Severe (n = 9)	J Pouch (n = 29)
Intestinal symptoms	1.3 ± 1.5	2.7 ± 2.5†	6.5 ± 3.3*†	11.7 ± 3.7*†	5.8 ± 3.5*†‡
Systemic symptoms	2.0 ± 2.0	4.6 ± 3.3†	5.5 ± 3.1†	10.4 ± 3.9*†	5.1 ± 3.6†‡
Emotional function	2.5 ± 1.8	5.6 ± 4.2†	6.3 ± 3.6†	9.5 ± 3.7*†	6.0 ± 3.9†‡
Social function	0 ± 0	1.0 ± 1.9†	3.1 ± 3.0*†	6.6 ± 4.6*†	3.2 ± 3.7*†‡

Mean values ± SD: * $p < 0.01$ vs. remission.

† $p < 0.01$ vs. controls.

‡ $p < 0.01$ vs. moderate/severe disease.

Mod = moderate.

the various scores, for UC or IAA patients or for healthy controls.

DISCUSSION

QOL may be altered in patients with UC, especially in those with active disease; and in the more severely ill patients, surgical treatment may be indicated. At present, the proctocolectomy with ileo-anal anastomosis and ileal pouch construction is the operation preferred for its satisfactory results (12). McLeod and Fazio (17, 18) reported that all patients who had undergone Koch ileostomy would have chosen again the same operation. Pemberton *et al.* (19) reevaluated 298 cases with an ileal reservoir and found that 95% of patients were in satisfactory condition and that 90% had returned to work. Pezim and Nicholls (20) showed that 97% of patients with ileal pouch preferred this surgical procedure to definitive ileostomy. Other authors, however, reported a high percentage of satisfaction also in patients with conventional ileostomy.

In most of these studies, the functional results of surgical procedures were well studied and compared. However, no specific evaluation was made of QOL, which depends not only on biological parameters, but also on the social and emotional status of the patient. McLeod *et al.* (14) evaluated QOL in UC patients already treated by various surgical methods, using a different approach: the time trade-off technique and the direct questioning of objectives; the evaluation of the preoperative period was carried out retrospectively. QOL improved after surgery, a finding with which our results agree, and this improvement was independent of the type of surgical operation performed. In our study, we used a specific instrument for measuring QOL in IBD patients that has been validated and the sensitivity and specificity of which have been defined (8).

In this study, we showed that UC patients have an impaired QOL even in the remission phases, and this QOL worsens with the worsening of the disease. QOL in patients with ileo-anal anastomosis and J pouch is significantly better in all functions explored, compared to that in patients with UC with moderate/severe disease activity. It may be

argued that patients who are operated upon may be highly motivated to have surgery, and this may influence the outcome. We do not think that this is a significant possibility in our cases, because the decision to operate did not depend on patient motivation, but in all cases was made based on the impossibility of prolonging medical treatment. Furthermore, it can be argued that the possible motivation bias would be more likely in the early postoperative phase, but after a mean of >3 years after operation, it might be less important.

The scores obtained from operated patients demonstrate that their QOL is comparable with that of patients in remission or with mild disease. Although still significantly altered in comparison with healthy controls, their QOL is much better than that of patients with moderate/severe disease activity. Given the relatively small number of cases studied, it could be hypothesized that, because men are overrepresented, their supposedly lower scores may influence the results in the IAA group. However, the relative overrepresentation of men is also present in the UC group, and the statistical analysis of scores in men *versus* women did not show significant differences.

The reason why operated patients still have a compromised QOL is difficult to explain, because scores are higher than for controls in all areas, and not only regarding the intestinal symptoms that we know may still be present to some degree after the IAA. It can be hypothesized that the subjective perception of being ill is still present, with the emotional and psychosocial consequences measured by the instrument. This may also be reinforced, in part, by the regular clinical and endoscopic follow-up that our patients undergo. This study was a cross-sectional evaluation, and we cannot state that surgery improves the QOL in the same patient. However, based on this comparison between patient groups, we believe that our findings support the view that, when surgical treatment is indicated, proctocolectomy with ileo-anal anastomosis and J pouch may allow a great improvement of QOL.

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