Effect of Surgery on Health-Related Quality of Life in Patients With Inflammatory Bowel Disease

A Prospective Study

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Background: Health-related quality of life (HRQL) has increasingly become a factor in management decisions in patients with chronic diseases.

Objective: To measure the effect of surgical resection on quality of life in patients with inflammatory bowel disease (IBD).

Design: A consecutive series of patients undergoing surgery for IBD between June 1994 and December 1997 were prospectively investigated as a cohort outcomes study.

Patients: Data were obtained in 63 patients. The primary diagnoses were Crohn's disease (n = 36) and ulcerative colitis (n = 27).

Intervention: Patients with Crohn's disease underwent resection with or without stricturoplasty for intractable disease; all but 3 patients with ulcerative colitis underwent ileoanal anastomoses with ileoanal reservoir.

Main Outcome Measure: Health status was measured using the Health Status Questionnaire preoperatively and every 3 months postoperatively.

Results: Preoperative measures of HRQL of the patients were low, with values well below the general population in all 8 scales of the Health Status Questionnaire. Postoperatively, HRQL measures improved significantly (P < .05) in both patients with Crohn's disease and those with ulcerative colitis, with scores equal to the general population in most scales. For example, average raw scores for general health in previously studied patient groups were 59 in patients with asthma, 55 in those with diabetes mellitus, 74 in the general population, and 54 and 73 preoperatively and postoperatively, respectively, in the present study.

Conclusions: The results of this study confirm that HRQL scores are low in many patients with IBD referred for operation and HRQL scores improve postoperatively to levels comparable to those of the general population. We believe these data justify early surgical intervention in many patients with symptomatic IBD.

Arch Surg. 1998;133:826-832
PATIENTS, MATERIALS, AND METHODS

STUDY DESIGN

Subjects eligible for this study were all patients with IBD seen by a single surgeon (R.C.T.) between June 1994 and December 1997. Three questionnaires were completed preoperatively on each patient: (1) a patient-completed disease-specific symptom questionnaire; (2) a physician-completed disease-specific assessment form; and (3) a patient-completed HSQ.

In addition, an intraoperative and perioperative form was completed by the physicians for each patient. The patient-completed disease-specific postoperative symptom questionnaire and the HSQ were obtained 3, 6, and 12 months postoperatively. The postoperative information was filled out at the time of regularly scheduled postoperative visit in the surgeon’s office and/or in response to survey questionnaires completed by mail.

HEALTH STATUS QUESTIONNAIRE

The HSQ includes 39 questions that are collapsed into 8 dimensions or scales of health status.3,5,6 (For a copy of the questionnaire, contact the author whose address is listed in the “Acknowledgments” section at the end of the article.) Three questions were added to the original 36-item Short-Form Health Survey to include mental health, accounting for the discrepancy between the 36-item Short-Form Health Survey and the 39 questions in the HSQ.5 The scores for each scale ranged from 0 to 100, with higher scores for better health status. The 8 scales (number of questions devoted to each scale) are general health perception (5 questions), physical functioning (10 questions), physical role limitations (the interference with work by physical health) (4 questions), mental health (5 questions), bodily pain (2 questions), social function (2 questions), emotional role limitations (interference with work by emotional problems) (3 questions), social function (2 questions), mental health (5 questions), bodily pain (2 questions), and energy or fatigue (4 questions). Demonstrated that this health survey was easy to understand, took only minutes to complete, and could be self-administered. Importantly, internal-consistency reliability was excellent with consistency between subgroups of patients with different chronic conditions and in general population studies.5,6 Therefore, the health profiles of patients with different diagnoses can be compared with regard to disease severity as well as monitoring the changes in HRQL over time in association with medical or surgical interventions. Previous studies9,11 have correlated the results of the HSQ in patients with IBD medically treated with the results of disease-specific questionnaires.

The purpose of this investigation was to study the effect of surgical resection of the diseased bowel on HRQL in patients with IBD. First, we wanted to measure baseline HRQL in patients with IBD referred to a surgeon. Second, we wanted to measure the short- and long-term changes in HRQL after surgery. Finally, we wanted to compare these results with those of the general population and other patients with chronic diseases.

PATIENT POPULATION

Eighty-one patients were evaluated. Of the 81 patients, 25 (31%) stated that they were self-referred, 51 (63%) stated that they were referred by a physician, and 5 (6%) did not respond to this question. Eighteen patients did not proceed with the operation. The study sample included 63 patients who underwent operation. The preoperative physician assessment form was completed for 59 patients (94%), the preoperative patient symptom questionnaire was completed by 59 patients (94%), and the preoperative HSQ was completed by 48 patients (76%).

The preoperative diagnosis was Crohn’s disease in 36 patients and chronic ulcerative colitis (UC) in 27 patients. The average age was 41 years (range, 19-69 years). There were 38 men (60%) and 23 women (40%). Of the patients with Crohn’s disease, there were 16 men and 20 women. The number of men was higher in the UC group, with 22 men and 5 women. Of the 36 patients with Crohn’s disease, 13 (43%) had had previous resections and 13 (37%) had multiple sites of disease. Of the 27 patients with UC, 18 (65%) had pancolitis. Table 1 summarizes the associated comorbidities and current medication use in the study cohort.

STATISTICAL ANALYSIS

Mean scores for all HSQs obtained were calculated and separated into preoperative and postoperative values. Gain scores (changes in HSQ results) were compared in the 32 patients with both preoperative and postoperative HSQ measures. Since the HSQ gain scores exhibited a nonnormal distribution, the Wilcoxon matched pairs signed rank test was used, with P values less than .05 considered significant.

To identify factors that may influence outcomes, several subsets of patients were analyzed. In patients with Crohn’s disease, subset analyses were performed in patients with or without resection of the terminal ileum, those who had or had not undergone previous operations, those in whom all detectable disease was or was not resected, and those with more or less than 30 cm of small-bowel resection. In patients with UC, subset analysis was done in patients with or without pancolitis.

RESULTS

SURGICAL INTERVENTION

All but 3 patients with UC underwent ileoanal anastomoses with ileoanal reservoir. All patients with Crohn’s disease underwent resections with or without stricturoplasties; stomas were required in 9 (24%) of 36 patients with Crohn’s disease. Of patients with Crohn’s disease, 19 (52%) required resections of the terminal ileum. Of the 31 patients who had small-bowel resections, 9 (30%) had more than 20 cm of the small bowel resected. Patients with Crohn’s disease were treated postoperatively with prophylactic 5-ASA compounds, methotrexate, or azathioprine.
Preoperative HSQ scores are summarized in Figure 1 and Table 2. As illustrated in Figure 1, scores were below those of the general population in all categories and lower than scores published previously for patients with diabetes mellitus or asthma. The mean scores for ability to function at work or at home due to physical health (physical role limitations) were low in both patient groups. Patients with Crohn’s disease had very low bodily pain scores (which means a high level of pain). The scores in both groups show markedly impaired energy levels and social function. Mental health scores were almost the same as those for the general population. Mean scores of all HSQs obtained after surgery are also summarized in Table 2, with results divided into follow-up at less than 4 months, 4 to 8 months, and 9 or more months. Marked increases occurred in all scales. In patients with Crohn’s disease, large increases occurred after operation in physical functioning scores, physical health and ability to work (physical role limitations), bodily pain, and energy levels. In patients with UC, marked improvements occurred in all scales, although many patients required as long as 9 months to achieve maximal benefit.

To assess accurately the results in individual patients, preoperative and postoperative HSQ results were compared in individual patients with both preoperative and postoperative HSQ data to calculate gain scores. The changes in HSQ scores and the statistical significance of these gain scores are summarized in Figure 2 and Figure 3 and Table 3, respectively. Patients with Crohn’s disease had sustained increases in all scales. These changes were statistically significant in all scales except role limitations attributed to emotional health. In some patients with Crohn’s disease, the HSQ gain scores were higher at the 5- to 8-month follow-up than at the 9-month follow-up, although these differences did not reach statistical significance. Patients with UC had improvements in all scales. These improvements were statistically significant in each category except mental health and bodily pain. Note that preoperative scores in mental health and bodily pain were comparable to those of the general population (Figure 1), making statistically significant improvement in these scales less likely.

There were no definite trends in the previously described subset analyses. In patients with or without terminal ileal resections, the gain scores were similar in most scales. However, there were exceptions. For example, patients with terminal ileal resections had 50-point gains in physical role limitations whereas those without terminal ileal resections had 17-point losses. Similarly, the mean gain in social functioning was 20 points in patients with ileal resections and 0 points in patients without ileal resections. The gain scores achieved in patients with all Crohn’s disease resected were similar to those achieved in patients without all disease resected in 6 scales, better in one, and worse in another. There were no consistent trends in patients with more or less than 30 cm of small bowel resected. Gain scores were higher in the group who had more than 30 cm of small bowel resected in physical role limitations, social functioning, and bodily pain but worse in general health perception scores. Similarly, there were variable changes in patients with or without previous resections for Crohn’s disease. Gain scores were higher in patients without previous resection in 4 scales, higher in those with previous resections in 3 scales, and identical in the eighth scale. Gain scores were actually greater in 7 of 8 scales in patients with limited or left-sided UC compared with those in patients with pancolitis. The relationship between the age of the patient and the changes in HSQ scores are summarized in Table 4. These data showed that younger patients (i.e., ≤ 41 years, mean age of study cohort) achieved greater improvement after operation than older patients in all 8 scales of the HSQ.

The present study demonstrated that patients with IBD seen in consultation with a surgeon, as a group, have low HRQL scores and that HRQL improves significantly postoperatively. These findings are important for several rea-

**Table 1. Preoperative Medications and Comorbidities**

<table>
<thead>
<tr>
<th>Medication or Comorbidity</th>
<th>Crohn’s Disease, % (n = 31)</th>
<th>Ulcerative Colitis, % (n = 22)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sulfasalazine use</td>
<td>33</td>
<td>45</td>
</tr>
<tr>
<td>5-ASA compound use</td>
<td>52</td>
<td>68</td>
</tr>
<tr>
<td>Current prednisone use</td>
<td>76</td>
<td>82</td>
</tr>
<tr>
<td>Azathioprine use</td>
<td>45</td>
<td>50</td>
</tr>
<tr>
<td>Methotrexate use</td>
<td>45</td>
<td>36</td>
</tr>
<tr>
<td>Arthritis</td>
<td>23</td>
<td>27</td>
</tr>
<tr>
<td>Skin problems</td>
<td>23</td>
<td>0</td>
</tr>
<tr>
<td>Primary sclerosing cholangiitis</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Long-term prednisone dependence</td>
<td>61</td>
<td>67</td>
</tr>
</tbody>
</table>

**Figure 1. Mean scores of all scales of the Health Status Questionnaire (HSQ) comparing the scores from previously published data for patients with asthma or diabetes mellitus, candidates for hip replacement surgery, and the general population with the preoperative scores of patients with inflammatory bowel disease (IBD) from the present study. HP indicates health perception; PF, physical function; R-P, physical role limitations; R-E, emotional role limitations; SF, social function; MH, mental health; P, bodily pain; and E, energy or fatigue.**
sons. First, functional status and well-being are highly valued by patients and are therefore essential outcomes of medical care. The original Medical Outcomes Study reported by RAND found that patient-reported gastrointestinal disorders had the greatest impact on HRQL of any disease group studied. Second, since measures of functioning and well-being have been shown to predict health care expenditures and patients with chronic conditions such as IBD account for the majority of US health care expenditures, this study suggests that bowel resections in patients with IBD, by improving HRQL, will have beneficial financial implications.

While there are many types of measurable outcomes after surgical interventions in patients with chronic diseases (eg, death, disability, complications, and disease-specific symptoms), we believe that HRQL is a crucial measure. Measures of disease activity, such as stool frequency, medication requirements, or nutritional parameters, in patients with IBD are inadequate to encompass fully the experience of these patients. Global measures of HRQL before and after treatment further our understanding of the impact of IBD on patients and improve our ability to make important decisions relating to medical and/or surgical treatment of these patients. While physiological measures (eg, stool frequency, weight loss, or nutritional parameters) provide valuable information to surgeons providing care for patients with IBD, they frequently correlate poorly with functional capacity and well-being, the areas in which patients are most interested.

In designing our study, we chose to use a generic (as opposed to a disease-specific) health status measure to assess HRQL. Previous studies in patients with IBD have used either disease-specific symptom scores (Crohn’s disease activity index) or, more recently, a disease-specific HRQL survey such as the IBD Questionnaire. The IBD Questionnaire examines 4 aspects of patients’ lives: symptoms directly related to primary bowel disturbance; systemic symptoms; and emotional and social function. The IBD Questionnaire has been shown to be re-
producing, with changes in scores reflecting changes in disease activity.13-17 While this test is an accurate measure of health status in patients with chronic gastrointestinal disease, it does not permit one to compare results with other patient groups or the general population. The measure we chose, the HSQ, has been tested in diverse population groups and has been established to have high internal consistency and validity.5,6,17 In comparison to other available health status measures, the HSQ appears to be the most suitable measure of health status in the general population.5,18

Maunder and coworkers4 recently reviewed the literature summarizing the effect of medical or surgical intervention in patients with IBD on HRQL. Most studies used multidomain HRQL instruments that lacked consistency and validity. Maunder et al11 concluded that the confidence and conclusions of these studies regarding surgical interventions in these patients is limited by study design and that validated instruments should be used in all future studies. In our opinion, the optimal study design should incorporate not only disease-specific questionnaires with both patient- and physician-derived data but also measures such as the HSQ that have been validated across diverse patient groups and the general population.

Previous studies have confirmed the validity of the HSQ in patients with IBD. For example, Provenzale et al10 obtained postoperative HSQ scores on 22 patients after ileal anastomosis with ileal reservoir procedures. They found that their patients scored higher than the national sample of patients with IBD and were similar to that of the general population. However, this study10 and others12,20 reporting high measures of HRQL in patients after ileal anastomosis with ileal reservoir had no preoperative data, limiting the value of any conclusions about the benefits of operation. The present study, which prospectively assessed quality of life using the validated generic HSQ, emphasizes the profound effects of IBD on HRQL.

Using subset analysis, we attempted to identify subsets of patients more likely to benefit from surgery. Gain scores were compared in patients with Crohn’s disease with or without all disease resected, more or less than 30 cm of the bowel resected, multiple or first operations, and with or without terminal ileal resections. Although the numbers were small, there were no apparent trends in any of these patient groups. In most subsets, scores increased in some scales and decreased in others. Our data suggest, therefore, that patients with symptomatic Crohn’s disease should be considered for surgery regardless of disease site, previous operation, and extent of disease. We also hypothesized that patients with pancolitis would benefit more from surgery than those with less extensive disease. We demonstrated higher gain scores in patients with left-sided UC compared with patients with pancolitis. The implication of this finding is that patients with UC limited to the left colon or rectosigmoid colon show poor HRQL and an excellent prognosis for improvement with surgery. The relationship between patient age and outcome may also be clinically significant. We found that younger patients (≤41 years, mean age of study cohort), benefited more than older patients, although both groups achieved positive gain scores in all 8 scales of the HSQ after operation.

In conclusion, the present study showed that the HRQL in patients with IBD referred for surgical opinion is low and that HRQL improves postoperatively. Postoperative health status was equivalent to that of the general population. Therefore, we believe that early surgical intervention should be considered in many patients with symptomatic IBD. Furthermore, we encourage others to study the effect of surgical interventions on patients with chronic diseases by collecting prospectively both disease-specific data and generic HRQL data, enabling valid conclusions regarding the true value of surgical interventions on patients.


The authors thank Karen Pethingell, PhD, for statistical support and Jane Lopez for manuscript preparation.

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by health care policy planners and purchasers of health care because of the recognition that clinical and economic end points are insufficient to completely describe the relative benefits of medical or surgical treatment. This is reflected by a rapidly increasing number of published articles dealing with quality-of-life assessment from its introduction as a subject in the early 1970s to the nearly 2000 papers published last year. Few surgeons, however, have addressed this topic. It is fitting that Thirlby et al have reexamined the issue in the treatment of IBD. One of the first citations in the quality-of-life literature is a landmark paper by Professor Kock in 1975 describing the effect of his continent ileostomy on the lifestyle of his patients with UC.

Should surgeons be interested in quality-of-life assessment? I believe so. In general surgery we have always taken pride in our desire and ability to care for patients in the broadest medical sense. We commonly fail our patients, however, by avoiding discussions of the implications of their disease or its treatment on their lives. One doesn’t have to look far in popular culture for evidence of this failure. Witness William Hurt’s portrayal of a surgeon afflicted with cancer in the recent film, The Doctor.

In 1947 in its charter, the World Health Organization defined health as a state of complete physical, mental, and social well-being not merely the absence of disease. It is this restoration of health that we should strive for in treating our patients. With that, I have 3 questions for Dr Thirlby.

First, it is well known in both anthropology and physics that it is sometimes difficult to study a subject without the observation itself altering the behavior. Patients want to please their doctors, especially when they are as likable as Dr Thirlby. Dr Thirlby, do you think that the good outcome in quality of life you noted following surgery could be related to the special attention patients received by being a part of this study?

Second, we are all aware of the aphorism, “Attitude is everything,” and the implications it has on the recovery of the patients we see in daily practice. The attitude a patient brings to the operating room is sometimes as predictive of the ultimate outcome as any objective clinical measure. Does the tool you used, the Health Status Questionnaire, have the sensitivity to identify this highly subjective variable?

Finally, on a more practical note, what is the effect of postoperative complication or the need for a stoma on patients’ perception of outcome in your study?

James E. Goodnight, Jr, MD, PhD, Sacramento, Calif: I congratulate Dr Thirlby on a landmark study. It is going to be critical that we look at quality-of-life measures. We have organized the profession around ourselves basically, which usually leads to the well-being of our patients, but we have subjectively assessed our results in terms of our own views. My question is, in parallel with this tool, did you collect information by the surgeon subjectively, in other words, pain improvement and social function, etc? I assume not, since it wasn’t presented. It would be interesting to know if the surgeon were to sit back and was challenged to eyeball these things and put them on some kind of scale, how that would compare with the patients’ observations.

Lawrence W. Way, MD, San Francisco: The median follow-up was about 8 months. The question in Crohn’s disease, however, is the durability of the result, and it seems questionable whether one assessment 8 months postoperatively would allow a valid generalization to be made regarding the quality of life of these patients.

Nancy L. Ascher, MD, San Francisco: I take some issue with your conclusions that the patient with IBD treated surgically has an improved quality of life without data regarding patients who are successfully treated medically. You stated that your patient population represented those in whom medical treatment had failed so you need a control group of patients who are stable and treated medically.
I wonder if you have data on the subset of patients with primary sclerosing cholangitis associated with IBD. I anticipate that they may show quite different results than your entire population.

Dr Thirlby: I had 2 objectives in the conduction and presentation of this study. The first objective was to confirm my bias and empirical observations that patients after operation for IBD are a very happy patient population and have improved quality of life. I believe I satisfied that objective today. Unfortunately, I think that I am preaching to the choir. I perhaps would accomplish more by presenting these data to a group of gastroenterologists.

My second objective was to provide encouragement to all of us to start using quality-of-life data when making treatment recommendations to our patients. There are 2 reasons why this is important. The first reason is that the patients are going to benefit. We must change our mindset. Quality of life is not like beauty. Beauty is in the eyes of the beholder. A lot of us think we are beautiful, when in fact we are not. Individual opinion is not important in beauty. Quality of life, on the other hand, is solely in the eyes of the individual or the "beholdee." If others think I am healthy because I have a rapidly growing tumor or I have a laboratory test that is increasing, I really don't care if I feel healthy. Too often we invoke our opinions regarding quality of life on patients' treatment. With beauty, that is okay. With quality of life, it may not be. The key to quality-of-life studies is patient-derived data.

The second reason to perform quality-of-life studies is a selfish one. I believe that if surgeons publish studies that show improved quality of life after operation, clinical volumes will increase.

Dr Mulvihill asked 3 very insightful questions, all the implications of which I agree with. First, he wondered whether the findings in this study were really just a placebo effect or, if you will, a Hawthorne effect. These patients know they are in a study, they know that I think that operations are helpful, and they like me. They may fill out the HSQ in a more positive fashion because they are in a study. That is not to say that the placebo effect is not a good thing.

The HSQ does not really measure attitude. The other short-fall to the HSQ is that it does not give you an aggregate score, one number you can put your finger on. Dr Mulvihill asked about stomas and complications. The complication rate seemed not to affect HSQ results. The number of patients with stomas was small but those patients, as a group, had equivalent HSQ gain scores to those patients without stomas.

Dr Goodnight made an excellent suggestion. It would have been nice if I had analyzed my opinion of outcomes in these patients and scaled the outcomes in a fashion similar to the patients.

Dr Way correctly pointed out that this is a short follow-up study. In the patients with UC, I have no doubt that these effects are durable and their quality of life increases with time in a linear way as shown in the present study. I have only reoperated on 1 of the patients with Crohn's disease. The longest follow-up is only 3 years. There is no question that these data will need to be reanalyzed in about 2 years. There is an interesting control group: I have HSQ data on 18 patients whom I evaluated who did not undergo operation. I am in the process of tracking these 18 patients as a control group. I do not have controls, as Dr Ascher recommends, that were managed in our gastroenterology clinic. Dr Ascher asked about patients with primary sclerosing cholangitis. Only 5% of my series of pull-throughs have primary sclerosing cholangitis. Anecdotally, they are doing as well as the other patients, although I think the numbers are too small to make any valid conclusions.