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PERCEIVED AND ACTUAL QUALITY OF LIFE WITH ULCERATIVE COLITIS: A COMPARISON OF MEDICALLY AND SURGICALLY TREATED PATIENTS

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Abstract

Purpose—Patients with chronic Ulcerative Colitis (UC) often refuse colectomy despite data indicating that it might improve quality of life. We hypothesized that perceived utility values are different for patients living with UC compared to UC patients after total proctocolectomy. Our aims were to compare the perceived utility assigned by UC patients with and without a colectomy to standardized chronic UC and post-colectomy scenarios, and to compare the utility of actual health states among groups.

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Methods—We surveyed patients in a tertiary referral center from 3 groups including non-UC, UC patients without colectomy, and UC patients who were post-colectomy. We measured the Time-Trade-Off utilities of subjects for standardized scenarios describing moderate UC and a post-colectomy state. Among all UC patients (with and without colectomy), we measured Time-Trade-Off utility for their own health state.

Results—Responses were obtained from 150 patients per group (n=450). The non-UC patients regarded UC and colectomy scenarios equally (0.92), which was similar to UC patients without colectomy (0.90 and 0.91). Post-colectomy patients strongly preferred the colectomy scenario to the UC scenario (0.86 vs. 0.92, $p<0.001$). The median utility of UC patients without colectomy for their actual health state was higher than that of post-colectomy patients (0.96 and 0.92, $p<0.05$). Patients with more social support were more likely to have undergone colectomy compared with patients with little social support (OR=1.20 per dependent/supporter).

Conclusions—Patients living with UC prefer their actual health state to a perceived UC scenario or a post-colectomy scenario. Patients who have undergone colectomy equate the quality of life in their actual state with that in a post-colectomy scenario and prefer each to a perceived chronic UC state. Given the variety of preferences and the importance of social support, opportunities to interact with UC patients who have previously undergone colectomy could help patients living with UC and their physicians to navigate these complex choices.

INTRODUCTION

Ulcerative colitis (UC) affects more than 500,000 people a year in the United States (1). Living with symptoms of active UC, including frequent urgent diarrhea, abdominal pain, and fatigue, profoundly diminishes patients' quality of life and productivity. Patients with UC report significantly more disease-related concerns, impaired social functioning, and a reduced sense of well-being compared with age-matched disease-free subjects (2). Medical therapies are only moderately effective for reducing UC symptoms. Moreover, they expose patients to substantial side effects and cannot eliminate the disease. By contrast, surgical intervention with total proctocolectomy may offer freedom from medications and measurable improvement in quality of life (3, 4).

In spite of the potential for substantially improved health and quality of life, many patients with UC are reluctant to consider surgery (4). It is understood that surgical intervention also includes risks of complications, which is clearly an important contributor to patient hesitancy in undergoing an operation. Fortunately, only a minority of UC patients experience a fulminant or toxic disease course. Among these patients, the relative benefit of surgical intervention is clear—and these patients have informed previously published quality of life literature comparing UC to the post-colectomy state (4). However, for the majority of patients, who have chronic smoldering UC, the decision to undergo colectomy may be more difficult to navigate. Typically, patients with mild or moderate UC receive immunosuppressive medical therapy for years prior to a surgical consultation. Published data are extremely limited regarding how these patients perceive colectomy and subsequent effects on quality of life. It is plausible that patients who live with UC for many years suffer a substantial cumulative impairment in quality of life and productivity relative to those with short, severe disease episodes and early colectomy. Counseling patients with chronic UC is

difficult due to knowledge gaps regarding the comparative benefit of colectomy versus continued medical therapy.

We hypothesized that the decision to undergo colectomy is influenced by patients' perceived quality of life or the utility value associated with immunosuppressive and surgical therapies. We also hypothesized that perceived utility values are different for patients living with UC compared with UC patients who have undergone total proctocolectomy. Our main study aims were (1) to compare the perceived utility assigned by non-UC patients and UC patients with and without a colectomy to standardized chronic UC and post-colectomy scenarios; (2) to compare the utility of actual health states among these groups; and (3) to explore patient factors associated with the choice of colectomy.

METHODS

Study population

After obtaining institutional review board approval, we surveyed a cross-sectional stratified sample of patients in general medicine clinics who did not have inflammatory bowel disease (n=150), UC patients who had not undergone colectomy (n=150), and UC patients who were post-colectomy (n=150). We invited participation from patients aged 18 years and older if they were able to give informed consent in this study. For the UC cohort, we recruited patients who had been diagnosed clinically with UC. We required that they had clinical and histological features associated with UC including diffuse mucosal involvement with changes of chronic colitis such as crypt distortion, crypt loss, and lymphocytosis in the lamina propria. We also required that they did *not* have clinical/histologic features associated with Crohn's disease including granulomas and chronic ileitis with patchy distribution of colitis in the colon. The UC patients without a colectomy were deliberately recruited in 3 strata of mild, moderate, and severe disease activity (N~50 each). Because the decision to undergo colectomy is necessarily made pre-operatively at a time when the post-operative outcomes are unknown, we elected to recruit *all* patients who had undergone colectomy for UC in the past 10 years. Thus, we attempted to capture the experiences of post-colectomy patients irrespective of surgical outcome, which would most accurately predict the breadth of actual patient experiences. In addition, the post-colectomy patients were recruited by mail solicitation to avoid bias toward patients with poor surgical outcomes and therefore frequent clinic visits. Patients were recruited from the general medicine, gastroenterology and general surgery clinics at the University of Michigan Medical Center in addition to general mailings. Based on *a priori* decisions, we excluded patients who were (1) younger than 18 years of age; (2) unable to provide informed consent; (3) employees of the university hospital; (4) students at the university; (5) family members of the study team; or (6) diagnosed with Crohn's disease or indeterminate colitis prior to the operation if they had an operation.

Data collection

Informed consent forms and surveys were completed during a face-to-face visit with the study staff. Patients were offered a \$10 cash incentive for participation. Survey questions included patient demographics and responses to standardized scenarios. For all UC patients,

surveys also included disease history including the Simple Clinical Colitis Activity Index(5) (SCCAI) of all UC patients, medication information and information about their social support system (Social Support Dependent Questionnaire; SSDQ) (6). This latter instrument was included based on open-ended responses from our pilot survey test group about the most important influence on their decision to undergo colectomy after clinical status, which was primarily “social support”. The instrument is designed to answer two specific questions: 1) the number of other people the individual feels he or she can turn to in times of need and 2) the number of others that are dependent on the individual for care or support. With IRB approval, we subsequently performed a medical chart review to determine the reason for surgery among patients who had undergone a colectomy.

Standardized scenarios

Measuring patient-assigned utility values allows researchers to compare subjects’ individual valuation of health status. Quality of life was assessed using utility values ranging from 0 to 1, with 0=death and 1=perfect health. Using the Time Trade Off (TTO) method, we informed subjects of their actuarial remaining life expectancy based on age and gender.(7) Several experienced IBD gastroenterologists and colorectal surgeons developed standardized scenarios of life with moderate ulcerative colitis and life in a post-colectomy state. Life in the post-colectomy state included difficulty distinguishing gas from stool, occasional stool seepage or incontinence, and occasional pouchitis. The scenarios were then beta-tested on 10 UC patients for accuracy and revised as appropriate. We then presented the standardized UC and colectomy scenarios to study subjects and queried them regarding the duration of life in the specific scenarios that they would trade away for perfect health in their remaining lifetime. Using pre-determined scenarios in TTO surveys allowed direct comparison between groups and minimized recall bias among post-colectomy patients. Finally, we assessed the utility of each subject’s actual UC or post-colectomy experience.

Analysis

We reviewed the literature to determine the minimal clinically important difference in utility for ulcerative colitis, as recommended by Norman *et al.* for studies using health-related quality of life instruments (8). The minimal clinically important difference in utility measurements is equal to approximately half a standard deviation. We used data from Muir *et al.*(4) to compute a pooled standard deviation for pre-colectomy and post-colectomy UC patients with the standard formula: Pooled standard deviation (s) = $\sqrt{((n1-1)s1^2 + (n2-1)s2^2)/(n1+n2-2)}$

From these data, the standard deviation of utility was 0.208. Therefore, we selected a minimally important difference in utility of at least 0.1. We estimated that for a power of 80% to detect a difference of at least 0.1 in utility with a two-sided α of 0.05, 70 patients per group would be required. To be conservative, we accrued 150 patients per group for a final sample size of 450 patients.

Descriptive statistics were used to characterize the study population. Median TTO was used as a summary statistic because the TTO was not normally distributed, and non-parametric tests were used for analysis. There was significant skew in the TTO, with very high (1)

outliers for utility. This ceiling effect was addressed using censored tobit regression to analyze the factors associated with high utility. All data preparation, logistic regression, and graphing was performed using Stata 10.1 (StataCorp, College Station, Texas), and two-sided p-values less than 0.05 were considered statistically significant.

RESULTS

Overall, 150 patients without UC, with UC and without colectomy, and with UC and post-colectomy consented to be surveyed, for a total of 450 patients in this study (Table 1). Relative to UC patients without colectomy, UC patients who had undergone colectomy were older and more likely to be Caucasian. They also reported longer durations of steroid therapy, and a higher average number of hospitalizations. Per medical chart review, UC patients who had undergone colectomy were primarily operated on for chronic activity (75%), dysplasia or cancer (7%), and acute severe disease (17%).

Utilities of Standardized Scenarios

We measured TTO utility (quality of life) values from each respondent group (non-UC patients, UC patients without a colectomy, and UC patients who had undergone colectomy) for the chronic UC and post-colectomy standardized scenarios (Table 2). The non-UC patients regarded the UC and post-colectomy scenarios as equally poor (median utility values = 0.92 and 0.92 respectively). UC patients without colectomy reported similar utilities for the UC and post-colectomy scenarios (median utility values of 0.90 and 0.91 respectively). By contrast, UC patients who had undergone colectomy perceived the utility of the UC scenario as significantly worse than the post-colectomy scenario (0.86 vs. 0.92, $p < 0.001$). These data indicate that patients who have had a colectomy for UC perceive living with UC— even in a standardized scenario—more negatively than patients who are living with UC or non-UC patients. In addition, patients who had undergone colectomy perceived the post-colectomy scenario as better than living with moderately active ulcerative colitis. This perception of superiority was not shared by the non-UC or UC without colectomy patients.

Utilities for actual health state

We measured actual utilities (quality of life) of UC patients without colectomy and UC patients who had undergone colectomy using the TTO method (Table 3). Quality of life was significantly lower for patients who had undergone colectomy than for those living with UC (0.92 vs. 0.96 $p < 0.05$). As expected, among those living with UC, patients with milder disease had higher utility scores compared with patients with moderate or severe disease (mild: 0.98 vs. moderate: 0.94 vs. severe: 0.96, $p < 0.001$). Among those who were post-colectomy for UC, patients whose operative indication was chronic disease had lower utility scores (0.92) than their counterparts whose indication was an acute exacerbation of disease (0.98). However, the improvement relative to their perception of the UC scenario was nearly identical (0.83 and 0.92, respectively).

We examined factors associated with a high TTO utility for actual health state and found that a previous colectomy was the most relevant, irrespective of severity of disease (Table

4). Older age, by decade, approached statistical significance when associated with higher utilities or better quality of life, $p=0.05$. Not surprisingly, greater duration of steroid use and frequency of hospitalizations were associated with lower utility.

Factors associated with previous colectomy

During the preliminary survey pilot period, we asked respondents in an open-ended fashion about the most important influences on their decision to undergo colectomy. Aside from clinical status, the only influence cited was related to social support—that is, family members or friends who relied upon them or upon whom they relied for support. Therefore, we included a measure of social support(6) in the survey for exploratory analysis of factors associated with colectomy.

As expected, patients with more severe UC disease activity or a longer course of disease, were more likely to have undergone colectomy (OR=1.29, 95% CI=1.20-1.37 and OR=1.05 per year, 95% C=1.02-1.08, respectively) (Table 5). Patients who preferred the UC standardized scenario to their actual health state were less likely to have had a colectomy (OR=0.08, 95% CI=0.02-0.40). Finally, patients with more social support were also more likely to have undergone colectomy compared with patients with little social support (OR=1.20 per dependent/supporter, 95%CI=1.08-1.34).

DISCUSSION

In this study, we compared perceived and actual quality of life or utility values among patients living with mild, moderate and severe UC; patients who had undergone colectomy for UC; and a control group of patients who had never been diagnosed with UC. All patient groups assigned an equal value to the quality of life perceived in the standardized post-colectomy scenario. Non-IBD and UC patients without colectomy perceived both post-colectomy and UC scenarios to have equivalent quality of life. Notably, patients who had undergone colectomy viewed the scenario that described life with moderate UC significantly less favorably than UC patients without colectomy and non-IBD patients. When patients assigned quality of life values to their actual health states, UC patients without colectomy had a significantly higher median utility than post-colectomy patients. Most of the patients who had undergone colectomy in our study were operated on for chronic disease. Although they reported the lowest utility among subgroups for their actual (post-colectomy) health state, this was substantially better than their perceived utility for living with moderate UC.

Living with UC profoundly influences quality of life among a patient population that is typically young and active. A previous study estimated the utility of severe UC from a cohort of 20 patients as 0.59 ± 0.28 preoperatively and 0.93 ± 0.09 postoperatively.(4, 9) A recent post-colectomy survey reported that 97% of post-colectomy patients would undergo ileal pouch-anal anastomosis again and 99% would recommend it to others.(10) Further work has shown that, following colectomy, UC patients have a quality of life comparable with the general population.(11, 12) But there are mixed results. For example, two studies using disease-specific questionnaires have shown that post-colectomy patients report HRQOL similar to that of patients with UC in remission. (13, 14) Taken together, these data suggest that patients with moderate to severe UC may experience an overall benefit from

colectomy in terms of quality of life—and that these UC patients should strongly consider elective colectomy. However, in spite of data indicating that colectomy is likely to improve quality of life, patients living with moderate UC often favor long-term immunosuppressive therapy over colectomy.

When patients with severe UC make choices to forego surgery, it is important to determine whether this is due to an optimistic misperception of the relative risks and relative quality of life value of the UC and post-colectomy health states. Patient decision making requires a complex assessment of risks and benefits, often comparing an imagined or predicted state to an actual, current state. Our use of standardized scenarios allowed us to separate perceptions of poor quality of life from actual poor quality of life under various conditions. In our sample, UC patients without colectomy had a higher median utility than post-colectomy patients, which suggests that it is appropriate for them to choose against colectomy. Patients must accept the risks associated with a technically challenging procedure to remove the entire colon with possible reconstruction, potential postoperative complications, infertility, life with a permanent ostomy or even re-operation for pouch related complications. (15, 16) Furthermore, surgical intervention may cure patients of colonic disease but does not completely abolish symptoms of fecal urgency and incontinence.

A surprising finding for our group was the consistent patient response that having social support was a major factor in their decision making. Much of the previous work on social support and social networks among patient groups has been centered on coping with potentially life threatening disease as opposed to chronic disease. Among cancer patients, the presence of a social network can affect adherence to treatment recommendations in several ways. Providers of social support tend to delay or neglect their own care (17, 18) while recipients of social support tend to pursue recommended care and have enjoyed a significant survival advantage (19). These data have been striking enough to motivate interventional studies that harness breast cancer patients' social networks and thereby improve self-efficacy and uptake of care, particularly among minority patients (20).

Our study is subject to several limitations. First, although we used rigorous methods in developing the scenarios and beta tested them on UC patients with revision until agreement prior to querying study subjects, it is possible that the scenarios we developed did not accurately represent the true patient experience. Post-colectomy patients may have perceived the UC scenario differently than other patient groups because of recall bias or a true change from their previous perceptions, also known as response shift (21). A response shift may occur due to rationalization of a previous choice or due to a heightened revulsion toward the UC experience. Second, we were unable to perform a subgroup analysis of the post-colectomy patients based on the outcomes of their operations. However, our purpose was to provide a comprehensive picture of the post-colectomy state, and therefore we recruited all post-colectomy patients by design. In addition, the consistency of utility values for the post-colectomy state among post-colectomy and other patients supported the accuracy of this representation of the post-colectomy state. Third, data may have been inaccurate due to subjects' difficulty understanding the TTO methodology. Although this is a legitimate concern, TTO has been validated in multiple settings(21) and a research assistant was available to aid survey completion in person. Fourth, the study's cross-sectional survey

design may have been inadequate to capture the ongoing experience of patients living with UC. However, use of cross-sectional data to represent a longitudinal experience is a highly prevalent limitation of many study designs and this tension is unlikely to be resolved in most health related quality of life research.(22) These data support a longitudinal study of the experiences of patients with moderately active UC and in particular a study that helps to elucidate the most appropriate timing of surgery. Our ultimate goal is to develop cost effectiveness analyses and decision tools for patient and providers facing these treatment choices.

In summary, our study shows that patients living with UC strongly prefer their actual health state both to a perceived UC scenario with similar or even milder symptoms and to a perceived post-colectomy scenario. By contrast, patients who have undergone colectomy equate the quality of life in their actual state with that in a post-colectomy scenario and markedly prefer each to a perceived chronic UC state. These data have important implications for patients and their physicians who are considering whether and when to undergo surgery. When patients with severe UC make choices to forego surgery, it is important to determine whether this is due to an optimistic misperception of risks and consequences of chronic medical therapy and endoscopic surveillance and/or pessimistic misperception of the risks of surgery. In fact, patients may be cumulatively better off with a colectomy from a quality of life standpoint. However, health care providers may be challenged to identify and respond to patients' possible misperceptions during abbreviated office visits. There are no decision aids that are currently available but others have proposed personal experiences as a way to help with decision-making (23). Given the importance of social support and the significant variation in perceived quality of life among groups, perhaps intentional opportunities to interact with post-colectomy patients could help patients living with UC to navigate these complex choices. These opportunities are available in some settings in the form of support groups, but access to such a service is not universal. Future studies should investigate specifically whether patients living with UC feel better informed and able to navigate treatment decision-making and have more realistic expectations of treatment, after exposure to institutionally supported contact with post-colectomy patients.

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What is current knowledge

Patients with chronic Ulcerative Colitis (UC) often refuse colectomy despite data indicating that it might improve cumulative quality of life.

What is new here

Patients living with UC prefer their actual health state to a perceived UC scenario or a post-colectomy scenario.

Patients who have undergone colectomy equate the quality of life in their actual state with that in a post-colectomy scenario and prefer each to a perceived chronic UC state.

Table 1

Characteristics of the study sample.

	All Patients N=450	Non-UC Patients N=150	All** UC patients without colectomy N=150	UC patients with moderate/severe disease (SCCA 4), N=95	UC patients post-colectomy N=150
Mean Age in years (range) *	45 (18-86)	44 (19-86)	42 (18-78)	41 (19-76)	48 (18-86)
Male gender (%)	216 (48)	80 (53)	70 (47)	50 (53)	66 (44)
White/Other* (%)	375 (83)	104 (69)	127 (85)	75 (79)	143 (95)
Mean disease duration in months	105.9 (106.7)	-	105.5 (106.9)	101.4 (108.2)	106.4 (106.7)
Mean duration of steroid use in months *	16.6 (24.8)	-	12.4 (20.9)	13.9 (24.4)	20.7 (33.9)
Mean number of hospitalizations * (range)	2.2 (0-100)	-	1.4 (0-15)	1.6 (0-15)	3.0 (0-100)

* p<0.05; UC=Ulcerative colitis

** "All" refers to mild, moderate, and severe UC.

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Table 2

Quality of life measured by Time Trade Off (TTO) utility values using standardized scenarios.

Time Trade Off Scenario	Non-UC patients, N=150 Median, 25%-75 %	UC patients without colectomy, N=150 Median, 25%-75 %	UC patients post-colectomy, N=150 Median, 25%-75 %
Living with Ulcerative Colitis	.92 [0.84-0.97]	.90 [0.79-0.99]	.86 [0.70-0.94] *
Post-colectomy	.92 [0.84-0.97]	.91 [0.79-0.98]	.92 [0.80-0.98]

* p<0.001

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Table 3

Quality of life measured by Time Trade Off (TTO) utility values for actual health state among patients living with UC (disease severity in italics) and among UC patients post-colectomy (indications for surgery in italics).

Actual Health State	TTO score (95% confidence interval)
All UC without colectomy	0.96 (0.89-0.99)
<i>Living with mild UC, N=55</i>	<i>0.98 (0.91-1.0)</i>
<i>Living with moderate UC, N=47</i> *	<i>0.94 (0.86-0.98)</i>
<i>Living with severe UC, N=48</i> *	<i>0.96 (0.88-0.99)</i>
All post-colectomy for UC **	0.92 (0.84-0.99)
<i>Chronic activity, n=113</i>	<i>0.92 (0.82-0.98)</i>
<i>Exacerbation of disease, n=25</i>	<i>0.98 (0.89-1.00)</i>
<i>Dysplasia/Cancer, n=10</i>	<i>0.95 (0.91-0.98)</i>
<i>Unknown, n=2</i>	<i>0.86 (0.82-0.89)</i>

Mild, moderate, and severe UC were determined by the Simple Clinical Colitis Activity Index = 0-3, 4-7, >8, respectively.

* Statistically significant compared to the mild UC state, p<0.05

** Statistically significant compared to living with UC, p<0.05

Table 4

Factors associated with high Time Trade Off utility among all UC patients (N=300, 238 uncensored).

Predictor	Coefficients [*]	P value
Colectomy	-0.046	<0.05
SCCAI ^{**}	-0.001	0.67
No. of hospitalizations	-0.002	0.08
Steroid use (Months)	-0.001	<0.001
Age category ^{***}	0.011	0.05

* Negative coefficient values are inversely associated with high utility.

** SCCAI = Simple Clinical Colitis Activity Index

*** Age categories were defined by decade.

Table 5

Factors associated with previous colectomy for Ulcerative Colitis

Predictor	Odds Ratio	95% CI	P value
Severity of disease*	1.29	1.20-1.38	<0.001
Duration of disease (years)	1.05	1.01-1.08	<0.05
Ulcerative Colitis Scenario utility	0.08	0.02-0.40	<0.05
Social support	1.20	1.08-1.34	<0.05

* Mild, moderate, and severe Ulcerative Colitis were determined by the Simple Clinical Colitis Activity Index = 0-3, 4-7, >8, respectively.

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