Proximity to Disease and Perception of Utility: Physicians' vs Patients' Assessment of Treatment Options for Ulcerative Colitis

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Abstract

BACKGROUND—Physician values regarding the benefit of continued medical therapy vs colectomy for moderate ulcerative colitis have not been defined. If physicians perceive these states differently than patients, their therapeutic recommendations may not align with patient values.

OBJECTIVE—This study aimed to compare physician and patient willingness to trade life years with moderately active ulcerative colitis vs undergoing colectomy.

DESIGN—This survey of physicians' and patients' utility values used standardized scenarios for moderately active ulcerative colitis and colectomy.

SETTING—The investigation was conducted at a tertiary academic medical center.

METHODS—Gastroenterologists, colorectal surgeons, and patients with ulcerative colitis who were either living with moderate disease or were postcolectomy completed the survey.

MAIN OUTCOME MEASURES—Utility values were measured by the use of the time trade-off method.

RESULTS—We surveyed 17 physicians, 150 postcolectomy patients, and 69 patients with moderate ulcerative colitis. Utility values for ulcerative colitis and colectomy states were (0.87, 0.95), (0.86, 0.92), and (0.91, 0.91). On average, physicians and postcolectomy patients assessed the utility of life with ulcerative colitis more poorly than the postcolectomy state. Patients with moderately active ulcerative colitis who had not undergone colectomy viewed both health states equally.

LIMITATIONS—This study was limited by the physician subject sample size.

CONCLUSIONS—Patients living with moderate ulcerative colitis value the pre- and postcolectomy states differently than physicians and postcolectomy patients. Recognizing the

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differences between their own and patients' values may help physicians to better counsel patients preoperatively. In addition, exposure to postcolectomy patients may help those with moderate disease who are weighing the comparative benefits of colectomy.

Keywords

Colectomy; Decision making; Health-related quality of life; Patient preferences; Patient-physician communication; Physicians; Proximity; Quality of life; Survey; Ulcerative colitis; Utility; Utility assessment

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Ulcerative colitis (UC) affects approximately 600,000 people in the United States,[1] for whom recommended treatment includes chronic anti-inflammatory therapy and frequent colonoscopic surveillance. Unfortunately, current medical therapies to treat UC do not eliminate the disease. Those who live with UC may also experience symptoms that have an impact on the quality of life, such as frequent and bloody diarrhea, urgent bowel movements, abdominal pain, and fatigue. Because UC patients are often young, long-term treatment with noncurative medical therapy results in many potentially productive life years affected by the disease course. Seeking a cure or more definitive therapy almost always requires surgical resection, with inherent risks and a separate impact on quality of life postoperatively.

From a physician standpoint, counseling patients with chronic, moderately active UC regarding a treatment strategy that optimizes shared decision making and quality of life can be challenging. No study to date has defined physician perceptions and values regarding the comparative benefit of continued medical therapy vs colectomy. If physicians perceive these health states differently than their patients, their therapeutic recommendations may not be in concert with patient values. Discordant patient-physician values have been demonstrated previously for other disease states,[2–6] with important ethical and clinical implications. For example, Solomon et al[6] examined utility values for colorectal cancer treatment and found that, although surgeons and oncologists expressed concordant values, their preferences frequently did not correspond to the preferences of patients with colorectal cancer themselves. In studies of breast cancer, discordant patient-physician values led to reduced patient satisfaction and increased decisional regret and decisional conflict.[7,8]

The goal of this study was to define and compare the preferences or the utility values of living with moderately active UC and of undergoing colectomy for UC as perceived by the physicians who treat patients in these health states and the patients themselves.

METHODS

Subject Recruitment

After approval by the human-subjects review committee at the University of Michigan, informed consent forms and surveys were completed during a face-to-face visit with the study staff. Physician subjects were recruited from the Division of Gastroenterology and the Department of General Surgery at the University of Michigan Health System, a tertiary academic medical center with an active UC outpatient and inpatient service. We approached all physicians who treated either patients living with UC or patients who had undergone

colectomy for UC and invited them to participate without compensation in a survey of standardized scenarios.

Patient subjects were recruited and offered a $10 cash incentive for participation if they were at least 18 years of age and able to give informed consent in this study. Survey questions included patient demographics, responses to standardized scenarios, and, among patients living with UC, the Simple Clinical Colitis Activity Index (SCCAI; range, 0–20).[9] Responses from UC patients living with moderate disease, defined by a SCCAI score between 4 and 9, were used in this study.

Because the decision to undergo colectomy is necessarily made preoperatively at a time when the postoperative 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 postcolectomy patients irrespective of surgical outcome, which would most accurately predict the breadth of actual patient experiences. In addition, the postcolectomy 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 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 before the operation if they had an operation.

All surveys were completed during in-person interviews with study staff.

Utility Assessment

We used the time trade-off (TTO) method to assess physicians' perceptions of utility, as in previous studies of UC.[10,11] The term "utility" is a measure of value for an outcome, in this case a health state.[12,13] TTO is a validated method for measuring utilities by providing descriptive scenarios of health/disease states and asking subjects to state how much time in perfect health they would be willing to trade for varying lengths of time in the disease states.[14] For example, the difference between physician A selecting TTO = 0.85 and physician B selecting TTO = 0.95 is that physician A would be willing to trade away 15% of his remaining life expectancy, and physician B 5% of his remaining life expectancy, to be in a state of perfect health rather than in the moderate UC or postcolectomy for UC health state. If both physicians had 50 years of expected remaining life, physician A would be willing to die 7.5 years earlier, and physician B 2.5 years earlier, to be in a state of perfect health rather than the scenario provided. As such, physician A believes the disease state in question to be more undesirable than physician B does.

Survey Development and Administration

Expert clinicians collaboratively wrote standardized scenarios of life with moderate UC and life in a postcolectomy state (Appendix). The scenarios were then β-tested on 10 UC patients for accuracy and revised as appropriate. The survey instrument was then administered to gastroenterologists, surgeons, patients who had undergone colectomy for

UC at the University of Michigan, and patients living with moderately active UC. Although personal experience may have influenced patients' or physicians' responses, we tried to mitigate this limitation by clearly asking respondents to state willingness to trade based on the moderately active UC and postcolectomy scenarios provided rather than their own experiences.

For the current study, after consenting to participate in the survey, subjects were given a detailed explanation of the survey instrument and allowed sufficient time to read the survey and ask questions. The first section of the questionnaire included questions regarding basic demographic information such as specialty, sex, race, ethnicity, employment status, education, marital status, and age. The remainder of the survey required subjects to assess quality of life in the standard health state scenarios for UC and colectomy. The questions were designed to measure utilities by TTO at the end of the subjects' actuarial expected life. It was made clear to each subject that the scenarios were based on hypothetical, standardized scenarios of UC and postcolectomy health states as determined by a health services researcher. In an effort to standardize responses, subjects were asked to imagine themselves in each of the scenarios provided when completing the survey, as opposed to relying on specific personal or anecdotal experiences of either state.

After reading each scenario, subjects were informed of their average remaining life expectancy according to data from the 2003 United States Life Tables, based on the age and sex they had provided in the demographic portion of the survey. While keeping their average number of years left to live in mind, subjects were next asked to determine how much time they would be willing to cut off the end of their life to live the remainder of their life in perfect health instead of with the symptoms of the scenario provided. For example, after presenting the standardized UC scenario and asking subjects to imagine living with the symptoms provided, the survey asked subjects:

> [Imagine] that there is an amazing new pill that can cure these symptoms within one day, and will prevent you from ever again be affected by UC. It only costs $1, you take it only once, and you will be free of symptoms. This will also restore your stool frequency to about once per day and none at night, and you will no longer experience abdominal pain. However, the pill has one side effect—it shortens the life span of the person taking the pill. The pill speeds up aging processes so that you will lose some time at the end of your life. If you take the pill, you will die earlier than you would have otherwise. Imagine that you are the person in this situation and you are offered this pill.

A table was then provided that asked subjects if they would take this pill if it would shorten their life by different amounts of time. The subjects' transition points (yes to no) were recorded within 1 month.

Statistical Analysis

The main outcome variable in our study was the TTO. Median TTO was used as a summary statistic because the TTO was not normally distributed. As is standard in TTO assessment, we first converted responses to a utility scale from 0 to 1.[15] On this scale, a utility of 0

indicates that the health state is equivalent to death, and a utility of 1 indicates a health state of good health.

All data preparation and utility comparison was performed with the use of Stata 10.1 (StataCorp, College Station, TX), and 2-sided *P* values less than .05 were considered statistically significant.

RESULTS

Seventeen physicians were recruited to the study (Table 1). All were practicing faculty at a tertiary academic medical center. Fifty-nine percent were board-certified gastroenterologists (n = 10) and 41% were surgeons (n = 7). Among the surgeons, 4 of 7 were board certified in General Surgery and Colon and Rectal Surgery, whereas the remaining 3 were board certified in General Surgery. The majority of them were white (n = 15), non-Hispanic (n = 16), and married (n = 16). The median age of the physicians surveyed was 49 years (range, 33–65 y, SD 9.26).

Sixty-nine patients living with moderately active UC and 150 postcolectomy consented to be surveyed (Table 1). Relative to UC patients without colectomy, UC patients who had undergone colectomy were older and more likely to be white. They also reported longer durations of steroid therapy and a higher average number of hospitalizations. According to a subsequent 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%).

Physicians strongly favored the postcolectomy health state over the moderate UC health state, with median utilities of 0.95 and 0.87 (Table 2). Only one physician assessed the scenario for living with moderate UC more favorably than the postcolectomy scenario. In previously collected patient data,[11] UC patients who had undergone colectomy similarly perceived the utility of the UC scenario as significantly worse than the postcolectomy scenario (0.86 vs 0.92, *P* < .001). By contrast, patients living with moderate UC viewed the utility of both health states equally. These data indicate that physicians and postcolectomy patients concordantly perceived living with moderate UC more negatively than patients living with UC did. In addition, physicians and postcolectomy patients perceived the post-colectomy scenario more favorably than patients living with moderate UC did.

Gastroenterologists reported a median utility of 0.88 and surgeons reported a median utility of 0.87 for the scenario that described living with moderately active UC. Respondents from both physician specialties preferred the postcolectomy state to the moderately active UC state (0.90 and 0.97), although this was not statistically significant among gastroenterologists (Table 3).

DISCUSSION

In this study, we examined the willingness to trade years of perfect health relative to living with moderately active UC and to life after colectomy among the gastroenterologists and surgeons who treat UC patients at a major academic medical center. We compared these

findings with data from patients living with UC or postcolectomy for UC at the same institution. We found that physicians and patients who had undergone colectomy for UC assessed the postcolectomy health state more favorably than living with UC. By contrast, patients who are currently living with UC view both health states equally. Thus, although UC patients hold varying values for surgical treatment, their preferences do not necessarily correspond with the preferences of their surgeons and gastroenterologists.

Utilities research has long established that health-related quality of life may vary because of a number of dimensions, including the type of disorder, duration of disorder, patient age and health status, and notably the respondent's proximity to or direct experience with the disease.[12] In one study, healthy subjects anticipated a significant decrease in quality of life when asked to imagine living with a spinal cord injury.[16] By contrast, patients who were living with a spinal cord injury rated their actual quality of life on par with that of the healthy subjects. In a previous study by our team, non-UC and UC patients perceived the scenarios of UC and colectomy as equally poor, whereas patients who had undergone colectomy for UC perceived the colectomy scenario more favorably.[11] Thus, the experience of having had a colectomy may change the utility of colectomy. Patients living with UC may have a difficult time imagining the uncertainty of life postcolectomy, and therefore may be less inclined to see colectomy in a positive light. Colectomy patients, in contrast, understand the health state through personal experience. Post-colectomy patients perceived the UC scenario differently than patients living with UC because of a worse experience in real time or, alternatively, because of a change from their previous perceptions, also known as a response shift.[17] A response shift may occur because of rationalization of a previous choice, heightened revulsion toward the previous UC experience, or adaptation to a current state.

A secondary goal of this study was to examine the validity of using the provider as a proxy respondent for the patient. Using a proxy respondent is a common and accepted method to determine patient utilities. A decision analysis study to determine when colectomy should be performed for hereditary nonpolyposis colon cancer appropriately used a range of primary data from previous studies in their model.[18] The authors then sampled 10 providers as proxies for patients to determine the utility values for relevant health states in each treatment strategy. They were able to use these data to compute quality-adjusted life years in each of the competing health states, adjusting for the standard 3% to 5% discount in value annually, with the limitation that utility values were not derived from the patients themselves. Our data could be used in a similar way for a decision analysis study, with the advantage that it was derived directly from patients. In addition, in previous work, we used these primary patient-derived data to estimate discounting in UC.[19] We found that adjusted discount rates varied widely (0%–100%) and that the overall median discount rate among UC patients was 55.0% (interquartile range, 20.6–100)—much higher than the normally assumed discount rate of 5%. The unusually large rate and range of discounting in this clinical situation reinforces the individuality of values regarding colectomy among UC patients.

Although ours is the first study to compare physician and patient values for living with UC vs undergoing colectomy, previous research has found that treatment values and perspectives may differ between physicians and patients for other diseases.[2,20–25] In a study of 16 physicians and 50 patients, Gu et al[23] found that surgeons were more likely than patients to

relinquish years of life when in "constant, severe pain." In a study of 13 providers and 46 patients, Otto et al[24] similarly found that health care providers were more likely to sacrifice years of life for quality of life than were their patients. In a study of 61 providers and 53 patients, Longacre et al[25] found that, in the primary prophylaxis of variceal hemorrhage, physicians' treatment preferences were most strongly influenced by the risks of procedure-related bleeding, sexual dysfunction, and perforation; whereas patients placed greater importance on shortness of breath or hypotension, fatigue, and procedure-related bleeding.

In our study, comparing responses from 17 physicians with those of 219 patients, we found that the preferences were more likely to be concordant when patients had previously experienced more invasive treatment. By contrast, preferences were discordant if the patients had not experienced invasive treatment, that is, if patients had colitis but had not undergone colectomy. Whereas the general public may perceive a patient's health state as worse than their own, physicians may be judging a patient's health state based on their experiences working closely with patients who have the disease. One explanation for discrepant utility values between physicians and patients may be that physicians value certain dimensions of health differently than their patients.[16] Future work in this area should focus on better defining the dimensions of health that matter most to patients living with colitis and those who have undergone colectomy, and disseminating these data to physicians.

Although our findings did not suggest that physician specialty significantly influenced the utility assessment for living with moderate UC, we did identify a trend toward a higher value for the colectomy health state among gastroenterologists and a significantly higher utility value among surgeons relative to gastroenterologists. These data suggest that future work is necessary to further discern differences in surgeon vs gastroenterologist values for the postcolectomy health states, and the resultant implications for patient counseling, as well.

The most important implication of our study is that improving patient-physician communication around these treatment decisions is crucial—especially when operative risk must be balanced against the cumulative effects on quality of life. In a related study on patient decision making,[26] when patients with UC were told that their risk of having colon cancer *at that time* was 50%, fewer than 20% were willing to undergo colectomy. In fact, most subjects were not willing to undergo colectomy until the risk of colon cancer was greater than 60%. These data highlight how poorly providers tend to communicate with patients about risk. Along with our current data, they support the next step in understanding these issues—to determine how and when these perception mismatches occur and how perceptions change longitudinally—so that we can better understand and guide our patients.

This study is subject to several limitations that should be noted. First, as with similar previous studies for different diseases,[23–25] the ability to generalize our findings is limited by the physician sample size. However, the fact that our study was from a single center experience did permit us to compare physicians' utility values with those of the patients they treated. Second, it is possible that differences in survey administration between physicians and patients could account for some of the differences in utility scores. To limit this possibility in both the physician and patient surveys, a study assistant was trained to give clear verbal and written directions for completing the survey and to explain concepts that

may have remained unclear. Third, although we used rigorous methods to develop the scenarios and β-tested them on UC patients before querying study subjects, it is possible that the scenarios did not accurately represent the true patient experience, which could bias a comparison of physician and patient responses. However, this is the precise issue that we intended to investigate—the possibility of a discrepancy in physician and patient perceptions regarding UC and its treatment. Whether this discrepancy is termed bias based on experience or simply called a difference in perceptions, our data point to a communication disconnect between patients and providers. Last, some physician subjects may have relied on their own frame of reference (either their personal experience as a patient or the anecdotal experiences of their patients) as opposed to the scenario provided when considering their willingness to trade for each health state. In an effort to standardize responses against this threat, we designed the scenarios to reflect moderately active UC, which could still be treated using medical therapy. We then explicitly asked physician and patient subjects to imagine themselves in each of the scenarios provided when completing the survey, as opposed to relying on specific personal or anecdotal experiences of either state.

CONCLUSION

We found that, although physician and post-colectomy patient values were aligned, they were not aligned with the values of the patients living with UC. Our data support the development of interventions to better align physician and patient views of colectomy for UC. Such interventions could take the form of decision aids, shared medical appointments, and a stronger focus on shared decision making. We also believe that the data derived from this study may prove useful at a clinical level. The Institute of Medicine defines quality as the degree to which health services for both individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.[27] Health care providers may be better able to provide high-quality care if they better understand both their patients' and their own values, and are able to respond to patients' genuine concerns and potential misperceptions of the postcolectomy for UC health state.

Acknowledgments

APPENDIX

Imagine that you are a patient who has had moderately active UC for the past 5 years. You have frequent loose bloody stools, from 5 to 8 per day, and for about half of your bowel movements you have to rush to the bathroom to avoid having accidents. When you have urgent stools, you often get rectal cramping. You often have 3 to 4 bowel movements in a row first thing in the morning, and spend the first 20 to 30 minutes of your day on the toilet. You have some blood in most of your stools, and mildly lower blood counts and inflammation that make you easily tired. You take naps 3 to 5 times per week. You limit your activities to avoid being anywhere where you cannot easily get to the bathroom. When

you go out for longer periods, you avoid eating, because it brings on bowel movements. Having to suddenly rush to the bathroom can be embarrassing, and the worry about having accidents can cause you a lot of anxiety. You often carry an emergency kit with spare underpants and pants. Having moderate UC interferes with your work and normal social activities.

Now imagine that there is an amazing new pill that can cure these symptoms within 1 day, and will prevent you from ever again being affected by UC. It only costs $1, you take it only once, and you will be free of symptoms. This will also restore your stool frequency to about once per day and none at night, and you will no longer experience abdominal pain.

TABLE A1

IF THIS PILL SHORTENED YOUR LIFE BY THIS AMOUNT OF TIME, WOULD YOU TAKE IT?	YES	=	NO
SHORTENS YOUR LIFE BY 1 MONTH			
SHORTENS YOUR LIFE BY 3 MONTHS			
SHORTENS YOUR LIFE BY 6 MONTHS			
SHORTENS YOUR LIFE BY 1 YEAR			
SHORTENS YOUR LIFE BY 2 YEARS			
SHORTENS YOUR LIFE BY 3 YEARS			
SHORTENS YOUR LIFE BY 4 YEARS			
SHORTENS YOUR LIFE BY 5 YEARS			
SHORTENS YOUR LIFE BY 10 YEARS			
SHORTENS YOUR LIFE BY 15 YEARS			
SHORTENS YOUR LIFE BY 20 YEARS			
SHORTENS YOUR LIFE BY 25 YEARS			
SHORTENS YOUR LIFE BY 30 YEARS			
SHORTENS YOUR LIFE BY 35 YEARS			

However, the pill has **one side effect**

—it shortens the life span of the person taking the pill. The pill speeds up aging processes so that you will **lose some time at the end of your life.** If you take the pill, you will die earlier than you would have otherwise. Imagine that you are the person in this situation and you are offered this pill.

You are male/female and _____ years old. The average person of your age and gender is expected to live another _____ years.

Please mark the following questions with an X for YES or NO. If you really can not decide for a particular question, mark the (=) column.

Imagine that you are a patient with UC who had a colectomy 6 years ago. During the operation, your colon was removed, a small internal pouch was formed out of the small bowel and then joined to the anus. You now no longer have an external bag, and all stool passes through your small bowel and out the anus. You have problems telling if you are about to pass gas or stool, and about twice per day go to the bathroom and find that you only

needed to pass gas. About once a month you have problems with stool leaking out of the anus. On average, you have 5 loose bowel movements per day and 1 bowel movement at night. You have had 3 episodes of pouchitis (inflammation of the internal pouch) with urgency, bleeding, and some cramping pain (about once every 2 years since the surgery). Each of these episodes of inflammation has cleared up after taking antibiotics by mouth for 2 weeks. You have not had any fistulas, bowel obstruction, or narrowing of the pouch attachment.

Now imagine that there is an amazing new pill that can cause you to grow a new, healthy colon that will never again be affected by UC. It only costs $1, you take it only once, and your new colon will no longer have UC at all and you will never get it again. This will also restore your stool frequency to about once per day and none at night, eliminate the possibility of getting pouchitis, and reverse any scarring problems due to the previous surgery.

TABLE A2

IF THIS PILL SHORTENED YOUR LIFE BY THIS AMOUNT OF TIME, WOULD YOU TAKE IT?	*YES = NO*
SHORTENS YOUR LIFE BY 1 MONTH	
SHORTENS YOUR LIFE BY 3 MONTHS	
SHORTENS YOUR LIFE BY 6 MONTHS	
SHORTENS YOUR LIFE BY 1 YEAR	
SHORTENS YOUR LIFE BY 2 YEARS	
SHORTENS YOUR LIFE BY 3 YEARS	
SHORTENS YOUR LIFE BY 4 YEARS	
SHORTENS YOUR LIFE BY 5 YEARS	
SHORTENS YOUR LIFE BY 10 YEARS	
SHORTENS YOUR LIFE BY 15 YEARS	
SHORTENS YOUR LIFE BY 20 YEARS	
SHORTENS YOUR LIFE BY 25 YEARS	
SHORTENS YOUR LIFE BY 30 YEARS	
SHORTENS YOUR LIFE BY 35 YEARS	

However, the pill has **one side effect**—it shortens the life span of the person taking the pill. The pill speeds up aging processes so that you will **lose some time at the end of your life.** If you take the pill, you will die earlier than you would have otherwise. Imagine that you are the person in this situation and you are offered the pill.

You are male/female and _____ years old. The average person of your age and gender is expected to live another _____ years.

Please mark the following questions with an X for YES or NO. If you really can't decide for a particular question, mark the (=) column.

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TABLE 1

Characteristics of physician and patient respondents

	Gastroenterologists n = 10	*Surgeons n = 7*	*UC patients living with moderate disease[a] n = 69*	*UC patients postcolectomy n = 150*
Mean age, y (range)	48 (33–62)	50 (40–65)	43 (19–76)	48 (18–86)
Male sex, n (%)	7 (70)	3 (43)	39 (57)	66 (44)
White/other, n (%)[*]	8 (80)	7 (100)	52 (75)	143 (95)
Mean disease duration, mo (SD)	–	–	116.8 (119.3)	106.4 (106.7)

UC = ulcerative colitis.

[a]Moderate UC is defined as Simple Clinical Colitis Activity Index = 4–9.

[*]$P < .001$.

TABLE 2

Time trade off utilities for UC and postcolectomy health states

Health State	Moderate UC scenario	Colectomy scenario	P
Physicians, n = 17	0.87 (0.82–0.93)	0.95 (0.88–0.98)	.0029
Median, 25%–75%			
Colectomy patients, n = 150	0.86 (0.70–0.94)	0.92 (0.80–0.98)	<.001
Median, 25%–75%			
Patients with moderate UC, n = 69	0.91 (0.80–0.97)	0.91 (0.79–0.97)	.2272
Median, 25%–75%			

UC ulcerative colitis.

TABLE 3

Median time trade off utility assessments for health states by physician specialty

	Moderate ulcerative colitis state	*Postcolectomy state*	*P*
Gastroenterologists, n = 10	0.88 (0.82, 0.93)	0.90 (0.84, 0.98)	.067
Surgeons, n = 7	0.87 (0.76, 0.96)	0.97 (0.94, 0.99)	.018

The values in parentheses are the 25th percentile and 75th percentile.