Quality of life assessment by patients with inflammatory bowel disease

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■ Using a direct-interview technique, 164 ambulatory patients with inflammatory bowel disease were evaluated for quality of life. The sample comprised 94 patients with ulcerative colitis and 70 with Crohn's disease, and included both surgical and nonsurgical patients. The interview questionnaire consisted of 47 items in four categories: functional/economic, social/recreational, affect/life in general, and medical/symptoms. Patients with ulcerative colitis had better quality of life than those with Crohn's disease, and patients without surgery had better quality of life than those with surgery. These results are of value in assessing the results of medical and surgical therapy. Quality of life assessment by patients with inflammatory bowel disease gives information not usually obtained by physicians and has implications for quality assurance and outcome measurement.

☐ INDEX TERMS: CROHN'S DISEASE; COLITIS, ULCERATIVE; QUALITY OF LIFE ☐ CLEVE CLIN J MED 1992; 59:35–42

INFLAMMATORY BOWEL disease (IBD), encompassing both ulcerative colitis and Crohn's disease, is a significant chronic disease which usually occurs early in life. Most patients are diagnosed between the ages of 15 and 35.[1] These individuals have a relatively long life expectancy and, presumably, will attempt to live as normally as possible.

■ *See Hellers, p 56*

It can be expected that these patients and others with chronic illnesses will perceive quality of life differently from those who have terminal illnesses or serious illnesses that are curable. As Wenger[2] has observed, "the major therapeutic goal for most patients with chronic illness is not a cure of the disease, but rather an improvement in function and life quality resulting from an alleviation of the symptoms of the illness or from a limitation of the progression of the disease."

The increasing emphasis on quality assurance and outcome measurement makes it important to assess quality of life as perceived by patients with chronic disease. Accurate assessments will be helpful in encouraging patients' participation in the management of their disease, promoting their understanding of its natural history, and guiding their expectations for the future. Furthermore, valid measures of quality of life may be useful to third-party payers and hospital administrators who are concerned about resource allocation.

Issues relevant to the assessment of quality of life include the nature of the illness; related disability; patient age, educational status, and economic status; the quantification of subjective information; and the ability to relate quality of life measurements for different diseases. Existing questionnaires emphasize disease and symptoms, functional status (such as ambula-

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TABLE 1
CHARACTERISTICS OF 164 PATIENTS

Variables	Number of patients (%)
Ulcerative colitis, surgery	51 (31.1)
Ulcerative colitis, no surgery	43 (26.2)
Crohn's disease, surgery	50 (30.5)
Crohn's disease, no surgery	20 (12.2)
Sex	
Male	85 (51.8)
Female	79 (48.2)
Education	
<12 years	5 (3.0)
12 years	50 (30.5)
12 to 16 years	40 (24.4)
>16 years	19 (11.6)
Attending school	26 (15.9)
Currently employed full- or part-time	130 (79.5)

tion), social and economic status, short-term response to procedural interventions, psychological factors, or "global long-term status."[3] Because they focus on disease activity and procedures, many current questionnaires are inadequate measures of the patient's perceived quality of life. As Garrett and Drossman[4] have recently noted, "the existing clinical measures of disease activity for inflammatory bowel disease are insufficient to explain a patient's illness experience or health outcomes."

The objectives of this study were to develop the following: (1) a questionnaire with which patients can assess their own quality of life; (2) a patient-oriented quality of life index that is applicable to the physician's day-to-day management of IBD; and (3) a quality assurance mechanism to assess outcomes in chronic disease.

METHODS

Patient characteristics

In 1973, an IBD registry was established at The Cleveland Clinic Foundation, with annual updates of its demographic, clinical, surgical, and pathological data. Patients were placed in cohorts based on age, disease, surgical status, and other factors. For this study, we selected 164 patients whose disease onset had occurred approximately 10 years earlier (mean age at diagnosis, 20.4 years; mean age at first administration of survey, 29.7 years; mean duration of interval, 9.3 years). This ensured a cohort of patients whose lives would potentially be adversely affected by IBD. Patients were categorized into four groups: surgical and nonsurgical ulcerative colitis patients, and surgical and nonsurgical Crohn's disease patients (*Table 1*). Of the 164 patients, 101 (61.6%) had undergone surgery; this reflects the nature of a referral center.[5,6]

Questionnaire design, administration

The survey questionnaire was designed for use with ambulatory patients functioning in society. This ensured its applicability to outpatient care, which characterizes most patients with IBD.[7,8] Therefore, questions were created that would assess activities of daily living rather than focus on medical or psychological issues.

The questionnaire (*Table 2*) included four broad categories of questions. The *functional/economic* category surveyed the ability to function in work, school, and home, to support self and others, and to advance professionally. The *social/recreational* category focused on interpersonal relationships (with spouse, significant other, family), sexual relationships, relationships in social settings, and the ability to perform recreational, leisure, and social activities. The *affect/life in general* category assessed an optimistic or pessimistic attitude toward life and health, and the ability to plan for the future. Finally, the *medical/symptoms* category focused on gastrointestinal and other symptoms, use of medication, history of surgery, and interaction with health care professionals.

Patients responded to 45 of the 47 questions using the Likert scale of 1 to 5 (strongly agree to strongly disagree). These questions were phrased both positively and negatively to avoid repetition of answers. The other 2 questions called for descriptive responses.

The survey was administered during a 2-month period in 1988 and was repeated in 1989. The 47 questions were administered by nonphysician interviewers in person or by phone; we avoided using physicians to administer the survey because of their orientation toward clinical manifestations of disease and treatment. The questions were short, grammatically simple, and free of clinical terminology. Completion took 15 to 20 minutes per patient. On rare occasions, the questionnaire was self-administered.

Reliability and validity

To assess the temporal stability of patient responses, two interviewers asked 23 patients (6 with ulcerative colitis, 17 with Crohn's disease) the same questions 2 weeks following the initial interview. (It was expected that patients would show minimal change in quality of life status in the 2-week interval.)

The construct validity of the questionnaire was investigated by comparing its results with scores derived from the Sickness Impact Profile (SIP),[9–11] which is considered a standard measure of overall health. The SIP was administered to 96 of the 164 patients (taking approximately 70 minutes per patient to complete), and its results were compared with the results of our patient interview. The scores from the IBD quality of life questionnaire were also compared with IBD registry follow-up data.

The questionnaire's content validity (the representativeness and completeness of each category of questions) was based on the study of other health status instruments,[12] review of the scientific literature, and the professional experience of the senior author.

Statistical analysis

Descriptive statistics for the patient groups were provided as mean, standard deviation, and frequencies. Categorical data were analyzed using Fisher's exact test or chi-square test, depending upon expected cell frequencies. Group differences in location were examined for each question using the Kruskal-Wallis and the Wilcoxon rank sum tests. Category scores were analyzed using a two-factor (surgery and disease) analysis of variance. When this resulted in a significant F value, specific linear comparisons among groups were conducted.

TABLE 2
INFLAMMATORY BOWEL DISEASE QUALITY OF LIFE QUESTIONNAIRE

Functional/Economic	1988	1989
1. I have been able to fulfill my educational goals.		
2. I am able to support myself and my family.		
3. I am receiving financial support from a source other than from my employment.		
4. I'm having difficulty getting insurance.		
5. I feel that I am able to get through each day as well as others.	++	++
6. My earnings are as good as others in similar jobs or activities.		
7. My disease has made it difficult for me to obtain a job.	++	
8. My symptoms interfere with my job or activities.		+
9. In comparing myself to others, I feel I have less energy.	++	++
10. I am able to carry out my regular activities in a way satisfying to me.	+	
11. I feel I have been able to move ahead in my job, family responsibilities, or school.		
12. My growth and physical development were affected by my illness.		
Social/Recreational		
1. I am able to enjoy activities with my family.	++	++
2. I have someone to talk to about the way I feel.		+
3. I feel isolated because of my disease.	+	+
4. I canceled an activity/activities this past month because of symptoms.	+	++
5. I feel frightened by the future.	+	+
6. I can participate in social activities with friends.		
7. I can depend on my family or friends for support.		
8. I am able to participate in a recreational/sport activity regularly.	++	
9. The physical activity I participate in at least once a week is:_______________.		
10. I belong to and participate regularly in a club/church/professional organization.		
11. I feel satisfied with my relationship with my spouse or significant other.		
12. I feel satisfied about the way I participate in family activities.	+	
13. My disease has made it difficult for me to have a family.	++	++
14. My condition has made it difficult for me to share intimate relationships.		+
15. I participate in a hobby or special interest in addition to my other tasks.		
Affect/Life in General		
1. I have made plans for things to do next month.		
2. Most of the time I sleep through the night.	++	++
3. I have made plans for things I'll be doing a year from now.	++	
4. My life is going along pretty much as I had planned.		
5. When compared with other persons of my age, I feel pleased with my accomplishments.		
6. I feel frustrated with my health problems.	+	+
7. I look forward to each day.		
8. I frequently worry about my health.		
9. In comparison to other people, I feel I become more easily discouraged.		
10. I find that I need mood-elevating medications to help get me through the day.		
11. Others see me as chronically ill.		
Medical/Symptoms		
1. I would describe my general physical condition in comparison to others as : __________.		
2. I find myself preoccupied with what I eat.		
3. My symptoms significantly affect the way I function each day.	+	++
4. I have abdominal pain frequently.	++	
5. My diarrhea is disruptive. (ie, does it interfere with your daily life?)	+	++
6. I have difficulty maintaining my weight.	+	
7. I take medications.		
8. I take the following medications once a day: __________.		
9. Do you feel your doctor has been supportive and understanding of your feelings?		

+, marginally significant ($P = 0.05$-0.01)
++, statistically significant ($P \leq 0.01$)

TABLE 3
QUALITY OF LIFE SCORES, 1988 GROUP

	Mean	Median	SD	Range	Distribution of scores <60	 ≥60
All patients (N = 164)	71.9	75.0	13.0	31 - 90	28 (17.1%)	136 (32.9%)
UC, no surgery (n = 43)	77.7	80.0	9.1		2 (4.7%)	41 (95.3%)
UC, surgery (n = 51)	72.4	75.0	13.0		8 (15.7%)	43 (84.3%)
Crohn's, no surgery (n = 20)	73.3	78.5	14.3		3 (15.0%)	17 (85.0%)
Crohn's, surgery (n = 50)	66.0	67.5	13.1		15 (30.0%)	35 (70.0%)

SD, standard deviation; UC, ulcerative colitis

Due to the multiple statistical tests performed, a value of $P \leq 0.01$ was considered significant. Test-retest reliability was evaluated using the Spearman correlation coefficient and the kappa statistic. SAS was used for all statistical testing and for management of the database.[13]

Quality of life index

Univariate analysis of responses to the 45 Likert-scale questions was performed to determine whether scores differed by patient group. Of the 45 questions, 18 yielded statistically significant or marginally significant differences between the four patient groups (*Table 2*). A quality of life index was constructed from these 18 questions. The responses were adjusted so that the most favorable response was represented by 5 and the least favorable by 1. The responses for each patient were then summed to derive a score that quantitated quality of life. The maximum possible score was 90, and a score of 60 or greater was arbitrarily established as indicating "good" quality of life, while a score of less than 60 was taken to indicate "poor" quality of life. The scores for each group of patients were then calculated (*Table* 3).

RESULTS

Initially, patients were asked to characterize their functional capability and symptoms in overall terms. Of 164 patients, 69 (43.4%) considered themselves to be functioning "reasonably well" and were virtually free of symptoms 10 years after diagnosis. The largest group, 80 patients (50.3%), were functioning suboptimally with some continuing IBD symptoms. Only 10 patients (6.3%) considered their IBD symptoms to be "severe" at the time of questioning. Response was not available for 5 patients.

Most of the asymptomatic and normally functioning patients (66%) had ulcerative colitis without surgery. Most of the patients with Crohn's disease who had undergone surgery (68%) continued to be symptomatic; 10% were severely symptomatic. Also severely symptomatic were 15% of patients with Crohn's disease who had not undergone surgery, whereas only 2% of all patients with ulcerative colitis continued to have severe symptoms.

The stability of patient responses across questionnaire categories was supported by Spearman correlation coefficients from the test-retest data, which were consistently between 0.75 and 0.95. High kappa values suggested significant agreement between interviewers in all question categories. The SIP and IBD quality of life questionnaires had statistically significant correlation between similar components. Both instruments were equal in discriminating Crohn's surgical patients from other subgroups; this probably reflects the clinical assessment of these patients as being the most severely ill, and suggests that surgical Crohn's patients need closer surveillance than the other groups.

Quality of life index scores

Patients with ulcerative colitis had better quality of life scores than did patients with Crohn's disease (*Table* 3, $P=0.009$). Surgery affected the score negatively ($P=0.003$), but there was no interactive effect between disease and surgery. Nonsurgical ulcerative colitis patients had better quality of life scores relative to the other three categories, and Crohn's disease patients who underwent surgery had the worst quality of life scores.

Repeat of survey

To continue assessing the validity of the survey, 110 of the 164 patients were re-interviewed by the same two interviewers during a 2-month period in 1989. These included 63 ulcerative colitis patients (57%) and 47 Crohn's disease patients (43%). Among these 110 patients, 68 (62%) had undergone surgery. At follow-up, 1 year later, 45 patients were asymptomatic (42%), 53 had relatively few symptoms (49%), 10 had severe symptoms (9%), and 2 responses were not adequate for classification. When information from each of the 47 questions was tabulated, the frequency counts and percentages were very similar to those of the original 164 IBD patients.

With these repeat surveys, 14 questions were found to have statistically significant differences between groups; these were also quite similar to the information derived 1 year earlier (*Table 2*).

TABLE 4
QUALITY OF LIFE SCORES, 1989 GROUP

	Mean	Median	SD	Range	Distribution of scores	
					<50	≥50
All patients (N = 110)	55.8	59.0	12.1	20 - 70	28 (25.5%)	82 (74.5%)
UC, no surgery (n = 29)	59.5	62.0	10.3		5 (17.2%)	24 (82.8%)
UC, surgery (n = 34)	55.4	58.0	11.7		8 (23.5%)	26 (76.5%)
Crohn's, no surgery (n = 13)	64.2	66.0	6.5		1 (7.7%)	12 (92.3%)
Crohn's, surgery (n = 34)	49.9	52.0	12.8		14 (41.2%)	20(58.8%)

SD, standard deviation; UC, ulcerative colitis

The total score for the 14 questions identified univariately as discriminatory between groups was tabulated by group and summarized by the mean, median, and standard deviation (*Table 4*). As before, the scores were reassigned to reflect a response of 5, rather than 1, as the most favorable. A score above 50 for the 14 questions identified as possibly discriminatory from the 1989 data was considered to be "good"; a "poor" score was below 50. The cutoff score of 50 was lower than with the original questionnaire since there were fewer patients and fewer questions as potentially discriminatory. Refinement of a scoring system requires additional studies.

Individual patient changes in response from the 1988 questionnaire to the 1989 questionnaire were also recorded; the vast majority of 1989 responses were consistent with the corresponding 1988 responses. Typically, these scores were high (4 or 5) both times. The status of nine patients changed from 1988 to 1989, including five patients who had undergone surgery (three with ulcerative colitis).

By far, the group with the most symptoms and the poorest quality of life were patients with Crohn's disease who had required one or more operations. In 1989, Crohn's patients not undergoing surgery had scores similar to those of all ulcerative colitis patients.

DISCUSSION

Standardized questionnaires have been developed to evaluate quality of life, but it is difficult for such instruments to be made relevant to a large number of clinical situations. In measuring outcomes as perceived by patients with chronic diseases, Feinstein and colleagues[14] encountered problems including variations in how patients perceive their disabilities, patients' inability to succinctly describe their condition relative to an extended period of time, inability to validate evaluation techniques, inability to evaluate aggregates of clinical presentations as a single factor, and subjective interpretation of data.

Quality of life measures

Much emphasis has been placed on interventions, particularly surgical procedures. A recent review of quality of life variables in surgical trials[15] found that in 99 therapeutic trials, 96 made no mention of quality of life. In 53 published studies specifically directed at evaluating patient quality of life, only 2 were randomized controlled trials (both included pre- and post-therapy assessments of quality of life). Most of the 53 studies considered patients with renal disease, cardiac disease, cancer, and "bowel procedures" (colostomies and ileostomies).

The SIP, considered by some to be the most versatile gauge of overall health,[16] is a behaviorally based measure of dysfunction related to sickness. Used for program planning and policy formulation, it consists of 136 statements in 12 categories (sleep and rest, eating, work, home management, recreation, ambulation, mobility, body care and movement, social interaction, alertness, emotional behavior, and communication). To complete the SIP questionnaire takes a patient 60 to 90 minutes.

Drossman and colleagues[17] used the SIP to assess IBD in 150 patients (63 with ulcerative colitis and 87 with Crohn's disease). On comparing the results with physician ratings of disease activity, they concluded that the SIP was a sensitive measure of function in IBD patients. Their data also provided preliminary evidence that patients with Crohn's disease have more functional impairment, primarily psychologic and social, than do patients with ulcerative colitis. They also observed that patients' functional status as determined by the SIP correlated better with ratings of quality of life and use of health care resources than did disease-related measures of patient functional status.

Pincus and associates compared patient assessments of quality of life (using a "self-report questionnaire" completed by 259 patients with rheumatoid arthritis) with physician assessments which used traditional means to measure disease activity.[18] The study confirmed that patient assessment of quality of life could correlate with physicians' clinical observations.

The Crohn's Disease Activity Index[19] was developed for use in the National Cooperative Crohn's Disease Study, a multicenter controlled clinical trial. It comprised eight elements, all related to symptoms or findings. Although the index proved valuable in a controlled setting, it was impractical for day-to-day management of the disease.[20] Subsequent attempts to assess disease activity in Crohn's disease include the "simple" index of Harvey and Bradshaw,[21] and the 10-point clinical assessment of disease activity produced by the International Organization for the Study of IBD.[22]

Guyatt and associates[23,24] recently published results of their IBD questionnaire (IBDQ). The Guyatt IBDQ consists of 32 items that assess four aspects of patient's lives (symptoms related directly to the primary bowel disturbance, systemic symptoms, emotional function, and social function). Their objective—to apply the results to clinical trials—is clearly different from the goals of the present study. They concluded that the IBDQ shows promise as a measure of quality of life for use in clinical trials, but that further studies are indicated to assess the relationships between variations in IBDQ results and changes in disease activity among patients with Crohn's disease.

Assessments of function and quality of life among IBD patients, dating from the work of Engel[25] in the 1950s, often have psychological overtones. This may contribute to the widely held impression that, in patients with IBD, psychological features are as significant as those relating to disease activity. For example, earlier studies referred to the "social toll"[26] of Crohn's disease and "social prognosis"[27] in patients with ulcerative colitis. These studies emphasized the significance of the early onset of disease and the relatively higher socioeconomic and educational status of outpatients with IBD. Both used age-matched controls and questions oriented to psychological features, and both emphasized that it was possible for a patient with IBD to successfully adapt to chronic disease, although Gazzard[26] noted that the patients' successful adaptation was "more closely related to their personality than to the activity or extent of disease."

The Copenhagen group (Sorensen et al) has continued to assess quality of life in patients with IBD.[28] Their premise is that a patient may feel threatened by a diagnosis of chronic disease, and that resulting anxiety would worsen the patient's condition. They assessed social activity, physical activity, medication, symptoms, and overall quality of life. They also found higher education levels and reasonably high economic status among Crohn's disease patients. Comparing Crohn's disease patients with controls, they found no significant difference in the amount of stress prior to the onset of disease. Dietary habits also did not differ significantly. Nevertheless, Crohn's disease patients generally felt that their daily lives were adversely affected by their disease, and more than half reported that during periods of disease activity, they felt "strained" in their professional and private lives. In an article accompanying this report, Gazzard[29] noted that one of the strengths of the study was that the study population was a cross-section group and that marital relationships and recreational, social, and employment activities were not different between Crohn's disease patients and controls. This continued the impression that, despite the often troublesome symptoms of IBD, many patients are able to lead a normal life.

A recent study from Germany[30] included a list of "fear factors" with the fear of cancer being the most significant. However, overall assessment of various elements of quality of life has proven difficult. Wenger[2] noted that quality of life may be more precisely defined in terms of its three principal dimensions: objective function, subjective perceptions, and symptoms and their consequences.

CLEVELAND CLINIC STUDIES

During the past two decades, our clinical research has emphasized the long-term follow-up of subsets of patients with IBD. Beginning in 1966 with a study of patients with ulcerative proctitis,[31] our studies have investigated the influence of the location of the affected site on long-term prognosis[1,5] and on recurrences following surgery in Crohn's disease[32,33]; the prognosis of patients with childhood onset of Crohn's disease and ulcerative colitis[34] and proctosigmoiditis[35]; the development of cancer in patients with IBD[36]; and the effect of having a family history of IBD.[37]

In all of these studies, attempts were made to assess patient-determined quality of life; however, the surveys were crude in design and, being developed from the physician's perspective, were oriented toward disease manifestations and treatment. For example, our long-term follow-up studies of patients with Crohn's disease and with childhood-onset IBD assessed quality of life in general terms ("good," "fair," "poor"). As would be expected, about 60% of patients fell into a "fair" or suboptimal quality of life category.

Recent years have witnessed an increasing emphasis on quality assurance in health care and the need to develop measurements of treatment outcome which would be helpful in health planning. We have performed outcome studies (which were not disease-specific) relating to readmissions to an acute care hospital.[38]

Our clinical, long-term follow-up, and organizational experience has emphasized the need for a quality of life assessment which could be used for clinical purposes but which was not designed specifically for clinical trials. The prospect of developing from our survey a 14- to 18-item questionnaire that can discriminate among types of IBD patients is appealing, but the instrument needs refinement and a validation study with other IBD patients. Defining "good" and "bad" scores would be helpful to physicians in the day-to-day management of IBD. A patient-determined quality of life index might serve in the assessment of prognosis, disease activity, or response to therapy and intervention. This could then lead to comparison of quality of life in patients with IBD with that of demographically similar groups of patients with other chronic illnesses. Such a study has already compared patients with IBD to those with rheumatoid arthritis and multiple sclerosis.[39]

The present study may lead to the development of measures of outcome[40] which may be of value in determining resource utilization for patients with chronic diseases, and in assessing the effectiveness of management by health care professionals for quality assurance purposes. Although for the present study only the survey questions that were suggestive of group differences were used in developing the quality of life index, other scoring strategies using this questionnaire might prove helpful in developing and refining a quality assurance mechanism. Such studies may be of benefit to third-party payers or hospital administrators concerned about resource allocation.

CONCLUSION

Our survey emphasizes four aspects of the daily life of patients with IBD: the ability to function generally, particularly in an economic manner supportive of others; social and personal interactions and leisure and recreational activities; patient attitudes, including the perception of illness and its effect over time; and specific symptoms.

Patients with Crohn's disease generally perceive their quality of life as poorer than do patients with ulcerative colitis. Patients who have undergone surgery generally percieve their quality of life as poorer than do patients who have not had surgery (this finding seems to reflect severity of illness). Patients with Crohn's disease who have undergone surgery perceive their overall quality of life to be less favorable than do others.

We believe that this questionnaire is an appropriate instrument to evaluate the quality of life of patients with IBD. It places minimal demands on both the physician and patient, is readily understood by both, and can be easily administered in less than 20 minutes. The results correlated well with those of the more lengthy SIP. We believe that data derived from this questionnaire can assist physicians in making therapeutic decisions that affect quality of life for patients with chronic illness.

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