Family Practice Grand Rounds

Surgical Treatment for Ulcerative Colitis: Clinical, Psychosocial, and Economic Considerations

H. Thomas Wiegert, MD, John G. Banwell, MD, Deborah E. Powell, MD, Madhira D. Ram, MD, John R. Neill, MD, E. Berton Whitaker, MS, and Carolyn Bacdayan, MS
Lexington, Kentucky

DR. H. THOMAS WIEGERT *(Chairman, Department of Family Practice)*: In addition to regular department-oriented Grand Rounds, the greater University of Kentucky Medical Center periodically meets to hear a selected patient case history presented and discussed from various clinical, psychosocial, administrative, economic, and other perspectives. The presentation today will give us an opportunity to see the social, emotional, and financial decisions that a particular patient with ulcerative colitis must make in terms of her illness as well as the public policy implications of that disease in terms of health and social welfare costs. The patient's attending physician will present the case.

DR. JOHN BANWELL *(Chief, Division of Gastroenterology, Department of Medicine)*: The patient was referred to the University of Kentucky Medical Center in September 1970 following a two-week episode of bloody mucus diarrhea and abdominal cramping with weight loss. The previous September she had been diagnosed as having ulcerative proctitis but had done well on sulfasalazine until March 1970. At that time she had diarrhea up to 15 times a day, with extreme loss of fluid, necessitating an 18-day hospitalization at Darnell Army Hospital. She received intravenous rehydration and treatment with steroid enemas. Again she did well until the episode leading to her referral to the University of Kentucky Medical Center.

On examination she was an apprehensive, 20-year-old woman. Her blood pressure was 130/70 mmHg, temperature 99° F, and pulse 74 beats per minute, with no significant abdominal findings apart from vague abdominal tenderness. A rectal examination revealed a rectal fissure. Sigmoidoscopy revealed a friable, granular mucosa with active ulceration present. A biopsy taken at that time revealed severe chronic inflammation with acute inflammatory changes associated with crypt abscesses. The diagnosis, ulcerative proctitis, was confirmed.

The patient was treated with sulfasalazine (2 g/d) and prednisone (up to 30 mg/d), for this and later exacerbations of the disease, and was given sulfasalazine (2 to 3 g/d) as maintenance therapy for prevention of recurrences. In addition, she received occasional anticholinergic medication for pain, diazepam for anxiety, and nocturnal sedatives.

Soon after referral to the Medical Center, the patient returned to the small town outside Lexington where her family lives. She has continued to be followed by the Medical Center.

In 1975 she became pregnant and colitis symptoms improved, although a severe relapse is a

From the Departments of Family Practice, Medicine, Pathology, and Psychiatry, University of Kentucky College of Medicine, the Department of Surgery, Veterans Administration, and Department of Business Services, Hospital of the University of Kentucky, University of Kentucky Medical Center, Lexington, Kentucky. Requests for reprints should be addressed to Dr. Joseph Engelberg, Department of Physiology and Biophysics, University of Kentucky Medical Center, Lexington, KY 40536.

0094-3509/82/080621-08$02.00

common feature of pregnancy for those having ulcerative colitis. The only temporary return to symptomatic illness for this patient occurred at about 22 weeks into her pregnancy, when she became upset following involvement in an automobile accident and started having gas, blood, and loose stools. She gave birth at term to a healthy 5 lb, 9 oz girl. Postpartum, however, she developed a relapse requiring steroid therapy to 30 mg/d. A barium enema demonstrated loss of the haustral pattern throughout the sigmoid, descending, and transverse colon with evidence of active ulceration in the sigmoid portion of the bowel.

During the following years, the patient continued to have relapses once or twice a year, sometimes when she forgot to use the steroid enemas or take other medication, and sometimes when she was clearly under emotional stress. She has not undergone further hospitalization for these episodes, although she has been advised to do so several times.

During this period, her disease process had been extended from rectum to cecum, with evidence of constant disease activity somewhat suppressed by medication. In 1973 her diagnosis was changed from ulcerative proctitis to chronic ulcerative colitis. A colonoscopy carried out in 1977 demonstrated presence of inflammatory changes throughout the colon, although the right colon showed a lesser degree of involvement. Further x-ray films in 1978 demonstrated changes maximally present in the left colon with apparent development of two polyps in the sigmoid region. These were removed and found to be pseudopolyps. Biopsies revealed marked inflammatory infiltration and persisting ulceration in areas of the bowel lumen.

The patient has not experienced any significant periods of remission, as ulcerative colitis patients sometimes do. In fact, she now represents the severe end of the clinical spectrum of ulcerative colitis with generalized colonic involvement. Most people do not experience symptoms as severe as those in this young woman. Watts et al[1] followed 50 patients whose disease was initially restricted to the rectum alone. By about three years after the first attack the disease in 32 of these patients was still confined to the rectum; this group was otherwise in excellent heatlh. In the remaining 18 patients, the disease had spread to part or all of the colon; five of these patients died. Thus, of the subgroup who do develop more extensive or total involvement of the colon, a significantly higher proportion die from the disease.

Currently, the patient in this case is on prednisone (15 mg/d) and sulfasalazine (2 g/d), although these medications do pose the risk of long-term side effects at such dosage levels. Her disability is primarily related to continuing diarrhea: She usually has ten bowel movements per day, mostly in the morning, although she is often awakened at night by one or two episodes of diarrhea. Her diarrhea is associated with such urgency that she is sometimes unable to reach the bathroom in time to avoid soiling her clothing. As a consequence, she has been unemployed since 1978, is precluded from leaving the house during most times of the day, and is depressed over the restrictions on her life.

QUESTION FROM THE AUDIENCE: Are such patients helped by special diets?

DR. BANWELL: No, not really. It is essential for patients to maintain their weight with a normal nutritious diet, of course, and there are certain foodstuffs that tend to be poorly tolerated in persons with ulcerative colitis. This patient, perhaps like most patients with intestinal disorders, was diagnosed as having trouble with lactose-containing foods such as milk or ice cream, and with fibrous vegetables such as cauliflower, cabbage, broccoli. We have provided her with nutritional counseling.

DR. WIEGERT: Can you speak about the long-term effects of ulcerative colitis?

DR. BANWELL: Yes, one of the major complications of ulcerative colitis is the increased risk of malignancy. Persons with a 10-year history of ulcerative colitis are at 5 to 10 times greater risk of developing carcinoma of the colon, and such carcinomas may be multiple and metastatic. Because of the early onset of disease in this patient and its unremitting nature and severity, she is now entering a time at which development of colon cancer becomes a serious consideration. Although there have been no features of precancerous changes identified in any of the multiple biopsies performed on this patient—which I believe Dr. Powell will show you in a moment—her high risk has caused us to advise her to undergo surgery for performance of an ileostomy, total colectomy, and

Continued on page 624

Continued from page 622

proctectomy. This operation also should put an end to her diarrhea and digestive problems.

DR. DEBORAH E. POWELL *(Professor, Department of Pathology)*: Ulcerative colitis is an inflammatory disease of young adults that involves primarily the left side of the colon but which can extend progressively and without interruption to involve the entire colon, as it has with this patient, and even the distal ileum.

Histologically, ulcerative colitis is a disease of the mucosa of the large bowel. It does not usually involve the deeper layers of the bowel wall. The multiple small areas of ulceration in the mucosa are one of the classic features of the disease.

This particular patient's disease was first diagnosed histologically by a biopsy in 1973, with earlier biopsies having been histologically normal. In a 1976 biopsy, the mucosa of the patient's rectum was found to be markedly inflamed. Her most recent biopsies show the inflammatory process extending to the transverse colon. The inflammatory process extends into and destroys the glands of the epithelium, forming what is characterized as a crypt abscess.

The colon malignancies that arise in patients with ulcerative colitis are similar to those arising in the general population. Because of the greatly increased risk of such malignancy among ulcerative colitis patients, recent interest has focused on detection of early changes that would diagnose undetected adenocarcinoma. Atypical epithelium with nuclear and cytologic atypia and dysplasia can be seen in a certain percentage of blind rectal biopsies from patients with ulcerative colitis later found to harbor undetected adenocarcinomas of the colon. Although these changes are not found in all such patients with malignancies, the technique is nonetheless a promising one.

QUESTION FROM THE AUDIENCE: What causes this ulceration? Is there a genetic component?

DR. POWELL: There are believed to be genetic factors suggested by an increased incidence in some populations compared with others; for example, whites get ulcerative colitis more frequently than blacks, Jews more than non-Jews, women more than men. It's sometimes stated that

Continued on page 627

Continued from page 624

there is a 10 percent familial risk, but the disease process itself is of unknown etiology.[2] No one knows what causes the mucosa of the bowel to be attacked, inflamed, and destroyed, although infectious agents, automimmune reactions, hypersensitivity reactions, and disorders of the autonomic nervous system have been proposed as possible causative agents.

DR. WIEGERT: We've seen in this particular patient that emotional and situational factors also influenced onset or exacerbated episodes. In fact, ulcerative colitis is sometimes referred to as a psychophysiological disorder. Dr. Neill is going to talk about that as well as this patient's particular psychosocial history.

DR. JOHN NEILL *(Associate Professor, Department of Psychiatry)*: An ulcerative colitis patient can be approached with a high degree of suspicion that psychosocial factors are of clinical significance. Not only is the bowel an end organ of affective experience (ie, it changes continually according to what is happening outside the body and the patient's reaction to it), but a review of the literature on ulcerative colitis suggests that the etiology, onset of episodes, and course of the disease, all have been observed to be clearly and dramatically influenced by psychosocial experiences.[3]

The literature also suggests that as a group, or subpopulation, persons who develop ulcerative colitis appear to be hypersensitive to common life events; in particular they tend to have a difficult time maintaining satisfactory interpersonal relationships and have even more trouble handling loss or symbolic loss in such relationships. As a group, ulcerative colitis patients also may be unusually sensitive to the demand for performance, perceiving themselves as unable to carry out even relatively simple tasks involving responsibility without someone's help.[3]

This patient is an attractive, well-dressed, articulate young woman. Born ten years after the last of three older sisters, she essentially was raised as an only child. She was popular and did well in school. The family's emotional tone was set by a dominant and overly critical father who demanded perfection from his daughters and spouse. As a consequence, the patient now perceives a need to have some other person, whom she herself calls "a father figure," provide guidance and direction as well as a degree of soothing. However, she is deeply ambivalent about dependency on such a figure.

She married at 19 years of age, and it was that year, while her husband was in the army, that her bowel symptoms began. At first she had idolized her husband but later became critical of him, although she never expressed these sentiments for fear he would lose his temper and then leave. She was 25 when her daughter was born; her divorce took place the following year.

Since then she has felt acutely the absence of a "father figure," despite a long and ambivalent attachment to a boyfriend who shows no signs of wishing to get married. Although she and her child live in the same small town as her family, her father has provided no comfort; instead, he visits her house and does not speak to her. She has difficulty being both parents to her child, particularly in providing discipline.

She worked for two years, enjoying the social aspects of a clerical position, but "retired" on disability at the age of 28 years, ostensibly because of her illness, but at least equally because of her discomfort with the level of responsibility sometimes given her.

At present, she spends much of her day visiting her sister in order not to be alone. She does not identify her illness as a factor in her otherwise limited socialization, since she generally tells people the reason for her frequent trips to the bathroom and perceives most people as understanding. In fact, she appears to be disinterested in discussing the effects of what she calls her illness and far more eager to talk of her loneliness and her relationship difficulties with her father and boyfriend. She feels the relationship with the boyfriend will have to be dissolved, and she has become quite fearful, worried, moody, anxious, and unable to relax.

It seems by her account, as well as by the several entries in her medical record, that how she lives her life has a tremendous effect on the course of her illness. She describes herself as a "nervous" person and sees any sustained affective arousal, even episodes lasting an hour, as worsening such symptoms as passing blood, diarrhea, and cramping. For example, when she gets angry at her boyfriend, she has bowel symptoms for days.

Despite her other worries being exacerbated by her fear of cancer and her physicians' reminders

that she needs a socially difficult operation, her experiences with her medical "father figures" have been good. It is important to be aware of the long-term dependency between the physician and a patient with ulcerative colitis that may become intense as the illness progresses.

DR. WIEGERT: Dr. Ram, could you discuss the operation recommended for this particular patient?

DR. MADHIRA D. RAM *(Chief of Surgery, Veterans Administration Hospital)*: A total proctocolectomy has been recommended to this patient for three reasons:

1. Despite medical treatment, her disease is not responding. She still has 10 to 12 bowel movements a day with loss of blood during acute colitis.

2. Ulcerative colitis of this severity threatens other possible complications such as massive bleeding from the colon, perforation, and toxic megacolon. If she develops any of these complications, a total proctocolectomy is mandated but with much higher mortality than if the procedure were done electively.

3. There is a tenfold increased risk of colon cancer, particularly in such a young patient who has already had the disease for more than ten years.

In a conventional ileostomy, the terminal end is everted like a nipple. The patient wears a bag on top of this nipple. The bag collects the excreta and must be emptied periodically. There is about a 10 percent risk of needed revision when the skin grows.

A second type of ileostomy, the continent ileostomy, consists of a small intestinal pouch created at the end of the ileum. The patient has to put a fine catheter into this pouch and empty it periodically, but it can be covered with a 4×4-inch gauze pad rather than a bulkier bag. Many patients prefer it for this reason, but it has a higher failure rate and a higher degree of possible complications than has a conventional ileostomy. Consequently, a standard ileostomy has been recommended to this patient with the suggestion that once it is working, a second operation might be performed in order to make a pouch.

For ulcerative colitis, unlike some other inflammatory bowel disorders, total proctocolectomy is curative. Patients who undergo this oper-

Continued on page 631

Continued from page 628

ation do not have further bowel problems. She would be able to return to work, as well as resume a more normal social life, without fear of the interruption of bowel symptoms.

QUESTION FROM THE AUDIENCE: May I ask, Dr. Neill, if psychotherapy might help this patient rather than surgery?

DR. NEILL: With regard to psychotherapy for patients with ulcerative colitis, studies on groups over the years have provided either negative or equivocal results, but individual successful cases have been reported.[4] The most useful therapy for ulcerative colitis patients may well be "environmental manipulation" of contributory events, possibly family therapy, and supportive therapy in conjunction with the referring physician. I feel that this particular patient would be helped by learning to get beyond the developmental block she has concerning dependency, especially since she clearly states the connection between arousal and symptoms. It is possible psychotherapy might help her in relation to her ulcerative colitis. But on the other hand, the damage to the bowel she is suffering now is irreversible, and the surgeon is offering her a real and immediate cure: If he performs this operation, her bowel problems are gone for good.

QUESTION FROM THE AUDIENCE: Since it appears to be up to her now, what is she likely to decide?

DR. NEILL: Obviously, there is a lot of initial resistance, but she responds easily to suggestion and support. Her way to do it would be to not think about it and then someday impulsively decide to do it.

DR. RAM: Dr. Neill has mentioned this patient's need for a father figure. I believe she would let me do the ileostomy if she thought I would take care of her for the rest of her life and she could depend on me or one of the other physicians.

DR. BANWELL: This patient is clearly concerned about the disfigurement involved and its effect on her relationship with men and other people in general. She has been introduced by Medical Center staff to someone who has had the ileostomy, and she has been referred to the Ostomy Association, a group of people who have had ileostomies and who act as counselors to patients undergoing the operation. These sources, as well as the intestinal therapists at the Medical Center, have immense knowledge about the practical and emotional aspects of having and living with the operation.

QUESTION FROM THE AUDIENCE: If she does decide to have this operation, how is she likely to respond?

DR. NEILL: I think she would do quite well. She does respond easily to suggestion and support, as I said earlier, and she would need a great deal of information and follow-up. The only other thing to consider is the timing, which would need to be ascertained. For example, her boyfriend is her sole support at the moment (and one gets the impression that there is a lot that needs to be sustained), and that relationship may be about to end. But with that precaution and supportive follow-up, I think she would do quite well.

MR. E. BERTON WHITAKER *(Director of Business Services, Hospital of the University of Kentucky)*: Dr. Wiegert has asked me to talk about the costs of this patient's illness, both to herself and to third party payers. Her medical care expenditures over the ten-year period 1970 to 1980 totaled $13,263. About 38 percent of this was for drugs, 40 percent for hospital charges (primarily outpatient), and 22 percent for physician services. About half of this sum, primarily hospital and professional expenses, was covered by Blue Cross/Blue Shield. The other half was paid directly by the patient. Much of this expense represents drugs. The government paid no portion of her medical care expenses.

The patient's average annual out-of-pocket expenditures ($660) for medical care for this condition as a proportion of her annual income is 7.8 percent. An additional $200 per year expended for other health care places her total annual out-of-pocket expense at $860 and raises her total health care out-of-pocket expenses to 10 percent of her income. The proportion of income available for out-of-pocket expenditures would necessarily vary according to an individual's income level; the 10 percent in this case is a substantial individual commitment. Nevertheless, about 9.2 percent of the income of families in the income bracket $5,000 to $9,999 go for out-of-pocket health expenses annually.[5]

In addition to the direct medical care expenses, there were indirect costs involved with seeking medical care including transportation, accommodation during outpatient visits, special clothing,

Table 1. Estimated Net Public Revenue With and Without Proctocolectomy over 10-Year Period

	Without Surgery and With Continued Public Support	With Surgery and Subsequent Employment
Disability	$ 30,000	0
Supplemental security income	36,000	0
Cost of surgery from public funds		$ 6,000
10-year tax revenue based on earnings of patient ($75,000)		10,000
10-year net public revenue	$ −66,000	$ +4,000

and child care. These expenses brought her total medical care expenses, borne out-of-pocket, to 14 percent of her annual income.

Her drug costs were the major component of her out-of-pocket expenses and were considerably above the national average for drugs as part of the total personal health expenditures: 38 percent compared with 12 percent nationally. Although her third-party coverage paid a higher percentage of her total medical care costs than is paid on the national average (50 percent vs 28 percent),[6] it remains that her insurance policy, which did not cover prescription drugs, was a significant deficiency in her medical care coverage. Exclusion of prescribed drugs from coverage is a nationwide problem, affecting many patients.

DR. WIEGERT: Two things are immediately noticeable about this patient's financial picture: (1) the absence of any government assistance, which assumes an average of about 40 percent of the nation's health care expense; and (2) the atypical hospitalization history. She has had only one brief hospitalization during this ten-year period. For most chronic diseases, including ulcerative colitis, we would expect the hospitalization costs to be a much higher proportion of health care expenses. Ms. Bacdayan, could you suggest to us how this financial picture might change depending on whether she decides to proceed with the recommended proctocolectomy:

MS. CAROLYN BACDAYAN *(Director of Planning, University Hospital, University of Kentucky Medical Center)*: The most immediate effect, of course, would be the shift in the balance between hospital and outpatient expenditures. The total cost of the surgery is estimated to be $6,000, including a ten-day hospitalization. But this should sharply reduce her medical expenses in the long run.

Another, and perhaps the major, long-term effect would be her ability to be gainfully employed following surgery and the cessation of her diarrhea and bowel problems. The income she would make if she were able to work needs to be compared with both her medical expenses and the cost of her support should she decide not to have the operation and thus continue to be ill and unable to work. Although the government did not contribute anything to her medical care in the past decade, she recently qualified for disability payments of $3,000 annually and supplemental security income of $3,600 annually. She also became eligible for a Medicaid card, which will cover her various medical expenses regardless of the route she chooses regarding the proctocolectomy.

Table 1 attempts to answer the question, What are the costs of public support for this individual with and without a surgical intervention that has been shown to be effective?

If the patient could be gainfully employed following surgery, the expected net benefit to the public over the next ten years would be a saving of $66,000 in disability and supplemental security income payments and net government revenues of $4,000 (based on $10,000 in taxes paid by the pa-

tient minus the $6,000 the government would pay for the surgery).

While a decision for proceeding with the surgery cannot and should not be made on the anticipated savings to the public alone, clearly there are implications for the public coffers in this individual case. Where there is proven effective treatment and where there are known risks of developing cancer for the patient without this treatment, what should public policy for continuing support be toward individuals who refuse the treatment? This question is germane, not just for individuals receiving public support, although it may emerge more clearly in this context. The overall cost to both public and private sectors of disability from chronic disease is an important problem. The dilemma of protecting consumer choice and privacy in the face of rising costs of health care and the increasing responsibility of the public sector for the support of disabled individuals is going to become an even more prominent public issue.

QUESTION FROM THE AUDIENCE: What do you do when you have recommended surgery and a patient asks, "Would you have this operation yourself, Doctor?"

DR. WIEGERT: First, we need to make it clear to the patient that we would have the operation ourselves—but under our own value system. And second, we need to understand the patient and what her own values are. We teach our family practice residents to help patients make decisions among various courses of action by clarifying objectives and assigning relative weights to their own values.[7] For example, this young woman obviously places certain values on life expectancy, physical pain, social discomfort, physical appearance, and so forth. Each alternative course of action can then be examined for how it fits the values held most dear by the patient. The physician's opinion of what is best would have some place in her value system, but her value system may be quite different from the value system of the surgeon offering an operation.

QUESTION FROM THE AUDIENCE: The assumption is that, once having had the operation, she would be employable again. Who actually makes the decision as to whether she actually will work or seek employment?

DR. BANWELL: The patients feel better after the operation and feel able to work.

MR. WHITAKER: Yes, but what I think the question implies is that she could continue on disability for the rest of her life if she wanted, which would not necessarily represent a saving or would be a different balance between chronic and short-term medical costs.

DR. WIEGERT: This is an appropriate place to end our discussion. This patient represents fairly severe advanced ulcerative colitis with generalized colonic involvement. Her history, both in the progression of active ulceration and in the interplay of emotional and personality factors with symptoms, is typical. The difficult decision to face surgery and the economic implications of that surgery for society and the patient are dependent on her value system, her personality, and the support she perceives from her environment and her medical care providers.

Acknowledgments

This article was derived from the Integrative Clinicopathological Conference series of the University of Kentucky College of Medicine, under the organization of Dr. Joseph Engelberg, Department of Physiology and Biophysics, and edited by Sylvia Wrobel, Department of Behavioral Science.

References

1. Watts JMcK, deDombal FT, Watkinson G, Goldigher JC: Early course of ulcerative colitis. Gut 7:16, 1966
2. Beeson P, McDermott W, Wyngaarden JB (eds): Cecil Textbook of Medicine, ed 15. Philadelphia, WB Saunders, 1979, p 1568
3. Weiner H: Psychobiology and Human Disease. New York, Elsevier, 1977, pp 495-574
4. Sifneos P: Ascent from Chaos. Cambridge, Harvard University Press, 1964
5. Family Out-of-Pocket Health Expenses, United States, 1975. In National Center for Health Statistics (Hyattsville, Md): Vital and Health Statistics, series 10, No. 127. DHEW publication No.(PHS)79-1555. Government Printing Office, 1979, p 11
6. Gibson RM: National health expenditures, 1978. Health Care Financing Rev 1:32, 1979
7. Wiegert TH: Teaching Interpersonal Skills: A Manual for Family Medicine Faculty. Lexington, Ky, University of Kentucky College of Medicine, 1980