Medium-term follow-up of ulcerative colitis in Cape Town

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Summary

The 114 patients with ulcerative colitis diagnosed in Greater Cape Town between 1970 and 1979 were followed up 11 years later. Ninety per cent of those contacted were in remission or had mild symptoms only. Eleven patients had died; 3 deaths (in total colitis patients) were disease-related but the overall mortality rate in ulcerative colitis was not increased. There was only 1 case of carcinoma of the colon.

The 5-year surgical rate was 5% increasing to 23% 10 years after diagnosis. Six patients (35%) had had a Park's pouch, 3 (18%) ileorectal anastomosis, and 8 (47%) panproctocolectomy or colectomy with an ileostomy. The incidence of surgery was higher in those with total colitis. In those patients who did not have the rectum removed, there was a 100% recurrence of proctitis. Park's pouch patients remained well and incontinence was not a problem. Thirty-one per cent of patients with proctitis at diagnosis had evidence of extension of disease to the colon at follow-up.

Ulcerative colitis may be a more benign disease than often believed, with mortality from the disease and need for surgery being associated almost exclusively with extensive disease.

Many follow-up studies of ulcerative colitis are from personal series or patients referred to hospital practice,[1-3] whose severity of disease is likely to bias the overall prognosis. In this study a consecutive group of patients with ulcerative colitis diagnosed between 1970 and 1979 in Greater Cape Town was followed-up in order to present a more balanced view of the course of the disease.

The majority of patients with proctitis appear to have a good prognosis over many years with no extension of the disease. However, in a certain number of patients the disease extends into the colon and the risk of surgery is increased.

While surgery can cure ulcerative colitis, the type of surgery undertaken and the morbidity and mortality rates associated with it must be weighed against the long-term risks of medical management and development of carcinoma.

Subjects and methods

The University of Cape Town Inflammatory Bowel Disease Register is a computerised database set up to record details of all known cases of Crohn's disease and ulcerative colitis diagnosed in the Greater Cape Town area (magisterial districts of Bellville, Goodwood, Wynberg, Simonstown and Cape Town).

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It was used to select patients with ulcerative colitis diagnosed between 1970 and 1979 inclusive, who fulfilled the diagnostic criteria of Lockhart-Mummery and Morson.[4]

The extent of disease was determined by double-contrast barium enema and sigmoidoscopy. If the disease involved the hepatic flexure it was classified as total colitis. The grading of severity of disease was based on the classification of Truelove and Witts.[5]

Patients were interviewed to confirm past details of their disease, including surgery and current clinical status, and to ascertain if they were on any regular medication for colitis or attending a doctor or clinic outside Groote Schuur Hospital. Details of the operations, histological findings in operative specimens and follow-up were obtained from the surgeon concerned.

The patients with an initial diagnosis of proctitis, who had not had surgery during the follow-up period, were asked to attend the clinic for reassessment of the extent of their disease by flexible sigmoidoscopy. In those who had had surgery, the operative specimen was examined to determine the extent of disease involvement.

Where patients had died and information as to the date and cause of death was not forthcoming, the Registry of Births and Deaths in Cape Town was contacted for detailed information.

Mortality rates for the general population was obtained from Central Statistical Services. A mean of the figures obtained from the 1970 and 1980 population censuses for the 5 magisterial districts which make up Greater Cape Town was used.

Normally distributed data, such as age, were tested in the different groups by means of Student's t-test, while most of the follow-up data were not normally distributed and were therefore tested by non-parametric methods. Discrete data were tested by means of the chi-square test. The follow-up data were tested by life-table analysis and the generalised Wilcoxon test. The level of significance was taken as $P < 0,05$.

Results

There were 114 patients who fulfilled the criteria for inclusion in the study. Eighty-five were interviewed between May 1987 and March 1988 after a median follow-up of 11,2 years (range 7,2 - 17,0 years) from diagnosis. Of the 29 patients who were not interviewed, 6 were followed for a year or more from the time of diagnosis (median 1,2 years, range 1 - 10 years) and 12 were lost to follow-up soon after diagnosis. A further 11 patients had died (Table I), 3 of them from causes related to their disease and all with total colitis (Table II). This gave an overall mortality rate for the colitis patients of 1,02%. The mortality rate for the general population in Cape Town was 1,79%. No deaths had occurred in the first year after diagnosis.

The extent of disease of the 29 patients not interviewed was not significantly different from the patients available for follow-up. Neither was there any significant difference in the race or sex of these patients.

The clinical pattern demonstrated by these patients at diagnosis was mild disease in 65% and moderate-to-severe disease in 35% (Fig. 1). The mean time from onset of symptoms to diagnosis was 170 days (range 0 - 33 years). Twenty-five per

TABLE I. CAUSES OF DEATH IN PATIENTS WITH ULCERATIVE COLITIS

Cause of death	No. of patients
Ulcerative colitis	3
Ischaemic heart disease	2
Cardiovascular accident	2
Violent death	2
Carcinoma of bronchus	1
Unknown	1
Total	11

TABLE II. DEATHS ATTRIBUTABLE TO ULCERATIVE COLITIS

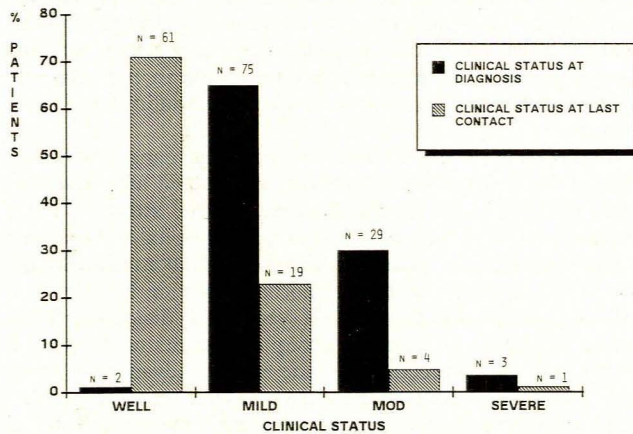| Patient	Age (yrs)	Yrs from diagnosis	Extent of disease	Cause of death
1	22	3	Total	Septicaemia
2	51	8	Total	Carcinoma colon
3	33	9	Total	Anaesthetic death

Fig. 1. Severity of ulcerative colitis at diagnosis and at follow-up. (Clinical status at diagnosis not recorded in 5 of the initial 114 patients and clinical status at last contact only recorded for the 85 patients followed up.)
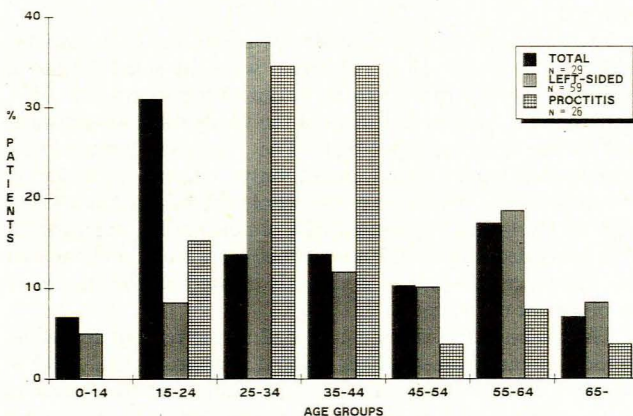

Fig. 2. Age distribution of patients presenting with ulcerative colitis according to extent of disease.

cent of patients had extensive or total colitis, 52% left-sided colitis and 23% proctitis. The extent of disease plotted by age at diagnosis combined with extent of disease (Fig. 2) showed a peak incidence in 25 - 34-year-olds. Total colitis was maximal in 15 - 24-year-olds with a smaller rise in 55 - 64-year-olds. Left-sided disease, together with proctitis, peaked slightly later — in 30-year-olds — and again demonstrated a slight rise in the older patients.

At the time of interview 41 patients (48%) had been in complete clinical remission for more than 1 year. Nineteen patients (22%) had had one relapse in the preceding year, 9 (11%) had relapsed twice and 16 (19%) had remained almost constantly symptomatic during that time. There was no relationship between disease severity at onset and the subsequent clinical course.

Seventeen patients had come to surgery (6 whose initial extent was total, 8 left-sided and 3 proctitis). The 5-year surgical rate was 5% overall (5 patients having had a colectomy in the 5 years since diagnosis out of the 91 followed to surgery or for 5 years), but there was the expected higher incidence of surgery among the total colitis patients ($P = 0,02$) of whom 17% had had a colectomy compared with 2% of those with left-sided disease and none with proctitis (Fig. 3). Ten years after diagnosis the rate had increased to 23% overall (14 having had a colectomy out of 61 followed to surgery or for 10 years). Of the total number of colitis patients, 44% had had surgery compared with 22% of those with left-sided disease and none with proctitis. There was evidence of extension of the disease in 8 out of the 17 surgical patients (Table III).
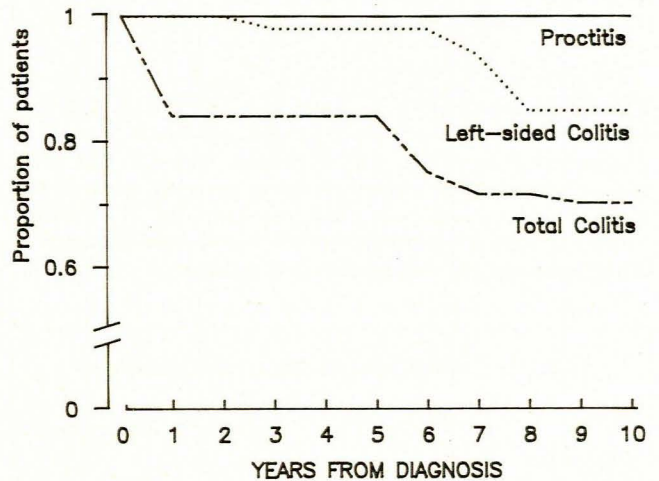

Fig. 3. Life table showing the time from diagnosis to definitive surgery in patients with ulcerative colitis ($P = 0,02$; generalised Wilcoxon (Breslow)).

TABLE III. EXTENSION OF DISEASE IN PATIENTS WITH ULCERATIVE COLITIS UNDERGOING SURGERY

Extent	Initial	Operative
Total	6	14
Left-sided	8	3
Proctitis	3	0

Of the 18 patients with proctitis, 3 came to surgery more than 10 years after diagnosis and a further 10 had their disease extent reassessed by flexible sigmoidoscopy. The remaining 5 refused re-examination. There was evidence of extension in all 3 surgical patients, 2 to beyond the hepatic flexure and 1 to

the left side of the colon. Among the others examined, there was evidence of extension of the disease to the sigmoid colon in only 1 patient. Therefore, 4 out of 13 of the proctitis patients (31%) who were reassessed had evidence of extension of the disease beyond the rectum.

Twenty-four per cent of the colectomies[4] were done within 1 year of diagnosis; all of these patients had total disease at operation. Seven operations were carried out as an emergency, 9 for intractable symptoms and 1 for resection of carcinoma of the colon.

There was no significant difference between the mean age of the surgical and non-surgical patients at diagnosis (33,5 years and 37,1 years respectively). The type of operation performed is shown in Table IV. The Park's pouches were all done after 1982. The partial colectomy was done as an emergency procedure before a diagnosis of ulcerative colitis had been made.

TABLE IV. SURGERY PERFORMED IN PATIENTS WITH ULCERATIVE COLITIS

Operation	No. of patients
Park's pouch	6
Ileostomy with	
Panproctocolectomy	5
Pancolectomy	2
Ileorectal anastomosis	3
Partial colectomy	1
Total	17

Complications in 12 patients after surgery are shown in Table V. Two patients died, as mentioned previously, 1 during induction of anaesthesia and 1 from metastatic spread of carcinoma of the colon. The 5 patients who had had their rectum left *in situ* developed recurrent proctitis, while of the other 5 complications, only 1 was long-standing. This patient, with an ileostomy, still has recurrent bouts of diarrhoea causing dehydration and necessitating hospital admission.

TABLE V. COMPLICATIONS FOLLOWING SURGERY

	Pouch	Panprocto-colectomy	Colectomy
Obstruction	2	1	—
Sepsis	—	1	—
Diarrhoea	—	1	—
Proctitis	—	—	5
Death	1	—	1
None	3	2	—
Total	6	5	6

TABLE VI. STOOL FREQUENCY IN PATIENTS WITH A PARK'S POUCH

Patient	Stools per day	Medication
1	3	4-5 x 30 mg codeine phosphate tabs/d
2	3	2 x 30 mg codeine phosphate tabs/d
3	2	None
4	3	None
5	3	2 x 30 mg loperamide tabs/d

All 5 patients with a Park's pouch have done well and cope with the increased frequency of soft stools with, or without, medication (Table VI). None of them have faecal incontinence by night or day or needs catheterisation of the pouch. One woman has had a baby since the operation.

Only 1 case of carcinoma of the colon was found during the follow-up period. Two separate tumours occurred in this patient 6 years after diagnosis of ulcerative colitis, but at least 9 years after the onset of symptoms. A colonoscopy 2 years earlier had not revealed dysplasia.

Discussion

This consecutive group of patients is believed to include all but a very few cases of ulcerative colitis diagnosed in Greater Cape Town during 1970 - 1979.[6] The age distribution of patients presenting with ulcerative colitis was similar to that found in Cape Town previously[6] and again shows a small peak in the incidence in the older patient.

The overall mortality rate was not increased in ulcerative colitis, but there were 3 disease-related deaths, 2 of which were attributable to the therapy for the disease rather than the disease itself, i.e. total parenteral nutrition and surgery. The third death was due to carcinoma of the colon, which was a direct consequence of the disease process. These patients all had total colitis, which supports previous reports that proctitis and left-sided colitis do not diminish life expectancy[3] and any excess mortality in ulcerative colitis occurs in patients with extensive disease. There was no excess mortality from other causes.

Earlier reports emphasised the potential danger of colitis during the first year after diagnosis and quoted high mortality rates of 3,9 - 14,5% during the first referred attack.[1,2] These studies were based on patients referred to hospital and included a high proportion of patients with severe initial attacks. Bonnevie *et al.*[7] reported an excess mortality rate of 1,3% in their colitis patients during the first year after diagnosis. Their study was based on a similar group of patients to the present study, but was conducted a decade earlier. Advances in medical management and postoperative care after emergency colectomy during the intervening 10 years may have contributed to the lower mortality rate in this study.

The consecutive series of patients studied is considered to give a truer reflection of how the disease behaves in the community as a whole. The majority of patients (65%) presented with mild symptoms and the vast majority (90%) were well or had only mild symptoms 11 years later, which suggests that ulcerative colitis runs a more benign course than is commonly believed.

The risk of having a colectomy is much higher in patients with total colitis. Even in the group with left-sided disease at diagnosis coming to colectomy, 6 out of 8 patients, i.e. 75%, were found to have involvement of the whole colon on examination of the operative specimen. The 3 surgical patients who initially had rectal involvement only, all had evidence of extension of the disease, 2 to the whole colon, and 1 to the left side. At the time of operation, 82% of patients had total colitis, 18% left-sided colitis and none proctitis, which confirms that the incidence of surgery is directly related to the degree of involvement of the colon.

The likelihood of disease confined to the rectum spreading to the sigmoid colon has been quoted as approximately 30% at 10 years[3] or 29% at 20 years.[8] It is probable that the disease in those who refused re-examination had not extended, since their symptoms had not been sufficiently severe to persuade them that re-examination was necessary. If this assumption is correct, the incidence of extension into the colon in the

proctitis patients was 22% at 11 years, which is similar to that reported previously.

Recurrent proctitis was a major problem in operated patients who had not had a panproctocolectomy. There were, however, no complications of sepsis, obstruction or intractable diarrhoea in this group, which compared favourably with the incidence of these problems in patients who had had a panproctocolectomy with or without a Park's pouch. At review, the Park's pouch patients were all leading full and active lives without any incontinence, and were well satisfied with the outcome of their operation. One woman had a successful pregnancy, which showed that normal sexual function can be preserved.

The follow-up time in this study was not long enough to give representative figures for the risk of developing carcinoma of the colon. The 1 patient who did so had had symptoms of colitis for at least 9 years.

In conclusion, the medium-term prognosis of ulcerative colitis appears to be good, with a 10-year surgical rate of only 23%, and nearly 50% of the remainder having been in remission for a prolonged period. Mortality from the disease itself and the necessity for surgery was almost exclusively associated with extensive disease.

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