# Factors affecting colectomy rate in ulcerative colitis: an epidemiologic study

C E Leijonmarck, P G Persson, G Hellers

#### Abstract

Factors affecting colectomy rate were studied in a retrospective population based series of 1586 patients with ulcerative colitis, in Stockholm County during 1955-84. Five hundred and sixty eight patients (36%) had total colitis at diagnosis, 603 patients (38%) left sided colitis, and 397 patients (25%) proctitis. During a median period of observation of 13 years 514 patients were treated by colectomy. The five, 10, and 25 year cumulative colectomy rate were 20% (CI 18-22%), 28% (CI 26-30%), and 45% (CI 41-49%) respectively. The main factor affecting the colectomy rate was the extent of disease at diagnosis. Patients with total colitis showed a five, 10, and 25 year cumulative colectomy rate of 32% (CI 28-36%), 42% (CI 38-46%), and 65% (CI 58-72%) respectively. Ten per cent of the 1586 patients had a colectomy during the first year after diagnosis, 4% during the second year and 1% during subsequent years. The age at diagnosis and sex did not affect the cumulative colectomy rate. Elective colectomy was performed in 322 cases (63%) and acute colectomy in 192. The duration of disease before colectomy fell during the study period due to a more standardised criteria for colectomy in severe attacks. One hundred and twenty nine (66%) of the acute colectomies were performed within two years from diagnosis.

Some patients with ulcerative colitis will require colectomy. A high colectomy rate reduces the cancer risk in the ulcerative colitis population, but leaves the patients with varying degrees of postsurgical discomfort. A low colectomy rate avoids postsurgical disadvantages but carries a higher cancer risk and also a risk for general manifestations of the disease.

It is therefore of interest to study factors that may affect the colectomy rate, particularly in relation to duration of disease. Statistical

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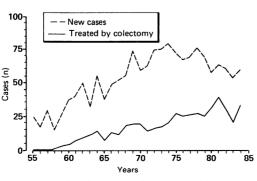


Figure 1: Number of new cases of ulcerative colitis and number of cases treated by colectomy during the period of study.

methods such as life table methods has to be used to calculate the cumulative colectomy rate.<sup>1</sup> This method has been used in one previous study from a referral centre.<sup>2</sup> The epidemiological approach would be to study all cases of ulcerative colitis diagnosed in a defined geographical area over a defined period of time. Only two studies of this type have been reported in the literature<sup>34</sup> both with fairly short follow up.

The aim of the present study was to determine the colectomy rate in Stockholm County in relation to duration of disease (cumulative colectomy rate), and relate this to age, sex, extent of disease at diagnosis and different time periods. The aim was also to investigate any changes with time in indications for colectomy that may affect the colectomy rate.

#### Methods

#### PATIENTS

The patients in this series were collected from two studies on the epidemiology of ulcerative colitis in Stockholm County (five unpublished observations). The patients had a definite diagnosis of ulcerative colitis between 1 January 1955 and 31 December 1984 and were registered citizens of Stockholm County.

All patients admitted to hospital are included in the Stockholm County central admission registry. This registry was searched as well as outpatient gastroenterology clinics for cases of ulcerative colitis and Crohn's disease diagnosed during 1955–84. These registries are reliable and the sample is therefore as complete as it is possible to make it. Patients with an initial diagnosis of ulcerative colitis later changed to Crohn's colitis were excluded. For further details concerning methodology and the inception cohort we refer to our previous study.<sup>5</sup>

In 1586 patients the diagnostic criteria of ulcerative colitis were fulfilled. The number of new cases of ulcerative colitis and the number of cases treated by colectomy during the time period is shown in Figure 1. In 514 patients (275 men and 239 women) a colectomy was performed during the period of observation. The age and sex distribution of these 514 patients is shown in Table I. The mean age at colectomy was 37 years

TABLE I	Age and sex distribution at colectomy	
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Age (yrs)	Men		Wome	m	All	
	( <b>n</b> )	(%)	( <b>n</b> )	(%)	( <i>n</i> )	(%)
<20 20-39 40-59 >60 Total	21 149 77 32 279	(48) (53) (54) (68)	23 131 66 15 235	(52) (47) (46) (32)	44 280 143 47 514	(9) (54) (28) (9)

(range six to 78). The mean duration of ulcerative colitis from diagnosis until colectomy was 5.4 years (median 3.3).

# DIAGNOSTIC CRITERIA

The diagnostic criteria were in accordance with previous studies and included a history of diarrhoea and/or rectal bleeding for six weeks or more, typical sigmoidoscopy findings and characteristic microscopic changes on biopsy and/or specimen.<sup>5</sup>

#### BACKGROUND AREA

The background area was the County of Stockholm. The population statistics were obtained from the Swedish Central Bureau of Statistics. The region comprised a population of 1.18 million in 1955 which increased to 1.59 million at the end of 1984. There were 14 major hospitals in the county during the period of study.

# FOLLOW UP

Follow up data were obtained from the Stockholm County central hospital admission registry, hospital records and personal interviews. The follow up data were collected from Jan 1987 to March 1988. Two hundred and seven patients (13%) were dead at the time of follow up and of these 63 were treated by colectomy. In these cases the date of death was taken as the time of follow up. Thirty four patients (2·1%) were lost to follow up and of these 34 cases the last recorded hospital admission was taken as the time of follow up. The mean period of observation in the 1586 patients was 13·3 years (median  $12\cdot7$  years).

# DURATION OF DISEASE

The mean time interval from onset of symptoms until definite diagnosis in the 1586 patients was 1.8 years (median 0.4 years) and did not change during the study period, irrespective of extent of disease. It is preferable to use the same time frame in all calculation including extent of disease at diagnosis. The duration of disease in patients treated by colectomy was therefore registered from the case records as the time interval from definite diagnosis until colectomy and in unoperated patients as the time interval from definite diagnosis until follow up.

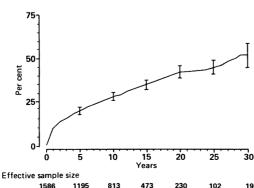


Figure 2: Cumulative colectomy rate in 1586 ulcerative colitis patients. (Vertical bars indicate 95% confidence intervals.)

#### EXTENT OF DISEASE

The extent of disease was evaluated according to the classification of Watts  $et al^6$  and thus based on radiological changes.

Proctitis was defined as mucosal changes in the rectum on sigmoidoscopy but with a clear demarcation between the affected rectal mucosa and the normal bowel above it, and a barium enema without further pathology.

Left sided colitis was defined as mucosal changes in the rectum and radiological evidence of disease in the distal colon, reaching in proximal direction at the most to the hepatic flexure.

Total colitis was defined as mucosal changes beyond the hepatic flexure.

At diagnosis 397 patients had proctitis, 603 left sided colitis and 568 total colitis. The extent of disease was unknown in 18 patients. The relative frequency of the three extent-of-disease categories at the time of diagnosis was stable throughout the study.<sup>5</sup> The specimen from the 514 patients treated by colectomy showed total colitis in 471 (92%), left sided colitis in 42 patients, and proctitis in one case.

In 14 patients a carcinoma was found in the specimen.

# INDICATIONS FOR COLECTOMY

With some modifications the indications for colectomy were registered according to the definitions used by Goligher.<sup>7</sup> Urgent and emergency colectomies were classified as acute.

In 322 patients there was an elective indication for colectomy; chronic continuous disease in 215, stricture in 36, dysplasia in 19, DALM (dysplasia associated lesion or mass) in seven, and preoperatively verified cancer in eight patients. The latter four groups are lumped together and expressed as 'verified lesions' in the subsequent text. In 34 patients the indication for colectomy was cancer prophylaxis (inactive colitis and a duration of disease of more than 10 years) and in three patients it was miscellaneous.

There was an acute indication for colectomy in 192 patients; fulminant colitis/failure of medical therapy in 129, toxic megacolon in 52, and massive haemorrhage in 11 patients.

The mean time interval between onset of symptoms and definite diagnosis was  $2 \cdot 3$  years (median  $0 \cdot 7$  years) in elective cases and  $1 \cdot 3$  years (median  $0 \cdot 3$  years) in acute cases.

# STATISTICAL ANALYSIS

The cumulative colectomy rate, with approximative 95% confidence intervals (CI), was calculated using life table methods as described by Armitage.<sup>1</sup> Statistical analysis was done by Fisher's exact test and significance was assigned to any p < 0.05.

# Results

The cumulative colectomy rate among all patients is shown in Figure 2. The five, 10, and 25 year cumulative colectomy rates were 20% (CI 18–22%), 28% (CI 26–30%), and 45% (CI 41–49%) respectively.

One hundred and fifty five (10%) of the 1586

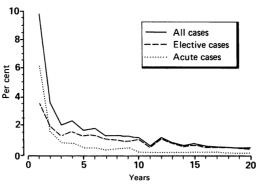


Figure 3: Percentage of 1586 patients treated by colectomy in relation to duration of disease.

patients had a colectomy during the first year after diagnosis and 4% during the following year and during the next 20 years from diagnosis the colectomy rate was about 1% per year (Fig 3).

#### AGE AND SEX

Figure 4 shows the cumulative colectomy rates in relation to age at diagnosis. The five year cumulative colectomy rate was lower in patients younger than 20 years and patients 60 years or older compared with the rest of the patients, but with no differences at the 95% level. In young patients this lower colectomy rate was eliminated with time and the 25 year cumulative colectomy rate was at diagnosis, but with no differences at the 95% level. There were no differences in relation to sex in cumulative colectomy rates.

#### EXTENT OF DISEASE AT DIAGNOSIS

In the 397 patients with proctitis at diagnosis 96 patients underwent colectomy during the period of observation. The five, 10, and 25 year cumulative colectomy rates were 14% (CI 11–17%), 21% (CI 17–25%), and 34% (CI 26–42%) respectively (Fig 5). One hundred and forty six of the 603 patients with left sided colitis at diagnosis showed similar cumulative colectomy rates as for cases with proctitis (Fig 5). In the 568 patients with total colitis at diagnosis 268 patients underwent colectomy during the period of observation. The five, 10, and 25 year cumulative colectomy rates were much higher in this group; 32% (CI 28–36%), 42% (CI 38–46%), and 65% (CI 58–72%) respectively (Fig 5). Four of the 18

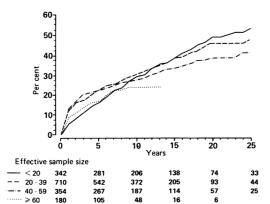


Figure 4: Cumulative colectomy rates in relation to age at diagnosis.

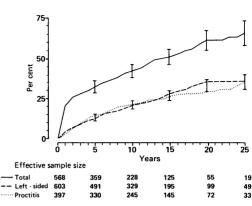


Figure 5: Cumulative colectomy rates in relation to extent of disease at diagnosis. Patients with proctitis/left-sided colitis are counted as one group concerning confidence intervals. (Vertical bars indicate 95% confidence intervals.)

patients with unknown extent of disease at diagnosis underwent colectomy and the specimens showed total colitis.

Of the 96 patients with proctitis at diagnosis and treated by colectomy the specimen showed proctitis in one case, left sided colitis in eight, and total colitis in 87 patients. The corresponding figures for the 146 patients with left sided colitis at diagnosis were 34 with left sided colitis and 112 with total colitis.

#### TIME PERIODS

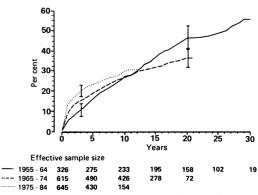
The cumulative colectomy rates in relation to different time periods are shown in Figure 6. There was a higher three year cumulative colectomy rate among patients diagnosed during 1975–84 compared with patients diagnosed 1955–64.

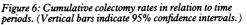
#### INDICATIONS FOR COLECTOMY

The time trends in indications for surgery are shown in Figure 7. The percentage of acute cases increased from 25% during 1960–64 to 44% during 1980–84 (p<0.05). Acute indications for colectomy may either be emergency or urgent. The emergency/urgent ratio was 9/2 (82/18%) during 1960–64 and changed gradually to 9/58 (13/87%) (p<0.001) during 1980–84 (Fig 7).

There were no differences in the number of acute colectomies in relation to age at diagnosis or age at colectomy.

The duration of disease before colectomy in





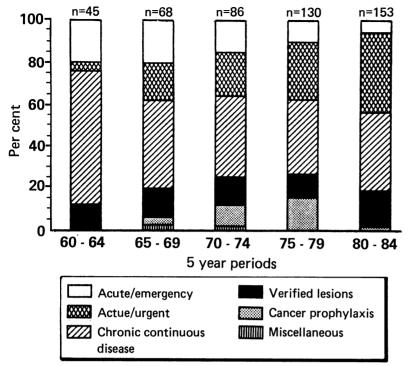


Figure 7: Time trends in indications for colectomy.

relation to acute and elective cases is shown in Figure 3. A colectomy was performed within two years from diagnosis in 66% of the acute cases.

#### Discussion

The cumulative colectomy rate in ulcerative colitis patients has previously been reported in three studies, one hospital series,<sup>2</sup> and two population based studies<sup>34</sup> (Table II). The five year cumulative colectomy rate has varied between 8% and 16% and the 10 year rate between 11% and 21%, compared with 20% at five years and 28% at 10 years in the present study. The differences could be because 70% of the patients had proctitis at the time of diagnosis in the Scottish study<sup>3</sup> and 40% in the Danish,<sup>4</sup> compared with only 25% in the Swedish study. In a study from St Marks Hospital<sup>8</sup> on patients with proctitis the cumulative colectomy rate at 10 years was only 5%. The low number of

proctitis and the high cumulative colectomy rate in these patients in the present study is probably due to the fact that our inclusion criteria are more rigid.

The present study has sufficient number of patients and length of follow up to produce results with reasonable confidence intervals which makes it possible to estimate factors affecting colectomy rate.

# DURATION OF DISEASE

A high proportion (10%) of the 1586 patients in the present study were treated by colectomy during the first year after diagnosis. This high early colectomy rate illustrates the potential danger of ulcerative colitis during the first year after diagnosis and this has also been reported in previous studies.<sup>910</sup> Three hundred and six (60%) of the colectomies in the present study were performed within five years from diagnosis.

In patients with a duration of disease of 10 years or more and still not treated by colectomy the probability of colectomy during the subsequent course of disease is very low (Fig 3).

# AGE AND SEX

Previous population based studies<sup>3 10</sup> have shown no marked differences in cumulative colectomy rate in relation to age at diagnosis and this is in accordance with the present study.

In Stockholm there was a tendency in young patients towards a lower colectomy rate during the first five years of the disease compared with the middle aged patients. This is probably because in young patients it seems rather naturally to wait as long as possible with the colectomy in order to prevent psychological problems caused by a stoma and possible sexual dysfunction related to pelvic dissection.

Bonnevie *et al*<sup>10</sup> did not find any difference in cumulative colectomy rate in relation to sex and the present study confirms these findings.

# EXTENT OF DISEASE

The main factor affecting the colectomy rate

TABLE II Cumulative colectony rates in ulcerative colitis: hospital and population based series

		Cases					
Study	Review period	Whole series (n)	Total colitis (n)	Treated by colectomy (n)	Follow up (median time)	Results Cumulative colectomy rate	
Hospital based St Marks Hospital Ritchie <i>et al</i> <sup>2</sup>	1966–75	269	37 (14%)	25	Not stated	5 years 8% 10 years 15% Total colitis 5 years 33% (CI 25–41%)	
Population based Northeastern Scotland Sinclair et al <sup>3</sup>	1967–76	537	59 (11%)	Not stated	Mean 5 yrs	5 years 8% 10 years 11% Total colitis 5 years 35% (CI 22–48%)	
Copenhagen County Hendriksen <i>et al</i> <sup>4</sup> (continuation of the Bonnevie study <sup>10</sup> )	1960–78	783	124 (16%)	149	6·7 yrs	5 years 16% 10 years 21% Total colitis 5 years 40%*	
Stockholm County Present study	1955–84	1586	568 (36%)	514	12·7 yrs	5 years 20% 10 years 28% Total colitis 5 years 32% (CI 28–36%)	

\*Binder (personal communication)

seems to be the extent of disease at time of diagnosis. If the patient had total colitis at diagnosis the probability of colectomy was much higher. The five year cumulative colectomy rate in patients with total colitis in the present study was 32% and this is in accordance with the findings in previous studies, from St Marks Hospital 33%,<sup>2</sup> from Northeastern Scotland 35%,<sup>3</sup> and from Copenhagen 40% (Table II).

The probabilities of colectomy in patients with proctitis and left sided colitis respectively are almost identical (Fig 5). This is in accordance with the clinical impression that proctitis and left sided colitis has a similar course with often complete remission and sometimes even normal histology between attacks. Our results and previous findings<sup>23</sup> indicate that proctitis/left sided colitis on one hand and total colitis on the other almost behave as two different diseases.

# TIME PERIODS

The duration of disease before colectomy decreased during the study period and this could be due to more liberal indications for colectomy. New surgical procedures have been introduced in the 1980s making colectomy a more attractive option for the patient.

The high 25 year cumulative colectomy rate in patients diagnosed during 1955-64 is explained by the high number of patients in this group with cancer prophylaxis as the indication for colectomy.

# INDICATIONS

The number of acute colectomies has increased during the period of study. This increase could be because the disease itself has changed over the years and become more acute in its manifestations or could be because of changes with time in indications for colectomy. During the late 1960s more standardised criteria for colectomy in severe attacks were developed.11 12 These criteria including early colectomy (within five days) were accepted in the Stockholm hospitals during the 1970s and could explain the increasing number of acute colectomies. The marked decrease in emergency colectomies also illustrates that the changes in indication for colectomy in severe attacks are the probable source of the increase in acute colectomies rather than that the disease itself has changed in its manifestations.

The postoperative mortality in acute cases has decreased markedly during the study period from about 37% in the early 1960s to 2% in the 1980s.<sup>13</sup> This is probably also a function of more liberal indications for colectomy in severe attacks and of an improved standard of general management of the surgical patient.

Cancer prophylaxis was introduced in the 1960s and increased during the early 1970s. Since approximately 1980 this indication for colectomy have not been used. Patients with a duration of disease of more than eight to 10 years are instead included in cancer surveillance programme.14 These programmes yield some patients with high grade dysplasia requiring colectomy. This is the explanation for the increase in the number of patients treated by colectomy with 'verified lesions' as the indication for colectomy during 1980-84.

The colectomy rate is one of the main factors determining the cancer risk in a ulcerative colitis population. In a previous study of the cancer risk in patients with total ulcerative colitis in Stockholm County during 1955-79 the cumulative cancer risk was 3% at 15 years and 5% at 20 years.<sup>15</sup> A recent cohort study<sup>16</sup> showed that patients with total colitis had a cumulative risk of cancer of 7.2% at 20 years from onset of disease. In the population based study from Copenhagen<sup>4</sup> the 18 year cumulative cancer risk in patients with total colitis was 1.3%. The cancer risk in the Copenhagen study was independent of initial extent of disease. The data are, however, based on small numbers.

This study has shown a 25 year cumulative colectomy rate of 45% (CI 41-49%) in patients with ulcerative colitis in general, 65% (CI 57-72%) in patients with total colitis at diagnosis. The colectomy rate was highest during the first years after diagnosis. It has also shown that the time interval between diagnosis and colectomy has decreased during the study period, which is partly the result of an increase in acute colectomies during the latter part of the study. The increase in acute colectomies is probably because of the acceptance of the five day regimen and the introduction of new surgical procedures.

Since 1980 cancer prophylaxis as the indication for colectomy has been abandoned in Stockholm County and replaced by cancer surveillance programmes.

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