Chronic ulcerative colitis: incidence and prevalence in a community

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SUMMARY Utilising the population based data resources of the Rochester Epidemiology Project, we determined the incidence and prevalence of chronic ulcerative colitis among Rochester, Minnesota, residents over the 20 year period, 1960–79. One hundred and thirty eight cases met diagnostic and residency criteria, for an overall age, and sex adjusted chronic ulcerative colitis incidence rate of 15·0 per 100 000 person years. The male:female ratio of age adjusted rates was 1·5:1. Age specific incidence was roughly bimodal in appearance but was not consistent in different patient subgroups. On 1-1-80, there were 120 Rochester residents with a history of chronic ulcerative colitis, corresponding to a prevalence rate of 225·2 per 100 000 population. Fifty three per cent of chronic ulcerative colitis incidence cases were 'definite' and 47% were 'probable', the former requiring consistent observations for at least six months. The definite group had proportionately more men and disease of greater extent and severity. Pancolitis comprised about one-third of all cases (4·6 per 100 000 person years). Proctitis and distal disease (7·1 and 2·0 per 100 000 person years) made up most of the rest. One-fourth of all patients had 'severe' or 'moderate' disease (3·8 per 100 000 person years), while the remainder had either 'mild' or 'transient' chronic ulcerative colitis (11·2 per 100 000 person years). In residents of Rochester, Minnesota, chronic ulcerative colitis is most often a mild disease. The over-representation of severe or complicated examples that results from selected referral to major centres probably distorts the natural clinical spectrum of the disease.

Chronic ulcerative colitis has the potential for substantial morbidity, and patients with extensive disease, frequent exacerbations, or major complications are usually referred to tertiary medical centres for care. In the absence of such problems, however, the disease is often managed by general physicians. Because most data regarding chronic ulcerative colitis have been derived from referral centres, where complicated patients are over-represented, the frequency and clinical spectrum of the disease in the community is not well known. The objective of the present study was to determine the incidence and prevalence of chronic ulcerative colitis among residents of Rochester, Minnesota, 1960–79, using the population based data resources of the Rochester Epidemiology Project.

Methods

Patients

Population based epidemiologic research is possible in Rochester, Minnesota, because medical care is virtually self contained within the community and is delivered by a small number of doctors. Most care is provided by the Mayo Clinic, which has maintained a common medical record system with its two large affiliated hospitals over the past 70 years. This dossier type record contains both inpatient and outpatient data and is easily retrievable for review. The diagnoses and surgical procedures entered into

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these records are indexed. The index includes the diagnoses made for outpatient office or clinic consultations, emergency room visits, nursing home visits, hospital inpatients, autopsy examinations, and on death certificates. The medical records of the other doctors in the area who have served the local population are also indexed and can also be retrieved. Thus, the details of the medical care provided to residents of the entire community are available for study. The potential value of this data system for population based studies has been described previously.²

Using this unique data base, 138 patients were identified who were residents of Rochester when first diagnosed with chronic ulcerative colitis in the 20 year period 1960–79. To assure complete ascertainment, we screened the charts of all Rochester residents with diagnoses of chronic ulcerative colitis; ulcerative/idiopathic/nonspecific colitis, proctitis or proctosigmoiditis; inflammatory bowel disease; or chronic colitis from a variety of other presumed causes. The records of patients with Crohn’s disease and related diagnoses were also evaluated. We discarded those who did not fulfill residency criteria and those whose diagnosis was clearly not chronic ulcerative colitis (see criteria below). In order to be considered a bona fide incidence or prevalence case, the patient must have been a resident of Rochester for at least one year before initial diagnosis or the prevalence date, respectively.

The mucosal nature and extent of disease were verified by endoscopic, radiologic, and/or histologic findings for each case. A positive diagnosis of chronic ulcerative colitis required typical findings – that is, diffusely granular or friable mucosa on endoscopy, with uniform involvement of the colon as observed by barium enema and/or colonoscopy. Involvement of the small intestine, with the exception of ‘backwash ileitis’, was reason for exclusion. If biopsies were taken, histologic data provided additional evidence. Cases with evidence of a specific infection or a history suggestive of antibiotic colitis, laxative abuse, or any other more obvious alternative diagnosis were not included. Exclusion of Crohn’s colitis was based on the anatomical distribution of the disease and histologic, radiologic, endoscopic, or surgical findings compatible with Crohn’s disease. The histories of patients who had inflammatory bowel disease, but in whom a clear distinction between chronic ulcerative colitis and Crohn’s colitis was lacking, were reevaluated, and their tissue specimens were retrieved for reassessment by one of our pathologists. Because a concurrent epidemiologic study of Crohn’s disease was underway in the same community, we were able to come to a decision for each of these ‘mixed’ cases and assign them to one study or the other. Thus, between the two studies, there was no overlap or exclusion of inflammatory bowel disease cases.

Cases that met the above criteria were further classified as either ‘definite’ or ‘probable’. Placement in the ‘definite’ category required radiologic or endoscopic documentation of chronic ulcerative colitis at least twice, with the observations being separated by a period of six months or more. Where there was only one observation or when observations spanned a period of less than six months, the diagnosis was considered ‘probable’.

The anatomical extent of disease by radiology or colonoscopy was recorded at initial diagnosis and at the time of maximal colonic involvement. Patients were divided into five groups with regard to the maximum extent of disease: (1) proctitis (no involvement proximal to the rectum), (2) distal (no involvement proximal to the splenic flexure), (3) extensive (involvement of hepatic flexure or transverse colon and distally), and (4) pancolitis (entire colon involved). A fifth category, segmental colitis, was used for a few instances of apparent non-uniform disease which could not be designated as Crohn’s disease of the colon.

In addition, four subgroups were identified based on the severity of disease. These subjective categories included: (1) transient – symptomatology and pathological features sufficient for a diagnosis of chronic ulcerative colitis but which then resolved (or were not documented) for the duration of follow up (by definition, these were all ‘probable’ cases); (2) ‘mild’, by exclusion, those patients not in groups 1, 3, or 4; (3) ‘moderate’, patients requiring one or more blood transfusions or more than two hospitalisations for chronic ulcerative colitis over the entire length of follow up; and (4) ‘severe’, patients who underwent total proctocolectomy, developed toxic megacolon, or died as a result of chronic ulcerative colitis.

For calculating incidence rates, the entire population of Rochester was considered to be at risk; denominator age and sex specific person years were estimated from decennial census data as described elsewhere.¹ Rates were directly age and sex adjusted to the population structure of United States whites in 1980 or, for comparisons between sexes, were age adjusted to the same standard population. The 120 patients with chronic ulcerative colitis who were residents of Rochester on 1 January 1980 (regardless of their residence status at initial diagnosis) were used to determine prevalence as of that date. Ninety five per cent confidence intervals (95%) were estimated from the cumulative Poisson distribution.⁴ The influence of age, sex, time period, and certainty of diagnosis (definite or probable) and their possible interactions were assessed by analysis of variance, using a square root transformation of the individual
Table 1  Incidence of 'definite', 'probable' and total chronic ulcerative colitis among residents of Rochester, Minnesota, 1960–79

| Age group (yr) | Men | | | | Women | | | | Both sexes | | | |
|----------------|-----|---|---|---|-----|---|---|---|-----|---|---|---|---|---|
|                | N   | Rate* | N   | Rate* | N   | Rate* | N   | Rate* | N   | Rate* | N   | Rate* | N   | Rate* | N   | Rate* |
| <15            | 2   | 1.3  | 3   | 2.0  | 5   | 3.4  | 0   | 0    | 0   | 0    | 2   | 0.7  | 3   | 1.0  | 5   | 1.7  |
| 15–24          | 9   | 13.6 | 8   | 12.1 | 17  | 25.7 | 8   | 7.3  | 11  | 10.0 | 19  | 17.3 | 17  | 9.7  | 19  | 10.8 |
| 25–34          | 17  | 21.6 | 4   | 5.1  | 21  | 26.7 | 10  | 11.7 | 10  | 11.7 | 20  | 23.4 | 27  | 16.5 | 14  | 8.5  |
| 35–44          | 5   | 9.2  | 5   | 9.2  | 10  | 18.4 | 4   | 7.1  | 2   | 3.6  | 6   | 10.7 | 9   | 8.2  | 7   | 6.3  |
| 45–54          | 5   | 11.5 | 4   | 9.2  | 9   | 20.8 | 3   | 6.0  | 3   | 6.0  | 6   | 12.1 | 8   | 8.6  | 7   | 7.5  |
| 55–64          | 5   | 15.2 | 4   | 12.2 | 9   | 27.4 | 3   | 6.7  | 3   | 6.7  | 6   | 13.4 | 8   | 10.3 | 7   | 9.0  |
| 65–74          | 0   | —    | 2   | 9.7  | 2   | 9.7  | 1   | 2.8  | 2   | 5.6  | 3   | 8.5  | 1   | 1.8  | 4   | 7.1  |
| ≥75            | 1   | 7.5  | 1   | 7.5  | 2   | 15.0 | 0   | —    | 3   | 10.0 | 3   | 10.0 | 1   | 2.3  | 4   | 9.2  |
| Total          | 44  | 9.6  | 31  | 6.8  | 75  | 16.4 | 29  | 5.2  | 34  | 6.1  | 63  | 11.4 | 73  | 7.2  | 65  | 6.4  |
| Adjusted       | 10-4†| 7.8† | 18-2†| 5-6† | 11-9†| 7-9† | 7-0†| 15-0†|

*Incidence per 100,000 person years; incidence per 100,000 person years, directly age adjusted† or age and sex adjusted‡ to the population structure of United States whites in 1980.

Results

During the 20 year study period, 138 cases of chronic ulcerative colitis were newly diagnosed among Rochester, Minnesota residents. With about 1011 300 person years of observation, the overall crude incidence rate was 13.6 per 100 000 person years (age and sex adjusted, 15.0 per 100,000 person years; 95% confidence intervals 12.4–17.5). Age and sex adjusted incidence rates were not significantly different for the first (16.1 per 100,000 person years) and second (14.3 per 100,000 person years) decades of study. All patients were white, reflecting in part the racial composition of the community. Men with chronic ulcerative colitis outnumbered women 75 to 63. Male incidence rates were greater in each age group and overall (Table 1). The male:female ratio of total rates was 1.4:1, and this was accentuated somewhat to 1.5:1 by age adjustment (men, 18.2 per 100 000 person years versus women, 11.9 per 100,000 person years). Prevalence rates were also greater among men but only marginally so (Table 2). The overall age and sex adjusted prevalence of chronic ulcerative colitis in Rochester residents was 225.2 per 100,000 population on 1 January 1980 (95% confidence intervals 184.2–266.3), based on 120 cases.

Of the 138 incidence cases, 73 were definite and 65 were probable, as defined in Methods. Incidence

Table 2  Prevalence of chronic ulcerative colitis among residents of Rochester, Minnesota, on 1 January 1980

| Age group (yr) | Men | | | | Women | | | | Both sexes | | | |
|----------------|-----|---|---|---|-----|---|---|---|-----|---|---|---|---|---|
|                | N   | Rate* | N   | Rate* | N   | Rate* | N   | Rate* | N   | Rate* | N   | Rate* | N   | Rate* | N   | Rate* |
| <15            | 1   | 16-1 | 0   | —    | 1   | 8.2  | 1   | 8.2  |
| 15–24          | 4   | 82-2 | 4   | 61-2 | 8   | 70-1 | 32  | 297-5|
| 25–34          | 16  | 310-4| 16  | 285-7| 32  | 297-5|
| 35–44          | 13  | 401-2| 11  | 322-2| 24  | 360-7|
| 45–54          | 9   | 373-3| 10  | 387-3| 19  | 380-5|
| 55–64          | 7   | 357-5| 11  | 475-4| 18  | 421-3|
| 65–74          | 5   | 428-1| 7   | 340-6| 12  | 372-3|
| ≥75            | 2   | 251-3| 4   | 189-7| 6   | 206-5|
| Total          | 57  | 220-8| 63  | 205-7| 120 | 212-6|
| Adjusted       | 228-7†| 221-9†| 225-2†|

*Prevalence per 100,000 population on 1 January 1980; prevalence per 100,000 population on 1 January 1980, directly age adjusted† or age and sex adjusted‡ to the population structure of United States whites in 1980.

Fig. 1  Changes over time in age and sex adjusted incidence rates of 'definite' and 'probable' chronic ulcerative colitis among Rochester, Minnesota, residents, 1960–79.
rates for these two categories appeared to change in opposite directions over the study period (Fig. 1). More detailed analysis, however, indicated no statistically significant trend for probable cases. A borderline significant (p=0.06) trend for definite cases was due to a decline in rates among men only; rates for women with definite chronic ulcerative colitis actually increased slightly (trend×sex interaction, p<0.05). These inconsistencies make it difficult to draw any firm conclusions about secular changes. Overall, rates for definite and probable cases were similar (age and sex adjusted, 7.9 per 100 000 person years; 95% confidence intervals 6.1–9.8 v 7.0 per 100 000 person years; 95% confidence intervals 5.3–8.8, respectively).

Male predominance was most evident among the definite cases (Table 1). The incidence of definite chronic ulcerative colitis among men was nearly twice the comparable rate for women (age adjusted, 10.4 v 5.6 per 100 000 person years), while the difference between men (7.8 per 100 000 person years) and women (6.3 per 100 000 person years) in the age adjusted incidence of probable chronic ulcerative colitis was much less. Overall patterns of age specific incidence were somewhat similar for men and women within the two diagnosis groups (Fig. 2), except among the elderly where rates were based on few cases. While bimodality can be imagined for both the definite and probable groups, there was no statistical evidence of consistent bimodality (quartic trend, p>0.05) for either group or for either sex within each group. Some of the peaks, especially that for women ≥85 years old with probable chronic ulcerative colitis, may be artifacts of the age groupings.

Pancolitis comprised about a third of total cases, while proctitis and distal colitis made up most of the rest (Table 3). Male predominance in incidence was most marked for pancolitis and distal colitis. The sex specific incidence of segmental colitis and proctitis was equal, while females had slightly more right-sided disease. Definite cases were more likely to have pancolitis than to have disease at any other one site, and the incidence of pancolitis in the definite group was about equal to that of all other sites combined. In contrast, the majority of probable cases had disease limited to proctitis. Bimodality in incidence by age was not striking for pancolitis, although a major peak of pancolitis incidence was apparent in young adults.
Disease of the distal bowel, on the other hand, was relatively more common later in life.

About three-fourths of cases were mild or transient and only one-fourth were moderate or severe (Table 4). The incidence of severe, moderate, and mild chronic ulcerative colitis was greater in men than women; but women had more transient disease. As there could be no definite cases in the transient group, and as a definite diagnosis required documentation of disease at least twice in a time span of six months or more, it follows that patients with more severe disease were more likely to be definite cases. Despite this, mild disease accounted for the majority of definite cases.

Discussion

Because of access to a comprehensive medical record linkage and indexing system, we believe our data incorporate all cases of ulcerative colitis diagnosed among Rochester residents during the time of the study. Rates most similar to those in Rochester were obtained from comparable studies based on all diagnosed cases (outpatient as well as inpatient) in England and Scotland (Table 5). In north eastern England, the average annual incidence was 15·1 per 100 000 population per year if both ulcerative colitis and distal proctitis were included.1 In north eastern Scotland, Sinclair and colleagues5 found an overall incidence of 11·3 per 100 000 per year; but rates were less in rural than in urban areas. The incidence in urban Aberdeen, 14·4 per 100 000 per year, was very close to that in Rochester. The Rochester age and sex specific incidence rates, if projected to the United States population in 1980, suggest an occurrence of over 28 000 new cases annually in whites. An additional 5000 cases would be expected in non-whites if the Rochester rates, based largely on whites, were applicable to that group.

Other studies from England,7-8 Germany,7 and Scandinavia,10-13 however, found incidence rates only about half as great as ours. This discrepancy may be due to a number of factors. First, such rates might be artificially low if mildly affected patients were incompletely ascertained. This was believed to be the case in some7 8 11 if not all studies14 but other authors discounted this possibility.12 Second, it has been
suggested that the incidence of chronic ulcerative colitis is rising, although not all have found this. This implies that lower rates would be found in earlier studies. Indeed, a previous study in Rochester found an overall incidence (excluding Crohn’s disease and discontinous or segmental chronic ulcerative colitis) of 9.7 per 100,000 person years in 1935–64. No additional increase was seen, however, between 1960–69 and 1970–79 in the present study.

A third, and more likely, explanation lies in different diagnostic criteria. In order to include all cases of chronic ulcerative colitis among Rochester residents, we designated a category of patients with a probable but less well documented diagnosis of chronic ulcerative colitis. To the extent that some of these individuals may not really have had chronic ulcerative colitis, our rates might be too high. We do not believe, however, that our results are more liable to this bias than those from other investigators. For example, the recognition of infectious colitis presenting with clinical features identical to chronic ulcerative colitis has increased in recent years. Although it was impossible for us to completely exclude a specific infection, even if cultures were negative, the likelihood of including such cases should have been less than in some older series. On the other hand, we felt that the requirement for a six months’ span of active disease was the most logical definition of a ‘definite’ diagnosis. Clearly, our breakdown into ‘probables’ and ‘definites’ can be interpreted as indicating maximal and minimal rates.

Conversely, restricting the study to definite cases only should cause the resulting rates to be too low. Other studies in which definite, probable and/or possible cases were defined used different criteria from ours. Whereas we required two objective documentations of disease ≥ six months apart for a definite diagnosis, the other studies generally required only one objective documentation plus a history of diarrhoea and/or rectal bleeding for ≥ six weeks. A ‘definite’ diagnosis in other studies usually indicated that other conditions were ruled out with a moderate to high degree of certainty; this was also true for cases of chronic ulcerative colitis accepted for the present study. Indeed, the diagnostic criteria from studies that did not distinguish such categories best match our criteria for ‘probable’ chronic ulcerative colitis.

Thus, when comparing various studies, it is best to refer to the combined (definite and probable) data from our study, as is done here.

Finally, studies based solely on hospitalised cases consistently produce low incidence rates (Table 5). This is not surprising as only 46% of our cases, for example, were hospitalised at any time during the study period. The Rochester prevalence rates on 1 January 1980, if projected to the total United States population in 1980, suggest that there may be nearly 500,000 individuals in the population at any one time who have a history of chronic ulcerative colitis. There were only 71,000 hospital discharges for all ‘chronic enteritis and ulcerative colitis’ together, however, in 1978 and only 23,000 for ulcerative colitis specifically. The incidence of hospitalisations (not individuals) for ulcerative colitis as a first listed diagnosis was 10.9 per 100,000 in that year. Other data show that the number of hospitalisations is about twice as great as the number of individual patients involved, and many patients are not hospitalised at all.

The prevalence of chronic ulcerative colitis in Rochester was substantially greater than that reported elsewhere (Table 6), although the ratio of...
prevalence to incidence of 15:6:1 was not unlike the 12:1 ratio described by others.35 Reasons for the higher prevalence rate may be the same as for the higher incidence rate, namely differences in definitions and underascertainment of cases elsewhere. The latter is especially important in prevalence (strictly, the prevalence of a history of the disease) because patients who have had the disease in the past but are no longer seeking care for it may be missed if the study period is relatively short.30 Thus, the prevalence of chronic ulcerative colitis was nearly three times greater in Copenhagen in 1978 after 17 years of study than it was in 1967 after only seven years.13 For the purpose of identifying prevalence cases, we could take advantage of a previous study extending back to 193517 so ascertainment of cases should have been largely complete. In addition, some studies calculated prevalence rates using only the prevalent cases that were also incidence cases, rather than all prevalent cases in the population regardless of time and place of onset;57 this approach artificially lowers the prevalence rate. Moreover, if incidence rates have risen somewhat and if survival after the diagnosis of chronic ulcerative colitis has improved,6 it should also be expected that prevalence would increase over time, as prevalence is a function of both frequency and duration of disease.

We found greater incidence rates among men than women, as have some other investigators.13 17 23 Most, however, have found greater rates among women,55 10 although differences are not striking. Whether these discrepancies reflect real differences in risk or only variations in reporting or in the use of medical services is unclear. With regard to sex specific differences in prevalence of disease, it is also unclear why men tended to have more pancolitis than women; but this may explain why the incidence of definite chronic ulcerative colitis was higher in men (because pancolitis tended to lead to a definite diagnosis). For both sexes, we found a distribution of chronic ulcerative colitis incidence with age that was roughly bimodal, as have most others.55 It is interesting that for disease of greater extent and severity, the older age group peak is less apparent. On the other hand, older subjects showed a predominance of mild disease, often in the form of proctitis. This may be because older patients are less likely to develop extensive and severe disease before death, because younger people actually tend to have more extensive and severe disease than those who develop chronic ulcerative colitis later in life, or because the mild disease of older persons is of different aetiology than the more severe disease of younger persons.

With regard to the severity of disease, it is important to note that the majority of patients had relatively mild disease. This is confirmatory of other population based studies, and consistent with the interpretation that data from referral centres are biased towards more severe disease. This bias is expressed more clearly in the extent of the disease. Proctitis does not usually manifest itself with major constitutional symptoms or blood loss and is frequently more a recurrent annoyance than a major disease. Many such patients are diagnosed and treated locally, without referral for subspecialist opinion. We assigned to the definite group those who had documented proximal spread of disease from an initial proctitis; these patients would fulfill conventional criteria for a diagnosis of chronic ulcerative colitis. We also designated as ‘definite’ well documented recurrent proctitis without proximal spread. In this instance, doubt has been raised as to whether or not this represents chronic ulcerative colitis or another disease.52 Despite these definitions, there was still a preponderance of proctitis in the ‘probable’ group, and it is impossible to say at this time whether these represent individuals whose disease will spread (to become chronic ulcerative colitis) or whether they represent another entity (‘non-specific proctitis’).

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References

CUC incidence and prevalence


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