

Juvenile-onset inflammatory bowel disease: predictors of morbidity and health status in early adult life

ABSTRACT—We interviewed and examined 70 young adults (50 Crohn's disease, 20 ulcerative colitis) from a geographically derived cohort of patients with juvenile-onset (≤ 16 years) inflammatory bowel disease at a mean of 14 years (range 5.2–29.5) after diagnosis. Patients with initially ileo-colonic Crohn's disease spent significantly longer in hospital than other groups. Thirty-nine Crohn's disease and 10 ulcerative colitis patients have had major surgery, with permanent stomas in 15 cases of Crohn's disease and seven of ulcerative colitis. In Crohn's disease the disease was still active at the time of review in 16 of 50 patients (10 of 20 women), whereas only two of the 20 patients with ulcerative colitis had active disease. The data show that the high early morbidity of juvenile-onset inflammatory bowel disease continues into adult life, with particularly severe and disabling manifestations in women with Crohn's disease.

Several important clinical and prognostic facets of inflammatory bowel disease (IBD) in children remain unresolved. Reports from referral centres are generally disheartening, highlighting an aggressive natural history, growth failure, higher cancer incidence than in adults with IBD, and significant mortality [1]. However, patients referred to academic institutes or centres with special expertise in this subject are unlikely to be typical of the general body of patients with IBD and, ideally, definitive studies of disease severity and natural history should be undertaken in population-based cohorts.

The Scottish Hospitals Inpatients Statistics (SHIPS) system is a unique epidemiological facility which we used to derive a geographically based sample of 105 patients with juvenile-onset IBD [1,2]. After a mean follow-up interval of 7.2 years we reported [1,3–5] that their clinical features and the high early morbidity and mortality were much the same as those found by others. Furthermore, some unexpected disease- and sex-specific differences in morbidity emerged. Five of the six deaths were in Crohn's disease (CD) patients; sur-

gical intervention and growth failure were more frequent in CD than in ulcerative colitis (UC); weight retardation in CD was more commonly observed in girls than in boys; surgical intervention in CD was highest in patients who had ileo-colonic involvement at the time of presentation, and lower in those who had had disease originally confined to the colon.

We have now undertaken a further review of this unique series of patients to establish their state of health in young adult life, and to assess whether there are subgroups with particularly good or bad prognoses, reflected in chronically active disease, ultimate height achieved, time spent in hospital, frequency of surgical intervention, creation of a permanent stoma, and mortality. Six of the original cohort of 105 patients had died and seven are known to have emigrated. The remaining 92 have been traced and 74 (70 adults and four children) have been seen and examined. This report concerns the health status of the 70 young adults, at a mean of 14 years (range 5.2–29.5) after they developed IBD.

Methods

Identification and tracing of cases

As previously described [1], our sample of 105 patients comprised patients admitted to a National Health Service (NHS) hospital in Scotland between 1968 and 1983, in whom the diagnosis was coded as CD (ICD 555.0–555.9) or UC (ICD 556.0); who fulfilled diagnostic criteria for one or other of these diseases; who had developed symptoms of IBD before they reached the age of 17; and who were resident in two of the 11 Scottish regions, Lothian (mainly urban), Highland (rural), or, for CD only, who were in a 10% sample of cases from the rest of Scotland. Subgroup analyses showed no differences between the 10% sample, Lothian and Highland sub-groups; accordingly all data were combined.

Patients were traced via hospital records, parents, general practitioners (GPs), and from NHS regional records. With the agreement of the hospital consultant or GP, they were contacted by letter and invited to attend for clinical assessment. For those unwilling to attend, we evaluated their current health status by a telephone interview with either the patient or a parent. The protocol was approved by the Lothian region research ethics committee.

ANNE FERGUSON, PhD, FRCP, FRCPATH, FRSE
Professor of Gastroenterology, University of Edinburgh
DAVID M SEDGWICK, FRCS (Ed)
Consultant Surgeon, Belford Hospital, Fort William

Distribution of disease at presentation

Macroscopic distribution of disease at the time of diagnosis was established from clinical descriptions, operative, radiological, and pathological reports. For CD we designated four categories: orofacial; small bowel; both small and large bowel affected (ileo-colonic); and colonic. Genital, peri-anal, and other extra-intestinal disease were noted separately. For UC the subdivisions were rectal, left-sided (upper limit of disease distal to the mid-transverse colon), and extensive.

Clinical review

Hospital case notes were examined for data on the patient's general progress, operations, the development of other diseases related or unrelated to IBD, the use of drugs and nutritional therapy. A decision was again made as to whether, on the basis of events that had taken place since the earlier study, the patient's diagnostic criteria for CD or UC were fulfilled.

With the agreement of the hospital consultant or GP, patients were contacted by letter and were invited to attend for clinical assessment.

At the time of the clinical interview:

- (a) the accuracy of the information derived from hospital records was checked;
- (b) patient's current symptoms were defined;
- (c) a clinical examination was performed;
- (d) blood samples were taken for a range of haematological and clinical chemistry tests;
- (e) the Crohn's disease activity index (CDAI) [6] was calculated (in both CD and UC cases), the patient having completed a symptom diary for the seven days preceding the interview. For patients who had a stoma, 'number of loose stools' on the diary card was taken as the number of times the patient emptied liquid faeces from the ileostomy bag;
- (f) information on education and employment was collected;
- (g) the patient was given the opportunity to express views on the impact of IBD on his/her current physical, emotional, and social well-being.

Statistics

Student's t-test, analysis of variance and the chi-square test were used for comparisons between CD and UC cases, and for assessment of the observed sex- and site-specific differences.

Results*Follow-up of patients from the 1968-83 geographically based sample*

Six of the original cohort of 105 IBD patients have died, five are known to have emigrated during the

1970s, and a further two emigrated in 1982 and 1985. The remaining 92 have all been traced and were alive in January 1991.

Since our previous review, the diagnosis in one UC patient was revised to CD, and two CD patients were redesignated as UC. A further patient with UC fell out with the age criteria for the study, because the age at onset of symptoms had been wrongly recorded in the hospital records. Four of the sample (one CD, three UC) were still children under 18 years of age. Thus 87 adults were eligible for review, of whom 70 (50 CD, 20 UC) were seen and examined. The remaining 10 CD and seven UC adults were contacted by telephone.

Details of patients interviewed or traced

As shown in Table 1, for CD the groups of patients interviewed and those traced but contacted only by telephone were quite comparable, whereas for UC those who declined to attend for clinical examination were predominantly men with less extensive disease at presentation. Thus the patients described below are likely to represent the full spectrum of juvenile-onset CD, but for juvenile-onset UC they are weighted in favour of the more severely affected cases.

Information on age at diagnosis and at interview is given in Table 2.

General morbidity as reflected in hospital admissions

The amount of time spent as a hospital inpatient was similar for CD (mean 6.6 admissions, 102 days) and UC (mean 6.4 admissions, 93 days) (Table 1), and for men and women. However, disease distribution at presentation of CD had a significant influence (Fig 1). Patients with ileo-colonic disease had spent a mean of 10.6 (SD \pm 7.2) days in hospital for each year of follow-up, significantly longer ($p < 0.03$) than the time spent by patients in whom disease had been confined to the small bowel (4.8 ± 4.2) or colon (7.5 ± 4.9) when the disease first presented.

Other diseases

Twelve of the 50 CD patients had significant extra-intestinal symptoms when IBD was active, involving the mouth (eight cases), joints (seven), eyes (five) and skin (five). In four of these 12 patients, and in three others, significant diseases unrelated to IBD were present: asthma in two, and one case each of eczema, duodenal ulcer (which had required vagotomy and gastroenterostomy), bilateral renal calculi, epilepsy, and psoriasis.

Four of the 20 UC patients reported extra-intestinal symptoms in the mouth (one), joints (four), eyes (one), and skin (one). One of these patients was badly crippled by ankylosing spondylitis, and another was virtually blind with steroid-induced cataracts. Four others

Table 1. Demographic and clinical details of IBD patients with Crohn's disease or Ulcerative colitis seen and examined, or interviewed by telephone

	Crohn's Disease	
	Clinical assessment	Telephone contact
Number of cases	50	10
Men:women	28:22	3:7
Year of birth (range)	1953-70	1960-73
Year of onset (range)	1960-83	1976-83
Disease distribution at onset:		
orofacial	2	1
small bowel	14	3
small bowel and colon	22	4
colon	12	2
Length of follow-up from onset (years):		
mean \pm SD	13.4 \pm 4.8	10.0 \pm 2.5
range	6.1-29.5	4.7 \pm 13.8
Days in hospital:		
mean \pm SD	102.5 \pm 85.6	122.8 \pm 149.7
range	7-483	9-512
Number of hospital admissions:		
mean \pm SD	6.6 \pm 4.1	5.2 \pm 5.3
range	1-20	1-19
One or more major operations	39	4
Permanent stoma	15	1
Patient's view of general health:		
well	31	6
reasonable	13	1
ill	6	3
	Ulcerative colitis	
	Clinical assessment	Telephone contact
Number of cases	20	7
Men:women	9:11	5:2
Year of birth (range)	1952-72	1959-67
Year of onset (range)	1967-82	1974-83
Disease distribution at onset:		
rectal	2	3
left-sided	3	3
extensive/total	15	1
Length of follow-up from onset (years):		
mean \pm SD	14.6 \pm 5.5	8.4 \pm 3.5
range	5.2-23.1	5.4-15.3
Days in hospital:		
mean \pm SD	93.4 \pm 70.7	65.4 \pm 96.1
range	7-294	3-275
Number of hospital admissions:		
mean \pm SD	6.4 \pm 4.9	3.2 \pm 2.5
range	1-21	1-8
One or more major operations	10	2
Permanent stoma	7	2
Patient's view of general health:		
well	17	7
reasonable	1	0
ill	2	0

Table 2. Age at onset of symptoms of inflammatory bowel disease and at clinical assessment, in 70 young adults (mean±SD, range)

	Crohn's disease	Ulcerative colitis
Age at onset	12.9 ± 3.3 (2.2–16.9)	12.2 ± 3.6 (3.6–16.4)
Age at assessment	26.3 ± 4.5 (18.9–35.6)	27.2 ± 6.1 (18.2–38.3)

suffered from epilepsy, renal calculi, asthma, and gastro-oesophageal reflux respectively.

No patient in the series had chronic liver disease, malignancy, milk protein intolerance, lactose intolerance or coeliac disease.

Three of the 70 patients were severely disabled but in only one case was this directly due to IBD—a woman with CD and duodenal ulcer who has had multiple resections leading to intestinal failure. One UC man was badly crippled by ankylosing spondylitis and one UC woman had an iatrogenic disability, blindness due to steroid-related cataracts.

Medical treatments used

Pharmacological and nutritional treatments prescribed are summarised in Table 3; pattern of use is similar to that used in the treatment of adult IBD patients in the period under review. Sulphasalazine or a derivative was used in 84% of CD and 95% of UC patients, and systemic corticosteroids in 72% CD and 60% UC. Relatively few were treated with second-line,

Table 3. Previous non-surgical or nutritional therapy for inflammatory bowel disease.

	Number of patients receiving treatment at some time prior to assessment	
	Crohn's disease (n = 50)	Ulcerative colitis (n = 20)
Rectal corticosteroids	12	13
Sulphasalazine or mesalazine	42	19
Oral corticosteroids	36	12
Azathioprine	9	1
Elemental diet	8	0
Total parenteral nutrition	4	0

steroid-sparing modalities. No patients had been given growth hormone or testosterone therapy.

Surgery

Ten UC patients and 39 CD patients have had one or more major operations performed (Table 4), the number of procedures ranging from one to seven. Frequency of surgical intervention was similar for men and women, and for the main categories of disease distribution at onset. No surgery was required in the two patients who presented with oro-facial CD and the two whose UC was originally confined to the rectum.

Seven UC patients and 15 CD patients have a permanent stoma; in addition, one man and one woman

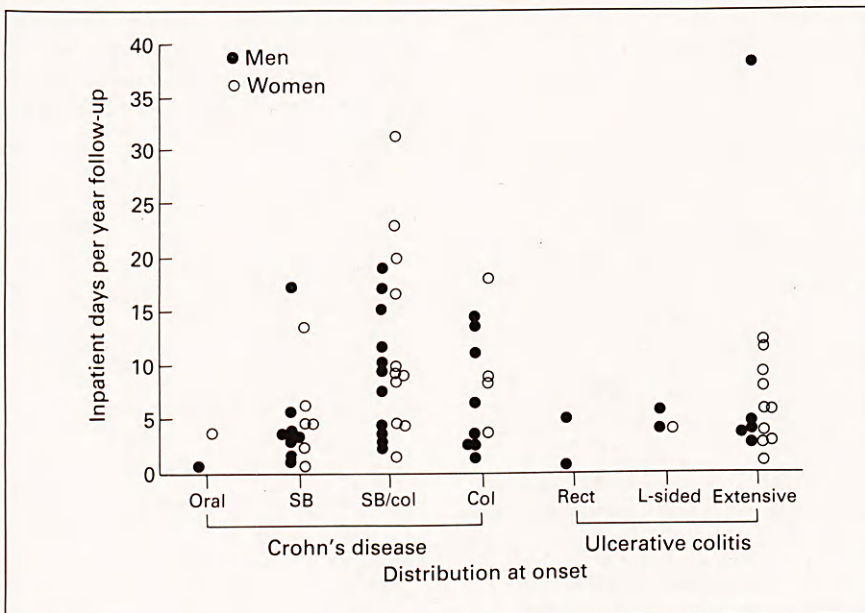


Fig 1. Number of days spent as hospital inpatients, per year follow-up from diagnosis, in 50 patients with juvenile-onset Crohn's disease or ulcerative colitis, subdivided according to the distribution of macroscopic disease at the time of diagnosis.

Table 4. Numbers of patients who have had major surgery or have a permanent stoma

	Number eligible	One or more major ops	Permanent stoma
Crohn's disease			
Men	28	21	8
Women	22	18 NS	7 NS
Distribution at onset			
orofacial	2	0	0
small bowel	14	12	2 $p < 0.05$
ileo-colonic	22	18 NS	7
colon	12	9	6
Perianal disease at onset			
absent	32	26	6 $p < 0.05$
present	18	13 NS	9
Ulcerative colitis			
Men	9	4	3
Women	11	6 NS	4 NS
Distribution at onset:			
rectal	2	0	0
left-sided	3	1	1
extensive	15	9 NS	6 NS

with UC have had colectomy with construction of a pelvic ileal reservoir. Patients with CD showed an obvious relationship between disease distribution at the time of their first symptoms of IBD and the creation of a permanent stoma during the period of follow-up.

Fifty per cent of the 12 patients whose disease was confined to the colon now have a stoma, as do 50% of those who had peri-anal disease at presentation. Four of the six patients with both colonic distribution and peri-anal disease at onset now have a stoma, as do four of the seven with ileo-colonic and peri-anal disease at presentation.

Current health status

This was assessed in several ways.

- (a) *Crohn's disease activity index (CDAI).* Values for CDAI are shown in Figure 2. For CD, a CDAI > 150, signifying active disease, was found in 10 of the 22 women but in only six of the 28 men. Overall, CDAI values were significantly higher for women than for men with CD ($p < 0.05$). The CDAI was also calculated for the UC patients, and was > 150 in only two cases. However, the absolute figures for CDAI in patients with UC must be interpreted with caution since the index was not designed to be applied in UC.
- (b) *Patient's view of his/her general health.* Of the patients with CD, 21 of 28 men considered themselves to be in perfect health, six reasonably well, and one currently in poor health (he had recently developed obstructive symptoms after a long clinical remission). In contrast, only 10 of 22 women reported good general health, seven felt reasonably well, and five considered themselves chronically ill (Table 1). The differences between men and women were significant ($p = 0.05$). These subjective reports correlated with CDAI values: all the

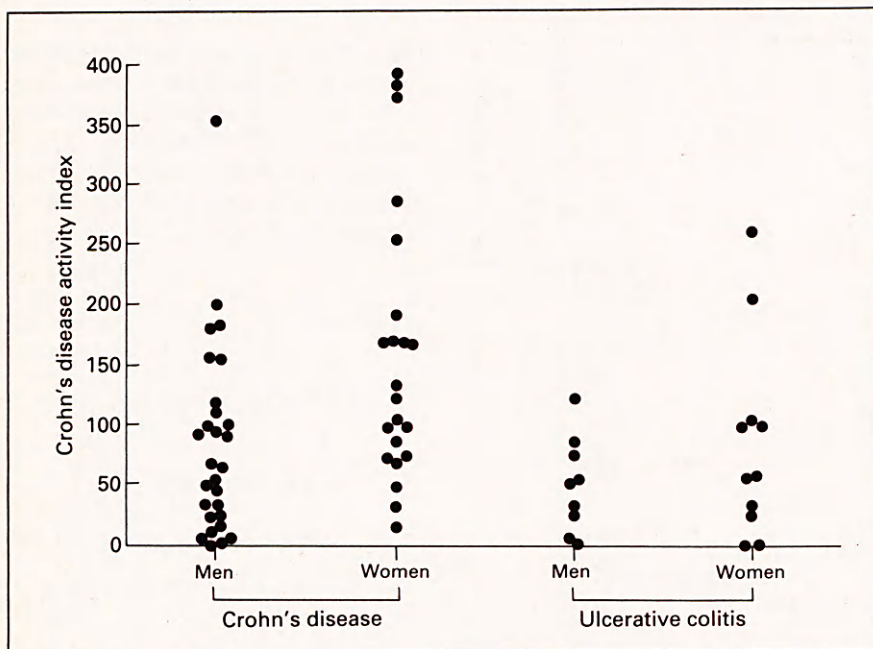


Fig 2. Crohn's disease activity index at the time of clinical assessment, a mean of 14 years after diagnosis, in 50 patients with juvenile-onset Crohn's disease and 20 with juvenile-onset ulcerative colitis.

'ill' patients and eight of those reporting reasonable health had high CDAI values, whereas only two of those who considered themselves healthy had high CDAI values. Only two of the UC patients reported poor health, and 17 of the 20 considered themselves to be entirely well.

- (c) *Current symptoms.* In the CD group only six patients complained of abdominal pain, but of the 35 patients who did not have a stoma 15 had significant diarrhoea and six admitted to faecal incontinence at times. None of the UC patients reported abdominal pain, and three of the 13 without a stoma had diarrhoea—one with recently relapsed proctitis, one with chronic UC symptoms, and a patient who had had colectomy with ileo-rectal anastomosis.
- (d) *Current therapy.* Seven CD patients were taking oral prednisolone, 5–15 mg/day, one CD patient was using a rectal steroid preparation, three were on azathioprine, and 19 were on sulphasalazine or a related drug. Most of the CD patients were taking a normal diet but one was on home total parenteral nutrition (TPN). One UC patient was taking oral prednisolone, 15 mg/day, two were using rectal steroids, and six were taking sulphasalazine or a derivative.
- (e) *Anaemia.* In the CD group, five men were technically anaemic (Hb < 13.0 g/dl), the lowest value being 11.5 g/dl, and five women were anaemic, with Hb in the range 10–11.5 g/dl. Serum B₁₂ and folate levels were normal in the 48 patients in whom they were assayed, but serum iron levels were low in 14 of 26 men and 17 of 22 women with CD. Of the 20 UC patients, only one woman was anaemic (Hb 10.4 g/dl); three women and two men had low serum iron levels.

- (f) *Hypoproteinaemia.* Plasma levels of serum albumin were normal in 46 of the 50 CD patients, and in all the UC cases.

Height, weight, and sexual development

Records of growth and development were incomplete and no formal attempt was made to assess the timings of growth spurt or the stages of puberty. However, when asked if they had developed at the same time as their peers, 11 of the 28 CD men and 13 of the 22 CD women reported delayed development; for UC the figures were two of nine men and three of 11 women. Differences between CD and UC were not significant in this respect. On clinical examination, all patients had normal external genitalia. Vaginal examination was not performed.

Details of height, weight, and body-mass index (BMI), weight (kg)/height (m)² measurements are described and discussed in full elsewhere [7]. There were three abnormally short CD women. All other patients in both groups were in the normal adult range for height. However, compared with the general population, BMI distribution was significantly skewed towards low values in men and women with CD (both *p* < 0.01), but was normal in UC men and women. Within CD, neither sex nor disease distribution was associated with the low values of BMI (Fig 3).

Although relative weight for height is a factor used in the calculation of the CDAI [6], low BMI was not specifically a feature of active disease. In the CD patients, BMI in men with active disease ranged from 14.9 to 27.1; with inactive disease from 16 to 25.6; in women with active disease it ranged from 16 to 24.7; and with inactive disease from 13.1 to 31.7 [7].

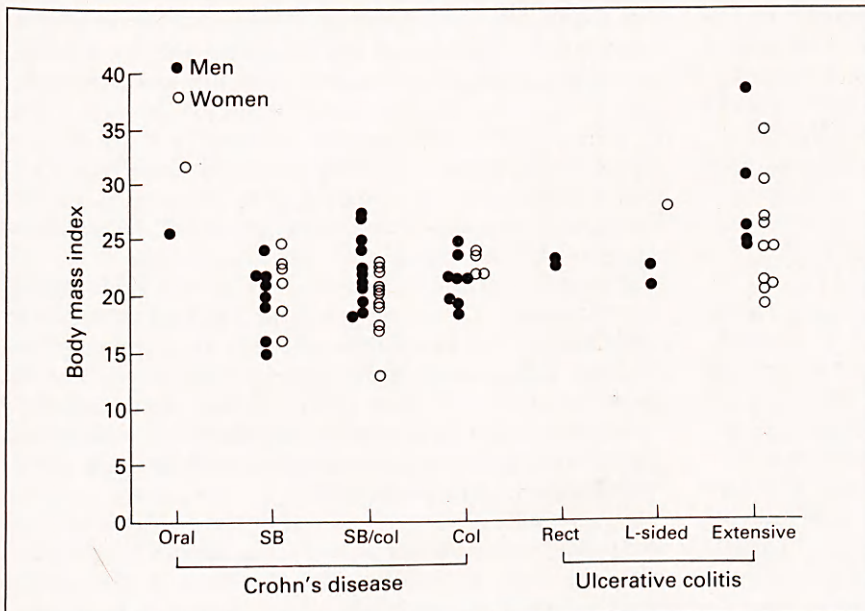


Fig 3. Body mass index at the time of clinical assessment, a mean of 14 years after diagnosis, in 50 patients with juvenile-onset Crohn's disease and 20 with juvenile-onset ulcerative colitis, subdivided according to the distribution of macroscopic disease at the time of presentation.

Menstrual problems and fertility

An unexpected finding was the high prevalence of menstrual problems in CD patients, comprising menorrhagia, severe dysmenorrhoea, and long periods of amenorrhoea (Table 5). The few pregnancies had been uneventful; one CD woman was infertile and judged unsuitable for attempts at assisted conception because of pelvic adhesions; at least one other young woman in this group (as yet unmarried), who has had seven abdominal operations, is also known to have extensive and severe pelvic adhesions.

Education and employment

Full details of education and employment are published elsewhere [8]. Thirty CD patients and 10 UC patients considered that their education had been adversely affected by their disease. Despite this, they performed as well as healthy children in the examinations held in Scotland at age 15–16 (O grades)—passes in five or more subjects are obtained by 51% of the general population, the figures for those with CD and UC being 54% and 45% respectively. Only four CD and two UC patients were unemployed, although 48% CD patients and 25% UC patients considered that IBD had created problems in employment and career prospects.

Deaths

In the first description of this series of patients, prepared in 1987, we reported that between 1970 and 1978 there had been five deaths in CD patients and one in a UC patient [2]. There had been no further deaths when data collection for this study was completed in January 1991. However, one patient has since died, in May 1992. She had presented at the age of 13 with ileo-colonic CD, and later had resections of the terminal ileum and sigmoid colon. She had severe recurrent disease at a low colo-rectal anastomosis communicating with a chronic pelvic abscess, and withheld consent for surgery (procto-colectomy with ileostomy) until she was moribund; she died four weeks postoperatively.

Discussion

Children and adolescents with significant or chronic gastrointestinal symptoms are almost invariably referred to NHS hospital consultants for investigation and treatment, and if admitted even as a day case, will be recorded in the SHIPS database. These circumstances, together with the spirit of cooperation within the medical community in Scotland, greatly facilitate studies of the epidemiology and natural history of chronic diseases in children. Our group of young IBD patients is unique in being geographically derived rather than a personal or hospital-based series, and we

Table 5. Menstrual and fertility problems in adult women with juvenile-onset inflammatory bowel disease

	Crohn's disease (n = 22)	Ulcerative colitis (n = 11)
None	7	9
Prolonged amenorrhoea	8	1
Menorrhagia/pain	7	1
Married/cohabit	10	3
One or more pregnancies	6	3
Infertile (10 yrs)	1	–

are not aware of any reports on morbidity and outcome with a comparable follow-up interval.

Our original cohorts of children with CD and UC were derived by sampling, on the basis of home address and ICD code, from the complete Scottish inpatients data base for the years 1968–83. It is possible that our series has therefore failed to include patients with IBD so mild that they have been diagnosed and treated exclusively as outpatients. However, we have good reason to believe that such patients are very few, if any. We identified 101 relevant cases from the SHIPS data on patients aged 16 years or less; screening the case notes of a further 110 patients aged 17–20 on first admission with IBD, and who fulfilled the geographic criteria, produced only four additional cases. No further eligible patients have been detected in the course of a follow-up audit of a new set of young IBD patients from 1984–89, and none have been seen in our regional and referral practice.

We have follow-up information on all the survivors of the original series who still live in the UK. For CD, the 50 patients interviewed and examined are likely to represent the full spectrum of the disease as it was seen in the 1970s and early 1980s, but the 20 UC patients generally had more severe disease than average.

When we first reviewed the original cohort of 105 cases, we reported six deaths, all during the 1970s. The one further death in a woman with CD need not have occurred, and was due to her refusal to consent to surgery with the creation of a stoma.

Overall morbidity, as reflected by the number of hospital admissions, was similar for CD (mean 6.6 admissions) and UC (mean 6.4). But the group of ileo-colonic CD patients spent significantly more time in hospital than did other groups. Ileo-colonic disease has been recognised by other workers as having a less good outcome; it is, for example, associated with early postoperative recurrence [9].

There is little worthy of comment in the medical treatments used. Azathioprine and primary nutritional therapy were rarely used, but this reflects prevailing practice during the period under review. A high pro-

portion of the patients (78% CD, 50% UC) have been treated surgically. These figures are typical of UK centres [3], and reflect more frequent recourse to surgery than in series reported from North America. Of 100 IBD children from Toronto, 36% had had an intestinal resection at 4.9 years follow-up [10]; at 10-year follow-up of 38 CD children from New York, only 42% had been treated surgically [11].

Most reports of growth and development in young people with IBD have emphasised retardation of sexual maturation and of linear (height) growth (reviewed by Kirschner [12]). Reassuringly, we can now report that for both CD and UC and for men and women, 67 of the 70 young people ultimately achieved normal adult height. These results are strikingly different from the only comparable series in the literature, a series from New York in which 37% of patients had a deficit of final adult height [11]. Whether or not the higher rate of surgical intervention in the UK is linked to the excellent outcome in terms of final height achieved remains to be established. The creation of a permanent stoma is a major event, particularly in the young. Permanent stoma rates in this series are 30% for CD, 35% for UC. In CD, 50% of those who presented either with disease confined to the colon or with perianal disease now have a permanent stoma.

Chronic high-volume diarrhoea (15 cases) and faecal incontinence (six cases) were the main complaints of CD patients, affecting 43% and 17% respectively of those who did not have a stoma; two of the UC patients had bloody diarrhoea at the time of assessment, and one other had a high faecal output due to ileo-rectal anastomosis. In all but two of the 70 patients, symptoms and general health at the time of clinical assessment were representative of their usual status. An unexpected finding has been the high proportion of women with CD who have had significant menstrual problems. So far, only one has been found to be infertile because of pelvic adhesions, but in view of the complex surgical histories of several other patients, more patients with this distressing and generally unrecognised complication of IBD and abdominal surgery may emerge.

Calculation of the CDAI and patients' freely expressed view of their general health gave broadly the same results. Only two of 20 UC patients were ill (one recently relapsed), in contrast to the high and sex-related morbidity in CD, when 23% of CD women, but only one of 28 CD men, considered themselves to be chronically unwell. This sex difference was also found in a survey of members of the Crohn's and Colitis Foundation of America [13]. Women with IBD were more severely affected than men, particularly in their perceptions of the impact of disease (being a burden on others, loss of energy, incontinence) and body stigma (feeling dirty or smelly).

This paper highlights the contrast between the disabilities of CD and UC, and the fact that women with

juvenile-onset CD are much more severely affected than men. Yet despite distressing symptoms such as diarrhoea, faecal incontinence and abdominal pain, we found the general demeanour of these young adults to be remarkably positive and their hopes and plans, both personal and work-related, virtually identical with those of healthy individuals of their generation.

Acknowledgements

We are grateful to the clinicians who allowed us to examine their patients, and to medical records officers in hospitals throughout Scotland. We acknowledge the help and advice of Dr J Clarke and his staff in the Common Services Agency, and the assistance of Mrs Jean Drummond in collating the data. This work is supported by CICRA (Crohn's in Childhood Research Association), and the Edinburgh Intestinal Immunology Research Fund.

References

- 1 Barton JR, Gillon S, Ferguson A. Incidence of inflammatory bowel disease in Scottish children between 1968 and 1983; marginal fall in ulcerative colitis, threefold rise in Crohn's disease. *Gut* 1989;**30**:618-22.
- 2 Barton JR, Ferguson A. Clinical features, morbidity and mortality of Scottish children with inflammatory bowel disease. *Q J Med* 1990;**75**:423-39.
- 3 Sedgwick DM, Barton JR, Hamer-Hodges DW, Nixon SJ, Ferguson A. Population-based study of surgery in juvenile onset Crohn's disease. *Br J Surg* 1991;**78**:171-5.
- 4 Sedgwick DM, Barton JR, Hamer-Hodges DW, Nixon SJ, Ferguson A. Population-based study of surgery in juvenile onset ulcerative colitis. *Br J Surg* 1991;**78**:176-8.
- 5 Barton JR, Ferguson A. Failure to record variables of growth and development in children with inflammatory bowel disease. *Br Med J* 1989;**298**:865-6.
- 6 Best WR, Becktel JM, Singleton JW, Kern F. Development of a Crohn's disease activity index: National Cooperative Crohn's Disease Study. *Gastroenterology* 1976;**70**:439-44.
- 7 Ferguson A, Sedgwick DM. Juvenile-onset inflammatory bowel disease, height and body mass index in adult life. *Br Med J* (in press).
- 8 Ferguson A, Sedgwick DM, Drummond J. Morbidity of juvenile-onset inflammatory bowel disease: effects on education and employment in early adult life. *Gut* (in press).
- 9 Griffiths AM, Wesson DE, Shandling B, Corey M, Sherman PM. Factors influencing postoperative recurrence of Crohn's disease in childhood. *Gut* 1991;**32**:491-5.
- 10 Griffiths AM, Nguyen P, Smith C, MacMillan JH, Sherman PM. Growth and clinical course of children with Crohn's disease. *Gut* 1993;**34**:939-43.
- 11 Markowitz J, Grancher K, Rosa J, Aiges H, Daum F. Growth failure in pediatric inflammatory bowel disease. *J Pediatr Gastroenterol Nutr* 1993;**16**:373-80.
- 12 Kirschner BS. Growth and development in chronic inflammatory bowel disease. *Acta Paediatr Scand* 1990;**366**(suppl):98-104.
- 13 Drossman DA, Leserman J, Li Z, Mitchell CD, et al. The rating form of IBD patient concerns: a new measure of health status. *Psychosom Med* 1991;**53**:701-12.

Address for correspondence: Professor A Ferguson, Gastro-Intestinal Unit, Western General Hospital, Crewe Road, Edinburgh EH4 2XU.