

Alimentary tract and pancreas

Life prospects and quality of life in patients with Crohn's disease

V Z SØRENSEN, B G OLSEN, AND V BINDER

From Medical-Gastroenterological Department C, Herlev Hospital, University of Copenhagen, Herlev, Denmark

SUMMARY A regional prevalence group of 106 patients with Crohn's disease were interviewed about their familial, social, and professional conditions. The results were compared with results from similar interviews of an age and sex matched control group of 75 previously healthy patients admitted to the hospital for acute diseases of less than 28 days' duration. An equal percentage of the patients and the controls were married (67% vs 71%) and had become parents (68% vs 79%). The number of children was slightly lower among Crohn's disease patients. The occurrence of familial problems and sexual problems did not differ among patients and controls. The intake of sedatives was low in both groups and no difference was found in alcohol and tobacco intake between patients and controls. A combined score for social activities comprising cultural, sporting, educational and private social arrangements showed that about one-third of patients and controls had high social activity and about half of both groups had moderately high social activity. A similar physical activity score showed no difference between the two groups. The socioeconomic level of the Crohn's disease patients was slightly, but significantly higher than that of the controls. Sixty five per cent of Crohn's disease patients were employed, 64% of controls; 6% and 7% respectively unemployed. Three per cent of Crohn's disease patients had disablement pension. Of Crohn's disease patients employed, a higher percentage (77%) had remained in the same job for more than five years (64% of controls). The number of sick leave days during previous year was less than 11 in 72/69% of patients and controls. In spite of these objectively good results 54% of patients with Crohn's disease felt exacerbations of their disease strained their professional and personal life. During the previous year 23% reported decreased working capacity and 21% reported decreased leisure activities, compared with their own expectations.

A diagnosis of a chronic disease will always be felt by the patient as a threat to his or her future life and the anxiety sometimes worsens the situation. We have had the opportunity to follow a regional group of patients with inflammatory bowel diseases for about 20 years in our outpatient clinic. The general impression of these patients is that in spite of their often troublesome symptoms they are able to lead a normal life. We found it necessary to examine the factual conditions for patients with Crohn's disease as in our previous report on the 'Social prognosis of patients with ulcerative colitis'.¹

Address for correspondence: Dr V Binder, Medical-Gastroenterological Dept C, Herlev Hospital, University of Copenhagen, Herlev, DK 2730, Denmark.
Received for publication 20 June 1986.

Methods

PATIENTS

Patients studied were from the area of Copenhagen County and comprised all those with a diagnosis of Crohn's disease² for more than one year who were attending the Medical-Gastroenterological Clinic at Herlev Hospital in 1984, and who were ≥ 20 years

Table 1 Patient material and controls

	N	Age	Sex	Duration
Crohn's disease	106	M: 44 years (20-85)	F/M: 1.5	M: 9 years (1-32)
Controls	75	M: 44 years (20-85)	F/M: 1.5	<28 days

Table 2 Clinical data of the Crohn's disease patients

Maximal localisation			Present clinical activity				Previous operation*			
Ileo-colonic	Colon only	Small bowel only	Inactive	Slightly active	Moderately active	Very active	Never	1 op	2 op	>2 op
60 (56%)	22 (21%)	24 (23%)	67 (63%)	25 (24%)	12 (11%)	2 (2%)	32 (30%)	33 (31%)	33 (31%)	8 (8%)

Ileostomy 6; (6%).

of age. In all 114 patients fulfilled these criteria and 106 agreed to participate in the interviews.

Seventy five patients of the same age and sex served as controls who in the study period – autumn 1984 were admitted to the hospital for acute diseases such as pneumonia, tonsillitis, salpingitis, urinary stones, etc. These patients had no other diseases than their acute condition and the duration of symptoms was less than four weeks.

Patients and controls underwent a personal interview by BGO or VZS concerning details of their professional conditions, family relations, and sexual life. Also living conditions, alcohol and tobacco intake, use of sedatives and other drugs, and their dietary habits and possible intolerances were registered. A score was kept for social activity, comprising frequency of participation in cultural activities, sports, courses, and frequency of contact with friends and of travelling. By use of the score the social activity was recorded as high, moderate, or low. The level of physical activity was similarly determined on the basis of participation in athletics, daily exercise, and capacity of body movement. Physical activity was characterised as high, moderate, or low. The interviews lasted about three quarters of an hour and took place in private. The information was put on to a questionnaire by the interviewer. The data were analysed on a computer by standard methods for multidimensional contingency tables.

The clinical data on Crohn's disease patients and controls are given in Table 1 and Table 2. The eight patients with Crohn's disease who refused to participate did not differ in respect to clinical severity of disease from the total group. These patients were generally older (21–78 years), median 56 years. There were seven women and one man. The duration of their disease ranged from two to 20 years, median five years.

Results

FAMILIAL AND SOCIAL CONDITIONS

Table 3 shows that most of the patients in both groups were married or cohabited, and that an equal number of patients and controls had familial and sexual problems. Regular sexual activity was admitted by

Table 3 Family relations

	Married or co-habiting	Parent-hood	Children (n)	Family problems	Sexual problems
Crohn's disease n=106	71 (67%)	72 (68%)	M: 2.0 (1-4)	10 (9%)	14 (13%)
Controls n=75	53 (71%)	59 (79%)	M*: 2.1 (1-4)	10 (13%)	9 (12%)

*p=0.05.

Table 4 Intake of alcohol and smoking

	Alcohol intake: g/d			Smoking: cigarettes/day		
	0	2-5	>5	0	<10	>10
Crohn's disease n=106	78 (74%)	25 (24%)	3 (2%)	34 (32%)	15 (14%)	57 (54%)
Controls n=75	59 (79%)	13 (17%)	3 (4%)	29 (39%)	17 (22%)	29 (39%)

72% of the Crohn's disease patients and 73% of the controls. A slight difference was found in that Crohn's disease patients had fewer children than controls. There was no difference between men and women with Crohn's disease in respect to number of children.

The use of sedatives was low both among patients and controls. Ten per cent and 8% respectively had seen a psychiatrist in the past, and an equal number in the two groups mentioned loneliness (6% and 11%). The intake of alcohol and tobacco did not differ in the two groups (Table 4).

Details of social activity is given in Table 5 showing

Table 5 Degree of social activity and degree of physical activity

	Social activity			Physical activity		
	High	Moderate	Low	High	Moderate	Low
Crohn's disease n=106	39 (37%)	54 (50%)	14 (13%)	26 (25%)	73 (69%)	7 (6%)
Controls n=75	28 (37%)	36 (48%)	11 (15%)	22 (29%)	48 (64%)	5 (7%)
			ns			ns

Table 6 *Level of education*

	School education			Level of education			
	≤9 years	10 years	≥11 years	University degree	Other theoretical	Skilled worker	Unskilled worker
Crohn's disease n=106	44 (42%)	34 (32%)	28 (26%)	5 (5%)	26 (25%)	50 (47%)	25 (24%)
Controls n=75	38 (51%)	24 (32%)	13 (17%)	7 (9%)	16 (21%)	29 (39%)	23 (31%)
			ns				ns

Table 7 *Socioeconomic status*

	Group				
	I	II	III	IV	V
Crohn's disease n=106	6 (6%)	8 (8%)	37 (35%)	45 (43%)	8 (8%)
Controls n=75	4 (5%)	9 (12%)	13 (17%)	34 (45%)	15 (20%)

p=0.02.

no difference between patients with Crohn's disease and controls. The social score comprised cultural, sporting, educational and social arrangements with friends. In each subgroup the same distribution was found as in the overall score.

Similarly the level of physical activity comprising athletics, ball games, bicycling and walking was almost equal in the two groups.

PROFESSIONAL CONDITIONS

Table 6 gives details of education and the final level of education for Crohn's disease and controls. A tendency for higher education in Crohn's disease was found but there were no significant differences. In Table 7, however, the present socioeconomic status is given according to the groups defined by the Danish National Institute of Social Research.¹ Significantly more Crohn's disease patients belonged to social group 3 and significantly fewer to the lowest social group 5 than among controls.

The present state of employment is given in Table 8. The patients and controls did not differ. For those patients attending the labour market a significantly higher percentage of Crohn's disease patients have stayed in the same job for more than five years (Table 9). There was no difference between patients and controls regarding stress at work and the majority of patients as well as controls had had less than two weeks' sick leave during the last year. Six Crohn's

Table 8 *Employment*

	Employed	Unemployed	Housewife	Student	Disabled	Pensioner
Crohn's disease n=106	69 (65%)	6 (6%)	1 (1%)	3 (3%)	3 (3%)	24 (22%)
Controls n=75	48 (64%)	5 (7%)	1 (1%)	2 (3%)	0	19 (25%)

disease patients in work (8%) had a so-called \$12 arrangement which means that the employer is indemnified against disease by direct payment from social authorities.

LIFE INSURANCE

Twenty five per cent of the Crohn's disease patients were insured *versus* 36% of the controls (p=0.04). Seventy two Crohn's disease patients (68%) had never applied for insurance while seven (7%) had applied but were refused by the insurance company because of their condition.

PERSONAL CONDITIONS

In Table 10 the occurrence of possible 'stress' before the onset of disease is given. No differences were found between patients with Crohn's disease and controls.

The dietary habits did not differ significantly

Table 9 *Professional conditions*

	Same job >5 years	Feels job stressful	Less than 11 days sick leave last year
Crohn's disease n=75	59 (77%)	31 (41%)	54 (72%)
Controls n=50	32* (64%)	24 (47%)	35 (69%)
		ns	ns

*p=0.03.

Table 10 *Stressful events in a three months' period before the onset of disease*

	Serious problems		No problems
	In family or close friends	Professional and/or economical	
Crohn's disease n=106	34 (32%)	34 (32%)	46 (43%)
Controls n=75	22 (29%)	21 (28%)	34 (45%)
			ns

Table 11 Food intolerance for one or more of following dietary groups

	Milk	Vegetables	Meat	Fruit
Crohn's disease n=106	26 (25%)	28 (26%)	0	21 (20%)
Controls n=75	13 (17%)	10* (13%)	2 (3%)	8 (11%)

*p<0.05.

between patients and in controls but Crohn's disease patients avoided one or more vegetables from their daily diet more often as shown in Table 11.

The Crohn's disease patients were asked whether they felt their daily life was influenced by the disease and a specification was made for different aspects of daily life. Fifty four per cent admitted that during exacerbations of their disease they felt strained both in professional and family life. Twenty four (23%) felt that their capacity for work had been reduced in the present year and 22 (21%) that their leisure activities had been reduced by the disease.

Discussion

In a previous study² we reported the prognosis of Crohn's disease on the basis of a cohort of 185 patients from Copenhagen County followed from the time of diagnosis – that is, the incidence group. We found a 10 years' survival of these patients no different from that of the general population. In the present study the material is a prevalence group comprising patients who at the time of the interview lived in the region and who attended our outpatient clinic. We know from the previous study that our Crohn's disease patients comprise slightly above half of all Crohn's disease patients in the County and that the patients in our hospital and those in the other hospitals in the area do not differ in respect to age, sex, and severity of disease.

The results reveal that patients with Crohn's disease are able to lead a normal life to a wide degree both concerning social activities, sexual, family life and professional life, as was the case with patients with ulcerative colitis previously reported.¹ Even if the Crohn's disease patients were not as the ulcerative colitis patients, educated to a higher level than controls, their final socioeconomic status was significantly higher. In ulcerative colitis patients the differences were obvious in social group 1 and 5, in Crohn's disease the differences are in group 3 and 5. The

findings are in accordance with those of Keighley *et al* from Nottingham UK.³

The fact that patients despite their often troublesome disease are able to participate in cultural and other social and professional life has been reported previously.⁴ More than half of the patients thus admitted that in periods of activity in the disease they felt strained in their professional as well as in their private life. The basis for results reported is an active medical approach to the disease with close contact to the hospital, immediate institution of medical or surgical treatment in exacerbations and only short term treatment periods with corticosteroids as previously described.²

In the actuarial calculations on working capacity of the incidence cohort of patients we found an increasing part, up to 20% of the Crohn's disease patients after 10 years with the disease, who were unable to work. In this prevalence group with a median duration of disease of nine years only 3% of the patients had disablement pension. Of the employed patients 72% had had less than two weeks' sick leave last year while 16% had more than 20 days. These figures do not differ from those in the control group.

We can conclude from this study that patients with Crohn's disease can remain healthy by regular control and vigorous treatment which allows a good prognosis for survival as well as the quality of life. It is obvious, however, that the patients' lives are more difficult during exacerbations of the disease. A minority of the patients with Crohn's disease need a disablement pension within the first decade of the disease.

This study was supported by the Danish Medical Research Council, grant No 5.52.14.27. At the time of writing this paper V Z Sørensen and B G Olsen were medical students.

References

- 1 Hendriksen C, Binder V. Social prognosis in patients with ulcerative colitis. *Br Med J* 1980; **281**: 581–6.
- 2 Binder V, Hendriksen C, Kreiner S. Prognosis in Crohn's disease – based on results from a regional patient group from the county of Copenhagen. *Gut* 1985; **26**: 146–50.
- 3 Keighley A, Miller DS, Hughes AO, Langman MJS. The demographic and social characteristics of patients with Crohn's disease in the Nottingham area. *Scand J Gastroenterol* 1976; **11**: 293–6.
- 4 Gazzard BG, Price HL, Libby GW, Dawson AM. The social toll of Crohn's disease. *Br Med J* 1978; **2**: 1117–9.