British gastroenterologists' care profile for patients with inflammatory bowel disease: the need for a patients' charter

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Summary

The follow-up of patients with inflammatory bowel disease (IBD) was investigated using a postal questionnaire sent to 359 members of the British Society of Gastroenterology (BSG), of whom 235 replied. Of patients with IBD, 96% were weighed on each outpatient clinic review and over 60% had their full blood count checked. Although few centres (20%) have computerized recall of their patients for cancer surveillance, 96% did perform such surveillance on patients with ulcerative colitis. The mean duration of disease before surveillance was initiated was 9.6 years. Most clinicians (80%) only surveyed patients with disease extending beyond the transverse colon.

Despite recent work on cancer risk age is relatively unimportant to 76% of clinicians in their decision to screen or not. Only 24% of clinicians undertake cancer surveillance in patients with Crohn's disease but these use similar criteria in their selection of patients. Few other tests were performed regularly. Clinic services vary considerably from centre to centre, 62% offer open access to patients with IBD, 8% have a stoma nurse in clinic and 17% a dietitian. Eighty-four per cent of respondents provide educational books and 22% videos. Forty-four per cent of clinicians refer patients for advice to fellow sufferers. We believe there should be a uniform minimum standard of care and services available in clinics throughout the United Kingdom and propose a patients' charter to ensure that this occurs. Such care profiles provide guidelines to those who need to develop standards for resource management.

Introduction

Traditionally patients with inflammatory bowel disease are followed in hospital outpatient departments for many years. The reasons are varied ranging from periodic review to detect malignant change early to an attempt to abort acute attacks rapidly. Recently the cost-effectiveness of screening for colorectal cancer in inflammatory bowel disease (IBD) has been questioned[1], although the connection between these conditions is not disputed[2,3]. The role of counselling and patient education is established in IBD[4-6]. In the era of clinical audit and resource management gastroenterologists must not confuse economic efficiency with the clinical objectives of uniform and good management. We have investigated the follow-up of patients with inflammatory bowel disease by experienced physicians who are members of the British Society of Gastroenterology (BSG) to establish a consensus view of what should be minimum standards of care for patients with IBD. We hope that these will be accepted by administrators who manage health care as a basic minimum which patients should receive.

Method

A questionnaire was sent to 359 consultant members of the BSG. It included questions on numbers of patients with ulcerative colitis (UC) and Crohn's disease (CD), their follow-up, surveillance colonoscopy, use of laboratory tests and clinic structure. The duration of follow-up and policies on management of relapse were reviewed. Student's t test was used to compare normally distributed data, χ^2 for other data.

Results

Of the total questionnaires 236 were returned: however in 10 cases one questionnaire was completed on behalf of several members of a department. The replies, therefore, represented 70% of physicians in the BSG. The modal number of patients cared for by respondents was 50-59 with CD and the same for UC (Table 1).

Ulcerative colitis

Ninety-six per cent of clinicians weigh patients at each clinic visit, 63% check full blood counts and 25% liver function tests. Thirty-four per cent of clinicians perform sigmoidoscopy, often with biopsy, each time they review a patient with UC.

Although 96% of clinicians undertake cancer surveillance only 20% have computerized recall, the remainder use card indices or case note based recall. Ninety-five per cent perform surveillance annually or biennially depending upon the duration of the disease and its extent. The mean duration of disease before surveillance is initiated was 9.6 years (SD, 2.5 years, range 2-20). Although some clinicians colonoscope patients with UC limited to the sigmoid

Table 1. Number of patients with inflammatory bowel disease followed by individual British gastroenterologists. British gastroenterologists were asked to report the number of patients they cared for with coeliac disease

	<10	*10-49*	*50-99*	*100+*	*Not stated*
Ulcerative colitis	4	73	104	54	1
Crohn's disease	7	83	83	62	1

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colon, the majority (80%) would only consider investigating patients with disease beyond the transverse colon.

The patients' age appears to influence the decision about colonoscopy for only 24% of clinicians. One respondent would consider beginning surveillance in patients as young as 14 years; others stop surveillance during patients' eighth decade.

Crohn's disease

Ninety-seven per cent of clinicians weigh patients at each clinic review. Laboratory investigations are performed significantly more often than for ulcerative colitis ($\chi^2=12$, $P<0.003$); 66% of gastroenterologists check full blood counts, 29% liver function tests and 8% serum B12 and folate levels. Fourteen per cent perform sigmoidoscopy at each review. Other respondents indicated they would perform such tests less often.

Sixty-one (24%) clinicians performed annual or biennial colonoscopy in patients with CD. Twenty-nine selected patients based on extent of disease, seven on duration and 19 took both into account. The other six clinicians considered extent, duration and the patient's age.

Management

As expected some clinicians (10%) wrote additional comments on the questionnaire to indicate that patients admitted with a relapse of IBD were treated individually, with therapy tailored to their specific needs. However, 77% routinely used steroids, 31% enteral nutrition and 4% use total parenteral nutrition (TPN).

Clinic structure

The majority (83%) of clinicians follow patients with IBD indefinitely. Only 8% wanted general practitioners to follow IBD patients instead of hospital based specialists and 62% have open access clinics which patients may attend without appointment or after notifying the clinician's secretary.

Few clinics are routinely supported by specialist nurses. Stoma care nurses assist in 8% of clinics and dietitians in 17%. Self-help groups are encouraged by 92% of clinicians and 44% refer patients to others to share experiences, but usually only before stoma surgery and not to discuss the practicalities of life with IBD. Patients receive information books in 84% of clinics and videos in 22%.

Discussion

This study shows a reasonably consistent approach to cancer surveillance in ulcerative colitis, though less so in Crohn's disease. The role of age at onset in cancer risk[1] as opposed to extent of disease[3] has not yet significantly affected clinical practice. The structure of clinics vary markedly. Differences appear to be more than simply of style. Some patients have access to self-help groups, specialist nurses, dietitians and fellow patients for 'counselling' and sharing of ideas. Others have none of these.

In 1984 the Royal College of Physicians and the British Diabetic Association[7] published recommendations for the provision of care for adult diabetic patients. This not only suggested the number of outpatient sessions held for managing diabetes, but also recommended employment of specialist nurses and dietitians as well as close liaison with disciplines such as ophthalmology, obstetrics and chiropody for screening and management of complications. Computerized registers are encouraged for follow-up purposes. Educational resources should be available in each clinic.

Physicians in general can learn a great deal from the counselling and liaison skills developed by diabetic care teams. Their organization of services, screening and counselling could be applied to the care of patients with inflammatory bowel disease. We have previously discussed the role of the specialist nurse[8] and would now suggest the adoption of a patients' charter to lay down uniform and minimum standards of care and service in IBD clinics. The mean conditions for surveillance shown in this study should be advocated as a national minimum that resource managers should accept as the basic care profile for patients with IBD.

Clinics should be reorganized so that all are open access, with support from a specialist nurse trained in counselling, a dietitian should always be available and information booklets distributed free and videos made available for loan. Laboratory tests should be performed regularly. Such activities will need to be costed and form a core service to patients and family doctors. Care profiles are administrative tools used to describe ideal treatment patterns for various conditions and should be defined by specialists in the field and reflect good rather than minimal practice.

Appendix

Inflammatory bowel disease patients' charter

1 A defined training programme in colonoscopy with a procedure booklet held by trainee.
2 Close supervision of junior doctors in outpatient clinics with consultant led discussion of patients seen in clinic.
3 Inclusion of all patients in a regular audit programme.
4 Availability of evening clinics.
5 A regular programme for training nurse specialists in gastroenterology to provide counselling and support in addition to stoma therapy.
6 Combined clinics with surgical gastroenterologists.
7 Regular monitoring of disease activity and patients' quality of life.
8 A regular screening programme for patients with colonic disease to detect dysplasia and early carcinoma.
9 Close links with patient organizations with the development of combined educational programmes.

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