

Information for patients about inflammatory bowel disease

ABSTRACT – In inflammatory bowel disease it is important that patients understand their condition since this helps to improve long-term management of the disease. The aim of this study was to assess the information given to patients with inflammatory bowel disease about their condition, its treatment and the National Association for Colitis and Crohn's disease. Two surveys were performed, using anonymous questionnaires. One was of all association members in north-east England, the other was a sample of patients attending medical outpatients. The surveys showed that more patients heard of the National Association for Colitis and Crohn's disease from the media than from medical sources. Of patients seen in medical clinics, 75% would welcome more information about their disease. In four of the six participating centres less than half the patients had been told about the existence of a patients' association. There was considerable variation in the instructions on what action to take in the event of a relapse. These findings suggest that the opportunity offered by outpatient clinics to educate and inform patients is often wasted. Clinicians often neglect to mention the National Association for Colitis and Crohn's disease, especially to patients with long-standing disease. A higher priority should be given to providing patients with appropriate information on inflammatory bowel disease. Three simple audit standards for the organisation of outpatient clinic information are proposed.

Long-term hospital-based follow-up is the usual practice for patients with inflammatory bowel disease. This gives an opportunity for patient education, allows easy access to specialist care when the disease flares up and facilitates prescription of appropriate maintenance treatment during remission. We have undertaken two complementary surveys of patients with inflammatory bowel disease to inquire about their knowledge of the patients' support organisation, the National Association for Colitis and Crohn's disease (NACC) and about the treatment of their condition. The aim was to examine how well current outpatient facilities and practices succeed in providing patients with inflammatory bowel disease with relevant information.

JOHN C MANSFIELD, MD, MRCP, Senior Registrar in Medicine, South Cleveland Hospital

ANDREW R TANNER, MD, FRCP, Consultant Physician, North Tees General Hospital

MICHAEL G BRAMBLE, MD, FRCP, Consultant Physician, South Cleveland Hospital

Methods

Two surveys were undertaken. The first, a survey of all NACC members in north-east England, was designed to identify where members had heard of the Association and how soon after diagnosis they joined it. In order to obtain information from patients who had either chosen not to join the NACC, or were unaware of its existence, a second survey was performed of patients attending medical outpatients for their inflammatory bowel disease. Both questionnaires were anonymous, carefully constructed for simplicity and clarity and had been informally validated by a small number of patients prior to distribution. Copies of the questionnaires are available from JC Mansfield.

Survey 1. NACC members survey

A postal questionnaire of twenty questions was sent to all 945 NACC members in the area; 732 replies were received (77% response rate). This included three local branches of the association: the Hadrian group (Newcastle upon Tyne, Northumberland, North and South Tyneside, Gateshead, North Durham), the Tees area group (South West Durham, Cleveland and North Yorkshire) and Humberside. Information was sought relating to the patient's age, time to diagnosis, time to joining NACC and other factors, such as whether the hospital clinician was a physician or surgeon.

Survey 2. Medical clinic survey

Six gastroenterology clinics participated. These clinics are run by physician-gastroenterologists in hospitals across north-east England. Questionnaires were handed out to consecutive inflammatory bowel disease patients by the nursing staff on arrival at the clinic, and returned to a central coordinator. Eighty-eight questionnaires were returned; the exact response rate is unknown but up to 140 were given out.

Results

NACC members survey

Of the 732 respondents, 683 members were sufferers from inflammatory bowel disease and 49 were relatives or friends. Analysis of the results was confined to the patient group. The age spectrum was similar to the known distribution of inflammatory bowel disease within the population.

The media (newspapers, magazines, TV, radio) were the most common source of information overall

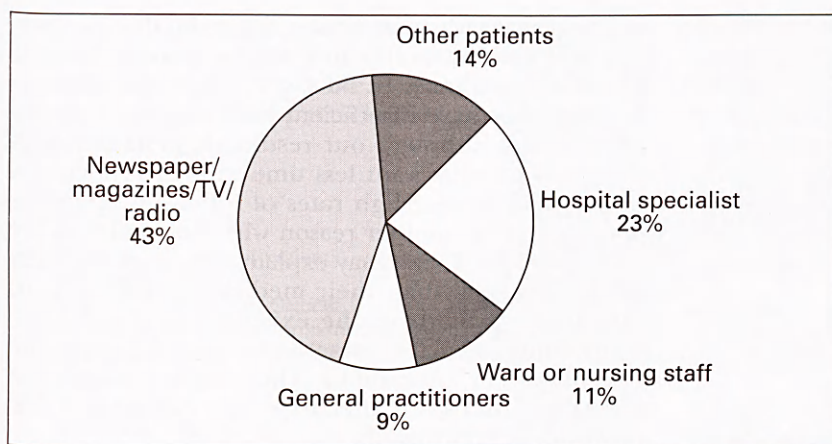


Fig 1. Source of patients' original information about the NACC

(43%). Only 23% of members learned about the NACC through their hospital specialist, a further 9% learning through their general practitioner (Fig 1).

Six hundred and two of the patients (88.2%) were under current hospital specialist care. Of these, 269 were under physicians and 266 under surgeons, the remainder being unsure. Patients were frequently referred between specialists, 447 (65.4%) having had their care transferred at some time: physician to surgeon 151 patients (22%), and surgeon to physician 128 patients (18.7%). In addition, 168 patients had been transferred between specialists of the same type, surgeon to surgeon and physician to physician.

Patients under the care of a surgeon were more likely to see a junior doctor (40%) than those under a physician (26%) ($\chi^2 = 11.6$, $p < 0.001$). Patients under physician follow-up were more likely to have heard of the NACC through medical sources, including hospital specialists, nursing staff and general practitioners, than patients under surgical review. Of 262 patients learning about the NACC through these three sources, 132 were under a physician compared with 87 under a surgeon; 43 patients did not know or were under joint care ($\chi^2 = 12.8$, $p < 0.001$).

Almost half the members (45%) joined the NACC within 12 months of learning the diagnosis although 29% had their disease for more than five years before joining. The longer the interval between diagnosis and joining the NACC, the more likely that the patient had learned of the association through the media.

Medical clinic survey

The 88 patients in this survey were 41 men and 47 women, mostly between the ages of 25 and 44 years. Thirty-one had suffered from their disease for more than five years. Sixty-seven of the patients were attending for routine review, 14 because of relapse and seven as new patients. Only four patients felt their appointment was unnecessary.

Most (94%) of the patients attending medical out-patients felt that the doctor had explained their condi-

tion clearly, and 45% had no other source of information. Other sources of information were the NACC (45%), booklets and other written information (40%) and videotape information (7%). When asked whether additional information should be provided, 75% responded positively, requesting booklets (64%), NACC leaflets (50%) and more videotapes (43%).

When patients were asked whether they required more time with particular individuals, 43% said that they did not want any additional time. However, 32% requested time with the dietician, 27% with the NACC representative, 25% with the doctor, 7% with the clinic nurse and 5% wanted to see a stoma nurse.

Only 25% of the medical clinic patients were NACC members. Overall, 64% had received information about the association. Of the NACC members 82% were women. Of the 35 patients who knew of the association but had chosen not to join, 20 were men and 15 women. Patients in the younger age groups were more likely to know about the NACC (73%), but patients in the older group were more likely to become members (33% compared with 14%).

The number of patients being told about the NACC varied between the centres. The two centres with the highest rates of NACC awareness had the lowest proportion of patients requesting more time for further information (Table 1).

Table 1. NACC information by centre

	% receiving NACC information	% requesting more time for information
Hospital A	100	35
Hospital B	80	40
Hospital C	42	58
Hospital D	41	65
Hospital E	47	73
Hospital F	44	100

When patients were asked whether they recalled being told about the treatment of their condition, 86% thought they had been told. The doctor supplied most of this (78%) but the NACC, booklets and nurses also contributed (23%, 18% and 7%, respectively). There was no consensus as to what to do if their condition deteriorated. The following instructions were recalled: see general practitioners (37%), phone consultant's secretary at hospital (34%) and increase steroids (9%).

Discussion

Patients with inflammatory bowel disease attend hospital clinics for treatment of acute exacerbations and supervision of maintenance therapy. These clinic attendances provide an excellent opportunity for patient education. Our surveys were designed to test whether patients were receiving information relevant to them.

Membership of the NACC has increased steadily since its foundation in 1979. The association provides useful support to patients both at the time of diagnosis and thereafter¹, including information booklets which have been shown to reduce the anxiety associated with the condition^{2,3}.

The two surveys presented here selected different patient groups and were intended to be complementary rather than comparative. By using two different surveys a wider picture has been obtained, not limited by attendance at one type of clinic or membership of NACC. In the main survey all NACC members were included (732 replied, 77% response rate) so the results are unlikely to be subject to sampling error. The smaller survey of medical clinic attenders is more likely to include a sampling bias, but complete disease-specific hospital-based patient registers do not exist, preventing a more rigorous approach to this problem.

The survey of NACC members inevitably selected the patients who want to know most about their condition (this motivation may explain the high response rate). Both surveys, however, suggest that doctors are failing to provide their patients with relevant information. Previous surveys have also found that the majority of patients with Crohn's disease and ulcerative colitis wanted to know more about their diseases⁴⁻⁶. In the surveys reported here we have focused on the provision of information about the NACC since this is specific to patients with inflammatory bowel disease and directly relevant to them. Only 23% of NACC members learned about the association from their hospital specialists in contrast to 43% from the media. On average more than 30% of medical clinic attenders had never heard of the existence of the NACC and in four of the six centres this was greater than 50%. The question here is not whether patients should join such an association, but whether they should be actively informed of its existence so that they can make up their own minds.

The reasons why patients are not given this information are not obvious. Doctors may be unaware of their patients' ignorance. In busy general clinics, doctors may feel they have insufficient time to discuss patient associations, although our results suggests that well informed patients want less time with their specialist rather than more. High rates of follow-up by junior doctors may be another reason why some patients are poorly informed, and may explain why surgeons seem to fare less well than their medical counterparts in informing patients of the existence of the NACC. Some clinicians may themselves be doubtful about the role of patient associations. There were considerable variations between the different centres in the provision of information.

Most patients expressed a wish to have access to more information. Leaflets, booklets and videos were all in demand. The offer of time with a dietician was also popular with patients. The NACC are currently responding to this perceived need for dietary advice by preparing a new leaflet on diet and inflammatory bowel disease.

The provision of information to patients with inflammatory bowel disease is a legitimate topic for clinic audit. In the light of these surveys we propose the following three audit standards:

1. All patients with an established diagnosis of inflammatory bowel disease should receive information about the NACC.
2. Clinics concerned with inflammatory bowel disease should have information regarding these diseases and related topics (such as diet) freely available to patients.
3. Patients with inflammatory bowel disease should have a clear and consistent understanding of what to do if their condition deteriorates.

Conclusion

The opportunity offered by outpatient clinics to educate and inform patients is often wasted. Clinicians often neglect to mention the National Association for Colitis and Crohn's disease, especially to patients with long-standing disease. A higher priority should be given to providing patients with appropriate information on inflammatory bowel disease. Three simple audit standards for the organisation of outpatient clinic information are proposed.

The doctor-patient communication gap highlighted here in inflammatory bowel disease may also exist in other chronic diseases. More attention should be paid to the provision of relevant patient information in outpatient clinics.

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Address for correspondence: Dr JC Mansfield, Endoscopy Centre, South Cleveland Hospital, Middlesbrough, TS4 3BW.

NUTRITION IN CHILD HEALTH

Edited by D P Davies

Nutrition is fundamental for a child's normal growth and development and it seems likely that nutrition, even as early as the fetal stage, may be a determinant of adult health. However, despite the great advances in knowledge, doctors as a whole tend to neglect this subject. This timely publication, based on a conference organised by the Royal College of Physicians and the British Paediatric Association, includes an overview of the current state of nutrition in children and adolescents and reflects the many aspects of paediatric nutrition.

This book will be a valuable source of information to paediatricians and other professional workers, particularly dietitians, involved in the care of children, and also to adult clinicians and medical scientists. It provides an up-to-date source of reference for both undergraduate and postgraduate educational and training programmes in childhood nutrition.

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