Communication of information to patients with inflammatory bowel disease: A European Collaborative Study in a multinational prospective inception cohort

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1. Introduction

Ulcerative colitis (UC) and Crohn’s disease (CD), together referred to as inflammatory bowel disease (IBD), are, after rheumatoid arthritis, the second most prevalent group of chronic non-fatal disorders on the European continent and as frequent as Insulin Dependent Diabetes. The majority of patients acquire these diseases in early adult life; the course of disease is characterized by exacerbations and remissions with the potential for life-long morbidity and functional disability.¹ There is increasing interest in researching patient-doctor communication and the need to teach and measure this specific clinical skill.² Effective communication of information about IBD is a key point in the management of patients. Health-care providers must be aware of the patients’ information needs and concerns³ and the psychosocial aspects of disease.⁴ In planning a communication project for patients with chronic disorders it is a prime necessity to analyze the demographic, educational and social situation of the target population, to know the current level of specific disease information of the patients, and to understand their familiarity with the whole range of information media. Access to and use of electronic media, particularly internet facilities, has become increasingly important⁵.

In the present study we aimed to evaluate the methods being used for communication of information about their disease to a multi-national IBD cohort, as well as patients’ preferences concerning current and future sources of information, including electronic media and patients’ associations, and their level of satisfaction with the information provided. It was surmised that an understanding of these characteristics of the communication process would reveal the current role of traditional and modern media and lead to an information strategy applicable to other chronic diseases.

In consideration of the growing conversion of national health care strategies to a pan-European standard, we explored these questions in a large European cohort of patients with IBD and 10 years follow-up.

2. Methods

2.1. Patients and centers

The European Collaborative Study Group on Inflammatory Bowel Disease (EC-IBD) created a prospective, population-based, uniformly-diagnosed inception cohort of 2201 patients with IBD in 20 well-described geographical areas in 12 European countries in the period October 1st 1991 to September 30th 1993.⁶ ⁷ The lower age limit for inclusion was fixed at 15 years. General practitioners, gastroenterologists, internists and surgeons in the study areas were notified periodically by letter about the study and encouraged to refer every case of possible IBD to the specialist EC-IBD centers for evaluation. At the same time pathology and radiology departments in hospitals were canvassed for likely cases. At the end of the recruitment period the inception cohort comprised 706 patients with CD, 1379 with UC and 116 with indeterminate colitis. Upon follow-up most cases with indeterminate colitis were reclassified as UC or CD. In the year 2000 all 20 centers were approached to take part in a follow-up study. The 13 centers (9 countries, 1580 cases) agreeing to participate in the current study were located in Denmark (Copenhagen), Greece (Ioannina, Iraklion), Ireland (Dublin), Israel (Beer Sheva), Italy (Cremona, Firenze, Reggio Emilia), the Netherlands (South Limburg), Norway (Oslo), Portugal (Almada) and Spain (Vigo). The cohort had been followed from inception until data inclusion of the present study between...
August 1st 2002 and January 31st 2004, or any date prior to this period indicated of being the date of death or loss to follow-up. There were no significant differences between patients without and with complete 10-year follow-up in terms of gender, disease diagnosis, disease location and disease behavior at diagnosis, except that patients not completing 10 years were slightly older at diagnosis, as reported.8

2.2. Data acquisition tools

Internet-based questionnaires for patients (in 9 languages, incorporating demography, education, life style habits and medical issues, with assistance from a nurse if required) and their physicians (in English, concerning disease diagnosis and progress, therapy and outcomes) were used to collect data, as described.9 The patient questionnaire contained specific questions (developed with the Department of Social Communication, University of Bologna, Italy) concerning how patients had received information about IBD, the degree of satisfaction with the data provided, preference for particular forms of media including computer and web technology, attitudes to mailing lists and patient organisations, and the type of future information desired. The present manuscript was prepared by the EC-IBD group focusing on the communication of information to IBD patients.

3. Statistical analysis

The data obtained for analysis reflected patient opinions about information communicated to them in the last year of follow-up, usually the 10th year of their illness. All data were analyzed using SPSS version 14 software for Windows (SPPS Inc. Chicago, Il, USA). Independent variables included sex, age, diagnosis, educational level, marital status and geographical area (northern or southern European countries, with Israel grouped with southern Europe). Descriptive statistics are expressed as mean + standard deviation (SD). Categorical variables are expressed as percentages. The significance of differences between categorical variables was calculated using the Chi-square test. P values of less than .05 were regarded as statistically significant.

4. Results

4.1. Characteristics of the IBD cohort

There were 917 (58%) eligible patients (out of a possible 1580 patients) with completed questionnaires. Of the 663 rejected patients, 26.9% were dead, 26.2% unwilling to participate, 36.8% untraceable, and 10.1% did not have IBD. The demographic characteristics of the 917 patients are listed in Table 1. There were 463 male and 454 female patients. The mean age of the patients was 48.3 years, and 62.1% were younger than 50 years. The ratio UC to CD patients was 2.08. There were 551 cases from northern countries (66.6%); Norway alone contributed 228 patients (24.9%).

4.2. Information received in the past year of follow-up

During the past year, usually the 10th year of follow-up, 21% of patients reported receiving information about the treatment of their disease 2 or 3 times, 13.5% most all of the time, and 64.4% none of the time (Table 2). The most commonly reported current source of information was the treating specialist (almost always a gastroenterologist); this was stated by 65.5% of patients. For 23.5% of patients the family doctor communicated the information. Additional sources of information recounted by the patients included the IBD patients associations (17.7% of patients), newspapers (17.4%), and the internet and broadcast media (24.6%). Many patients were utilizing multiple sources of information. The majority (77%) of patients were satisfied with the information received in the past year.

4.3. Future preferences for information

Over half the patients were curious about new fields of research, medical treatment, risks and complications (Table 2). Genetics was of interest to 42% of patients. 15% wanted information to assist them in their social interactions. The majority (77%) of patients were willing to receive information from an international IBD organization. Concerning modes of communication, 76% preferred a paper bulletin, 30% e-mail, and 27% a web-site. Only a small number of patients preferred to receive information at meetings of IBD patients associations.

4.4. Factors affecting patients’ preferences

In Table 3 the effects of disease diagnosis, level of education, geographic position and gender on patients’ preferences are detailed. The specialist was the prime source for information...
in two-thirds of UC and CD patients. CD patients utilized the family doctor for information less than UC patients (P<0.001). CD patients were significantly more interested in the patients’ association and the internet than UC patients. 25% of CD patients were members of a patients’ association compared with 11% of UC patients (P<0.01). CD patients were significantly more interested in new research, use of a web-site and attending patients’ association meetings than UC patients. Education played a significant role in patients’ choice of sources of information and their preferences. Patients in the higher education range relied less on the general practitioner for information, and more on the patients’ association and the internet than those with less education. Likewise, the better educated patients were more interested in genetics, disease complications, new research, e-mail and web-site than the others. On the other hand, those less educated were more reliant on paper bulletins. Geographic position, defined as northern and southern countries, had a significant impact on patients’ present and future choices of source of information, areas of interest and information media. Patients from northern countries preferred receiving information from the patients’ association and electronic media compared with those in southern countries; they were more interested too in genetics and research. Patients from southern countries were more reliant on their treating specialist as a source of information. Northern versus southern patients had more access to computers (70.6% vs. 49.2%, P<0.01) and to e-mail and internet (64.8% vs. 36.6%, P<0.01), and were more likely to belong to an IBD patients’ association (18.8% vs. 11.2%, P<0.01). Southern patients were less concerned about having their names on a mailing list (35.8% vs. 30.7%, P<0.05) than northern patients. Female patients preferred paper bulletins more than males (80.5% vs. 72%, P<0.01) but had less demand for e-mail (26.4% vs. 34.6%, P<0.01). Males and females did not differ with respect to the use of a web-site (29% vs. 25%) or the patients’ association (11% vs. 11.4%) as a source of information.

4.5. Access to web-based information and mailing lists

Access to personal computers was reported by 569 patients (62.1% of the cohort). Access to the internet (including an email address) was available to 491 patients (53.5%). Of the patients having access to personal computers and internet, 84% were under the age of 54 years and 16% were older. Of the 917 patients in the cohort, only 144 were members of a patients’ association (15.7%), and 300 patients (32.7%) expressed concern about having their names on a mailing list.

5. Discussion

The main findings of the present study were that the majority of patients appeared content with the information received, the bulk of information provided by health care workers was conveyed by specialists, and modern web-based and traditional media were both in demand. Significant factors impacting on patients’ choices included disease diagnosis, education, country and gender.

Our study has several unique features. To our knowledge this is the first simultaneous evaluation of the communication of information to a large multinational cohort (Europe and Israel) of IBD patients and a survey of their preferences for future modes of communication. The EC-IBD patient cohort is distinctive as demographic, medical and sociological data have been collected in a uniform way throughout a whole decade. A second exclusive feature of this study is the collaboration between a dedicated pan-European study group of clinicians and epidemiologists and an academic research center specializing in health care information science.

Thirdly, since the cohort was community-based and representative of typical IBD patients seen in clinical practice during the first decade of their disease, the results of this research have good external validity with the potential to influence health care information delivery to IBD patients in other countries as well as to patients with other chronic diseases. The facilities at all the EC-IBD centers were found to ensure a good and fairly equal standard of health care.

A disadvantage was that of the original EC-IBD cohort of 2291 patients, only 917 participated in the current research. There were a number of reasons for this. Firstly, several of
the original centers did not participate in the 10-year follow-up study for technical and logistic reasons. This however did not jeopardize the population-based nature of the work since each participating center had met the criteria for epidemiological studies in 1991. Secondly, there was a natural attrition of the database caused by patient deaths and misdiagnosis. Thirdly, almost 250 patients were lost to follow-up and many patients declined to participate. This could perhaps bias the study outcomes as it may be speculated that a more “information-conscious” segment of the patient cohort has taken part in the study.

There was a high rate of satisfaction among patients with the information presently offered to them. This notable finding may be explained by two reasons. The majority of the patients were still under specialist care after 10 years of disease, with likely good access to medical and medico-social information. Furthermore, the patients were interviewed in a chronic disease phase when the need for new medical information would be less acute. While the initial two years of IBD are characterized by frequent flares, investigations, complications, acute surgical interventions, and high health resource consumption, the recurrent flares of the next eight years affect less than half the cases in any calendar year. Also, intestinal malignancy seldom appears in the first decade of disease. Naïve patients with IBD would be expected to be in great need of knowledge about their disease and would likely be far less satisfied with the information presented to them. It was not clear why so many patients reported not receiving new information in the past year; this should clearly not be the case.

The type of information supplied in the empathic two-way communication between doctors and patients is traditionally

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<th>Table 3 Present sources of information, topics of interest and future preferred media in IBD patients</th>
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<td>Present information source</td>
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<td>Ulcerative colitis %</td>
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<td>Family doctor</td>
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<td>Specialist</td>
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<td>Patients’ Association</td>
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<td>Newspaper</td>
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<td>Internet</td>
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<td>Current access status</td>
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<td>Have a personal computer</td>
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<td>Have e-mail and internet</td>
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<td>Concern about mailing list</td>
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<td>Membership in Patients’ Association</td>
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<td>Topics of interest</td>
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<td>Genetics</td>
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<td>Risk, complications</td>
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<td>Web site</td>
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<td>Patients’ Association meetings</td>
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a High secondary school and university.
b Primary and low secondary school.
focused on the physical (rather than psychological) nature of illness and its treatment. It is evident from the present work that the 10-year cohort has greater expectations than this, demanding detailed information about the genetics of IBD, disease course and prognosis, and the advantages and disadvantages of oncoming new drugs. There is in addition an expectation that the doctor will elaborate on the current research into the disease, this itself being a complicated topic which only a specialist can handle. Perhaps this attitude of our cohort results from the fact that the time period of data collection for the study coincided with numerous lay publications about the first description of genes connected with IBD and the wide-spread application of therapeutic TNF-\( \alpha \) antagonists in this disorder. Patients’ concerns regarding IBD have been identified in eight domains: body energy, bowel control, body image and stomata, social isolation, dependency, reduced work potential, feeling dirty, and lack of communication from the medical community.\(^2\) Being afflicted with a disease of unknown cause generates a sense of uncertainty; physicians cannot provide patients with definitive answers to the inevitable questions about the etiology of IBD. Patients have reported specifically the difficulty in gaining information about the psychological and emotional implications of IBD.\(^{14}\) EC-IBD patients have reported psychological and functional impairment in a disease-specific quality of life questionnaire.\(^{15}\) Clearly, doctors have to be educated to provide more information to patients on these issues, and such skills should be communicated in the curricula of medical schools.\(^2\)

About a quarter of the patients reported obtaining information via the internet. However, this facility was used much more commonly in northern European (31%) than southern European (15%) countries in the study, and by better educated patients. For many citizens of most developed countries the internet has become a powerful and familiar healthcare information tool.\(^{16}\) In the Eurobarometer 58.0 study carried out among citizens of the European Union, the percentage of persons (illnesses or lack thereof not specified) accessing the internet at least monthly to obtain health-related information varied considerably by country, with the rates exceeding 7% in Denmark, the Netherlands, Sweden and Finland compared with less than 4% in France, Portugal and Greece, and a pan-European average rate of 23%.\(^{17}\) Nevertheless, 42% of people in the European Union thought that the internet was a good way to get information about health. In a representative United States population it was found that 11% of persons with chronic (not IBD) medical conditions were accessing the internet at least monthly to obtain health-related information, and over half the internet users described an improved understanding of their illnesses and treatments.\(^5\) Another USA survey performed in a gastroenterology out-patients clinic found that 25% of patients were using an internet facility to glean information about their illnesses.\(^{18}\) The high rate of use of the internet in our IBD cohort likely reflected the great and specific need for communicating information in IBD. Yet, there is a need to increase the use of electronic facilities in all European countries in consideration of the patients’ expectations for the future. Internet sites were found to vary considerably in the scope of information provided to patients.\(^{19}\) The Crohn’s and Colitis Foundation of America and the National Society for Colitis and Crohn’s Disease (UK) appear to be the only patient association websites accessed by a reported Google\(^{20}\) search.\(^{19}\) There is also concern that uncontrolled communication of health-related information to patients can be detrimental.\(^{20}\) A further issue under consideration is the provision of direct patient access to their electronic medical records; this however requires the invention of suitable technology to make its use practical and informative.\(^{21}\) Despite the modern trend to use internet facilities, this is an impersonal method and we feel strongly that this medium should never replace proper doctor-patient communication as the primary source of information.

We have noted that almost 80% of our surveyed population preferred paper-based rather than web-based information. In particular, the elderly, female, and southern European patients requested hardcopy information. This traditional modality remains a most useful means to communicate information to patients. Such materials can be supplied directly to patients by mail or handed over by their managing physicians and nursing staff. This facility too requires further development and improvement, but will always take second place to direct doctor-patient communication of information. A detailed list of information to be made available to IBD sufferers by internet or other media has been developed.\(^{19}\) We endorse the suggested topics of disease definition, symptoms, methods of diagnosis, etiology, course, complications, drugs, surgery, nutrition, psychosocial and quality of life issues, and complementary therapies. We feel in addition that there should be a greater role for patients’ associations in the communication of information. This could be done at meetings, as a paper facility, and via the web. The proportion of patients in our cohort actually belonging to patients’ associations was disappointing low, but interestingly the rate in CD patients was higher than in UC, reflecting the greater morbidity and increased patients’ concerns in this entity. Patients who were members of patients’ associations demonstrated significantly more knowledgeable about their disease than non-members.\(^{22}\) There is also a need for an international IBD association, such as EC-IBD, to play a greater role in providing patients with information. The reticence on many persons to have their names on a list will likely be overcome with time, provided that safe-guards concerning privacy are in place, particularly with regard to electronic media.

In conclusion, we have recorded the methods of communication of health-related information to patients in the EC-IBD cohort and the patients’ preferences for future modes and content of communication. Information strategies are changing fast and have to be re-designed continuously. Future research on this subject should be extended to other populations, be stratified prospectively according to the year and severity of illness, bearing in mind the great need for information in the early years after disease onset, and be correlated with quality of life. The education of doctors in new methods of communication of knowledge is a challenge for medical educators.

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Statement of authorship

PP participated in the design of the study, in collection of data, analysis of data, drafted the manuscript.
BP participated in the design of the study and analysis of data, provided significant advice.

MMG participated in the design of the study and analysis of data.

BM participated in the design of the study, collection and analysis of data.

FG participated in the design of the study, collection and analysis of data.

FD performed statistical analysis.

MP participated in the design of the study, provided significant advice.

RL participated in the design of the study and collection of data.

WF participated in the design of the study and collection of data.

KK participated in the design of the study and collection of data.

OC participated in the design of the study, provided significant advice.

SM participated in collection of data, provided significant advice.

LP participated in the design of the study, in the analysis of data, provided significant advice.

DFM participated in the design of the study, in the analysis of data.

PS participated in the design of the study and collection of data.

FJ participated in the design of the study and collection of data.

OS participated in the design of the study, in collection and analysis of data, in writing the manuscript, provided significant advice.

SRW participated in the design of the study, in the analysis of data, in writing the manuscript, provided significant advice.

All authors read and approved the final manuscript.

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