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ORIGINAL ARTICLE

Information resources used by patients with inflammatory bowel disease: Satisfaction, expectations and information gaps

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KEYWORDS
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Abstract

Background and purpose: Information received by IBD patients about their disease is of particular importance. The objective of the study was to determine the information resources these patients used, together with their perceived information gaps and expected preferences.
Patients and methods: A prospective, observational, cross-sectional study conducted on IBD patients attending 13 Spanish hospitals during 2008. Patients completed a semi-structured 52-question survey.
Results: Survey was adequately completed by 379 of 385 patients (98%), of whom 57% had Crohn's disease and 43% ulcerative colitis. Mean patient age was 37.9 years (range, 16–76 years). Gastroenterologists were the most commonly used resource (98%), followed by the Internet (60%), and general practitioners (50%). More than 90% reported good to excellent satisfaction with gastroenterologists, nurses, and patients' associations. Only 56% considered their

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information needs to be covered. The Internet was mostly used by young patients and those with a high education level. In the future, 85% of the patients would like to receive information from the gastroenterologists, and 92% by face-to-face interviews. Patients mainly want additional information on treatment (medical and surgical), clinical manifestations, cancer, and mortality risks. They also think that they are poorly informed about their social and work rights, risks of cancer and death, and research trials.
Conclusions: Patients with IBD use and prefer gastroenterologists as the main source of information, but only half of them consider their information needs to be covered.

PALABRAS CLAVE
Enfermedad inflamatoria intestinal;
Enfermedad de Crohn;
Colitis ulcerosa;
Pacientes;
Información;
Internet;
Satisfacción;
Prioridades

Recursos de información utilizados por los pacientes con enfermedad inflamatoria intestinal: satisfacción, expectativas y lagunas en la información

Resumen

Antecedentes y objetivos: La información recibida por los pacientes con EII sobre su enfermedad es de particular importancia. El objetivo de este estudio fue determinar los recursos informativos que utilizan estos pacientes, así como las lagunas de información que perciben y sus preferencias.
Pacientes y métodos: Estudio prospectivo, observacional y transversal realizado en pacientes con EII atendidos en 13 hospitales españoles durante el año 2008. Los pacientes cumplimentaron un cuestionario semiestructurado de 52 preguntas.
Resultados: El cuestionario fue cumplimentado adecuadamente por 379 de los 385 pacientes participantes (98%). De ellos, el 57% presentaban enfermedad de Crohn y el 43% colitis ulcerosa. La edad media de los pacientes fue de 37,9 años (intervalo: 16-76 años). Los gastroenterólogos fueron el recurso más utilizado (98%), seguido de Internet (60%) y de los médicos de familia (50%). Más del 90% de los pacientes señaló un grado de satisfacción con el gastroenterólogo, el servicio de enfermería y las asociaciones de pacientes de buena a excelente. Solo el 56% considera que sus necesidades informativas están cubiertas. Los pacientes jóvenes y aquellos con un nivel educativo alto son los que más utilizan Internet. Al 85% de los pacientes le gustaría recibir información de los gastroenterólogos en el futuro, y el 92% preferiría tener entrevistas presenciales. Los pacientes quieren principalmente información adicional sobre tratamientos (médicos y quirúrgicos), manifestaciones clínicas, cáncer y riesgos de mortalidad. También piensan que están mal informados acerca de sus derechos sociales y laborales, los riesgos de cáncer y la mortalidad, así como sobre los estudios de investigación.
Conclusiones: Los pacientes con EII utilizan y prefieren tener a los gastroenterólogos como fuente principal de información, pero solo la mitad de ellos consideran que sus necesidades informativas están cubiertas.

Introduction

The onset of chronic inflammatory bowel disease (IBD) tends to occur in young adults. It has a typical course with exacerbations and remissions, with the resulting long-term morbidity (including hospitalisations, surgery, etc.).[1] As with other chronic and disabling diseases, an adequate doctor–patient relationship is required to improve the communication and well-being of patients and their relatives. Moreover, adequate information is an important factor to improve self-management of the disease.

Healthcare professionals who care for IBD patients should be aware of their information needs, as well as their concerns and degree of satisfaction with care received.[2] Improvement in health-related quality of life (HRQL) should be one of the essential objectives in the treatment of IBD.[3] Specialised clinics and multidisciplinary IBD units are proliferating in Spain and other countries to provide appropriate care to these patients. They allow for a more personalised and efficient relationship, with coordinated involvement of various departments and implementation of cross-disciplinary, patient-focused management models.[4] Provision of adequate information is considered a key element because: (1) there are very different ways to provide it (brochures, books, healthcare staff, the Internet, conferences, etc.)[5]; (2) adequate information seems to have a positive impact on quality of life[3]; and (3) acquisition of knowledge about the disease and the emotional adjustment to living with it seem to be closely related.[6,7] Recent studies have shown the importance of providing good information on aspects related to IBD[2] both after diagnosis and during disease progression.[8]