

# A Systematic Review of Patient Inflammatory Bowel Disease Information Resources on the World Wide Web

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**BACKGROUND AND AIMS:** The Internet is a widely used information resource for patients with inflammatory bowel disease, but there is variation in the quality of Web sites that have patient information regarding Crohn's disease and ulcerative colitis. The purpose of the current study is to systematically evaluate the quality of these Web sites.

**METHODS:** The top 50 Web sites appearing in Google™ using the terms "Crohn's disease" or "ulcerative colitis" were included in the study. Web sites were evaluated using a (a) Quality Evaluation Instrument (QEI) that awarded Web sites points (0–107) for specific information on various aspects of inflammatory bowel disease, (b) a five-point Global Quality Score (GQS), (c) two reading grade level scores, and (d) a six-point integrity score.

**RESULTS:** Thirty-four Web sites met the inclusion criteria, 16 Web sites were excluded because they were portals or non-IBD oriented. The median QEI score was 57 with five Web sites scoring higher than 75 points. The median Global Quality Score was 2.0 with five Web sites achieving scores of 4 or 5. The average reading grade level score was 11.2. The median integrity score was 3.0.

**CONCLUSIONS:** There is marked variation in the quality of the Web sites containing information on Crohn's disease and ulcerative colitis. Many Web sites suffered from poor quality but there were five high-scoring Web sites.

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## INTRODUCTION

Crohn's disease and ulcerative colitis are lifelong conditions that can have a significant impact on the quality of life. They are complex diseases for which a considerable amount of patient education is warranted. Patient education therefore should be an integral part of patient management. Patients want a wide range of information including how inflammatory bowel disease is diagnosed, the possible etiologies, different treatment options and when they are indicated, and how the disease is monitored. Studies have identified concerns that patients have about their disease, including worries about the possibility of having an ostomy bag, need for surgery, the side effects of medications, and the impact on well-being (1). In an Italian outpatient study, only 30% of IBD patients on average considered the knowledge of their disease adequate (2). Patients in that study identified knowledge gaps with respect to pregnancy, cancer, and the role of diet in management of their disease. They placed greatest emphasis on information concerning the cause of IBD, diet, symptoms, and new treatments. Similar results are reported in other studies (3–5).

The information need of patients is often incompletely met during clinic visits (6). Patients therefore turn to other sources for medical information. The World Wide Web provides a new

avenue for patients and their relatives to obtain health-related information. In a U.S. study of gastroenterology outpatients published in 2000, 50% of all patients had Internet access and 51% of these reported using the Internet to find medical information related to their medical conditions (7). A recent study of U.S. cancer patients showed disease-related Internet use at 44% for patients and 60% for their companions (8). Another study found over half of patients used the Internet for medical information (9).

Concerns have been raised about the quality of information that patients may find on the Internet (10–12). Although there is little documented evidence of harm caused by Internet-derived (mis)information (10, 13), there are concerns that patients may encounter medical information that is inaccurate, inappropriate, or is not being updated according to new evidence (12, 14). Most patients are not aware of evidence-based medicine and its importance to patient management (15) and consequently may not be aware that a lot of information available on the Internet does not reflect best clinical practice. In spite of concerns about quality, the Internet has the potential to play an important role in facilitating patient education about medical conditions.

The objective of our study was to systematically evaluate the quality and integrity of Web sites containing educational information about inflammatory bowel disease.

## METHODS

The protocol for the study had specific objectives that evaluated IBD Web sites for: (a) quality of general information provided about Crohn's disease and ulcerative colitis using a Quality Evaluation Instrument (QEI); (b) a Global Quality Score (GQS), which assessed overall quality, flow of the Web site, and ease of use; (c) readability of the Web site; and (d) integrity of the Web site, that is, information about ownership of the site and who is responsible for the content and updates.

### Internet Search Strategy

Web sites were identified by searching the World Wide Web with the search engine Google™ using the following terms: "Crohn's disease" OR "ulcerative colitis" (quotations included). All sites were examined for information on Crohn's disease and ulcerative colitis, whether this information was on the paged linked immediately from Google™ or found elsewhere on the site.

### Criteria to Identify Web Sites

The inclusion criteria for Web sites to be eligible for review were that they (a) provided educational information on inflammatory bowel disease (IBD; Crohn's disease and/or ulcerative colitis) and (b) were written in English. Web sites were excluded if they served primarily as portals, serving links to third-party sites without containing any specific educational information within the site itself. If a site was primarily focused on non-IBD (*e.g.*, irritable bowel syndrome), it was also excluded. It was decided that the first 50 Web sites appearing in Google™ would be further evaluated as Internet searchers do not typically view more than 10 results (16), and it was assumed that 50 Web sites would provide sufficient information about quality of the Web sites.

### Development of Web Site Quality Evaluation Instrument

The QEI was developed, which evaluated the following knowledge domains of an IBD Web site: general IBD information, symptoms, diagnosis, etiology, disease course, nutrition, complications, medical and surgical treatment, quality of life, new treatments, and complimentary therapies (Table 1). For each domain, a checklist with relevant items was created based on discussions with three gastroenterologists and a review of the literature to select knowledge areas deemed important by patients (2, 3). If a criteria item was not discussed or named, it received zero points for that item. If the provided information was incorrect, no points were given. Domains and item checklists were pretested three times prior to final use to confirm validity using a random selection of Web sites. The QEI score is based on the sum of points from individual items. The maximum possible score was 107. To ensure accuracy of the QEI, two reviewers (AB and SH) reviewed the Web sites independently to calculate a QEI score. Any differences were corrected by re-review of the Web site to generate a single QEI score for that Web site.

**Table 1.** Description of the Components of the Quality Evaluation Instrument Used to Evaluate Web Sites With Information on Crohn's Disease and Ulcerative Colitis, Score Range Is 0–107

#### Defines IBD

- Describes Crohn's disease and ulcerative colitis generally as diseases of chronic inflammation. Differentiates diseases. Differentiates IBS from IBD. Discusses relevant anatomy.
- Generally describes Crohn's disease as a disease of chronic inflammation of the GI tract.
  - Generally describes ulcerative colitis as a disease of chronic inflammation of the large intestine.
  - Defines inflammatory bowel disease as a general term for Crohn's disease and ulcerative colitis.
  - Makes the distinction between IBD from irritable bowel syndrome (IBS).
  - Defines/describes terms (plain language or diagram or general description):
    - Large intestine/bowel/colon
    - Rectum
    - Ileum/terminal ileum
    - Duodenum
    - Jejunum
  - Discusses the epidemiology of Crohn's disease/ulcerative colitis.
  - Describes Crohn's disease most commonly affecting terminal ileum but can occur anywhere in GI tract.
  - Describes ulcerative colitis as affecting the rectum and other parts of the colon.

**Symptoms and Signs:** Describes symptoms and signs of Crohn's disease and ulcerative colitis.

Describes common symptoms of UC:

- Rectal bleeding/blood in stool
- Mucus in stool
- Diarrhea/bowel frequency
- Urgency
- Tenesmus/false urge
- Abdominal cramping or pain/discomfort
- Loss of appetite
- Fatigue
- Weight loss

Describes common symptoms of Crohn's disease:

- Abdominal pain, may be right lower quadrant
- Diarrhea
- Loss of appetite
- Weight loss
- Aphthous ulcers in mouth
- Fatigue
- Perianal disease

Describes extraintestinal signs and symptoms of IBD:

- Eye symptoms (iritis/uveitis)
- Ankylosing spondylitis (axial arthropathies)
- Joint pain/arthritis (especially joints of lower extremities)
- Erythema nodosum/pyoderma gangrenosum
- Hepatic/biliary disease (PSC, gall stones, etc.)
- Other

**Diagnosis:** Discusses how IBD is diagnosed.

- Based on symptoms and physical exam.
- Discusses role of blood work (CBC, CRP, ESR, albumin, LRTs)
- Explains potential diagnostic tests including:
  - Barium enema x-ray
  - Upper GI series with small bowel follow through
  - Endoscopy/sigmoidoscopy/colonoscopy
  - Stool: occult blood, cultures, O&P
  - Biopsy
  - Indium scan

*Continued.*

Table 1. Continued.

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- CT
- MRI
- ERCP

**Disease Cause:** Discusses what causes IBD (Crohn's and ulcerative colitis)

- Unknown etiology
- Genetic predisposition
- Potential environmental trigger – organism or food
- Abnormal immune response

**Disease Course:** Discusses the nature of Crohn's and UC with respect to disease course.

- Variable disease course: describes Crohn's disease and/or colitis as often waxing and waning with flare-ups of symptoms and spontaneous remissions or persistent disease or disease that spontaneously resolves.
- Hospitalization may be necessary if flare-ups are severe.
- Surgery is a possibility to treat complications or for severe disease.
- Discusses that stress may aggravate existing symptoms but does not cause IBD symptoms or IBD.
- Smoking may adversely affect disease course in Crohn's disease and may lead to start of UC in first 2 yr after quitting.

**Nutrition and IBD:** Discusses issues of nutrition and diet in inflammatory bowel disease.

- Discusses that diet does not cause UC or Crohn's but may affect symptoms depending on the individual; individuals may have food intolerances.
- Discusses the importance of maintaining a healthy, balanced diet.
- Discusses malabsorption and malnutrition in IBD: as a result of inflammation, diarrhea, bleeding, or surgical resection of the bowel.
- Discusses possibility of lactose intolerance in IBD and the recommendation to avoid milk products.
- Discusses tube feeding.
- Discusses TPN.
- Discusses elemental diets.
- Discusses simple sugars as aggravating diarrhea (causing an osmotic diarrhea).
- Discusses nutrient deficiencies including sequelae from treatment:
  - Vitamin and/or nutrient deficiencies in general
  - Vitamin B<sub>12</sub> deficiency
  - Folate deficiency
  - Iron deficiency
  - Calcium and vitamin D (also related to corticosteroids)

**Disease Complications:** Discusses the complications that may arise from Crohn's or UC

- Strictures/bowel obstruction
- Perforations, abscesses, fistulas
- Perianal disease
- Malabsorption
- Iron deficiency anemia
- Low albumin
- Bleeding
- Toxic megacolon
- Greater risk of colon cancer
- Progressive disease unresponsive to treatment requiring surgery.

**Medical Treatment:** Discusses drug treatment

- 5-ASA preparations
- Prednisone

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Continued.

Table 1. Continued.

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- Prednisone side effects and complications
- Budesonide
- Role of calcium and vitamin D supplementation with corticosteroids
- Role of broad spectrum antibiotics – metronidazole and ciprofloxacin
- Role of immunosuppressive therapy – azathioprine/6-MP/methotrexate
- Role of probiotics
- Biologic agents (infliximab)

**Surgical Treatment**

- Discusses the possibility and indications for surgery
- Discusses fears about surgery
  - Crohn's disease:
    - Bowel resection
    - Surgery for small bowel obstruction
    - Surgery for abscesses and fistulas
    - Discusses ileostomy and colostomy
  - Ulcerative colitis:
    - Discusses total proctocolectomy
    - ...With ileostomy
    - ...With Kock pouch (continent reservoir ileostomy)
    - ...With ileo-anal pelvic pouch anastomosis (J-pouch or S-pouch)
    - Discusses potential complications of surgery

**Psychosocial and Quality of Life Issues Related to Living With IBD:** Discusses:

- IBD and sexuality (e.g., drive, function, medication-related)
- Effect of IBD on fertility and pregnancy
- IBD and travel
- IBD and insurance issues
- Costs of living with IBD (e.g., drug costs, drug plans, etc.)
- IBD and depression
- IBD and children/youth/young adults
- IBD and relationships (marriage/spouse, social functioning)

**New Treatments and Complimentary Therapies:** Discusses the existence of complementary (naturopathic, diet, etc.) therapies and describes their evidence/lack of evidence.

- Discusses new/future treatments and their evidence.
- Discusses new treatments and complementary therapies

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### Global Quality Score

Independent of the QEI, the overall quality of each Web site reviewed was subjectively rated using the GQS, which is a five-point Likert scale developed for this study described in Table 2. Apart from overall quality, it takes into account the flow and ease of use of each Web site.

### Readability Assessment

A 100 word sample of text describing IBD symptoms was extracted from each included Web site and pasted into the program Word by Microsoft®. The text was examined using the Flesch-Reading Ease score in the program. This reading ease score is graded out of 100, where text that is easier to read scores higher based on the average sentence length and the average number of syllables per word. The Flesch-Kincaid Grade Level score was also used, which compares

**Table 2.** Description of the Global Quality Score Five-Point Scale Used to Evaluate Web Sites Containing Information on Crohn’s Disease and Ulcerative Colitis

Global Score	Global Score Description
1	Poor quality, poor flow of the site, most information missing, not at all useful for patients
2	Generally poor quality and poor flow, some information listed but many important topics missing, of very limited use to patients
3	Moderate quality, suboptimal flow, some important information is adequately discussed but others poorly discussed, somewhat useful for patients
4	Good quality and generally good flow, most of the relevant information is listed, but some topics not covered, useful for patients
5	Excellent quality and excellent flow, very useful for patients

the text to an approximate U.S. grade-school level. This is also calculated using average sentence length and average syllables per word.

**Integrity Score**

Based on a review of other tools used to evaluate health Web sites (17, 18), a six-point Integrity Score was generated using criteria which rated the credibility of a Web site and its content on the disclosure of information related to ownership of the Web site, sources of funding, and privacy (Table 3).

**RESULTS**

The Google™ search carried out in August 2004 using the term “Crohn’s disease” OR “ulcerative colitis” returned 271,000 results. The top 50 results were evaluated. Sixteen sites did not meet inclusion criteria because they were either portals or their main content did not deal with IBD. Of the 34 sites reviewed, 28 addressed both Crohn’s disease and ulcerative colitis (CD&UC), five addressed only Crohn’s disease (CD), and one addressed only ulcerative colitis (UC).

The Web sites as ranked by QEI scores and their corresponding Google™ search ranking are listed in Table 4. Two reviewers independently generated QEI scores for each Web site. Differences in scoring between reviewers were primarily a result of data extraction errors, where one reviewer overlooked a point of information for that Web site. Fourteen sites had initial inter-rater QEI score differences of ≥7. Dif-

ferences were reconciled to generate a single QEI score for each Web site. Twelve Web sites were identified as being part of general health information Web sites and 22 Web sites were identified as IBD-specific.

The QEI scores varied widely with a minimum score of 19 and a maximum score of 103. The median QEI score for all Web sites evaluated was 57 (N = 34) with a first and third quartile (Q<sub>1</sub>, Q<sub>3</sub>) of 42 and 68, respectively. For CD&UC sites (N = 28), the median QEI score was 62 with a Q<sub>1</sub>, Q<sub>3</sub> of 49 and 71, respectively. The Web sites with information on CD only (N = 5) had a median score of 26 with a Q<sub>1</sub>, Q<sub>3</sub> of 25 and 36, respectively. One Web site had information on UC only; it achieved a QEI score of 44. Six sites appeared primarily to promote a commercial product even though they were not portals. These commercial Web sites had a median QEI score of 47. The Web sites with information on CD only or UC only were graded using the entire checklist containing information on both CD and UC. Two sites achieved a QEI score ≥80 (<http://www.ccfa.org> and <http://www.healingwell.com/ibd>). Three Web sites achieved scores from 75 to 79 (<http://ibdcrohns.about.com>, <http://www.crohns.org.uk>, and <http://groups.msn.com/CrohnsDiseaseintheUK>). Eighteen sites scored ≤60.

The median global score of all Web sites evaluated (N = 34) was 2.0. The median GQS for Web sites with information on CD&UC was 3, while the five Web sites with information on CD only had a median value of 1. The Web site with information on UC only had a GQS of 3. The six commercial Web sites had a median GQS of 2. The highest GQS of 5 was achieved by one site (<http://www.ccfa.org>). Four sites received a global score of 4: [http://yourmedicalsourc.com/library/ulcerativecolitis/UC\\_what.html](http://yourmedicalsourc.com/library/ulcerativecolitis/UC_what.html), [http://www.medicinenet.com/ulcerative\\_colitis/article.htm](http://www.medicinenet.com/ulcerative_colitis/article.htm), <http://www.digestivedisorders.org.uk>, <http://digestive.niddk.nih.gov/ddiseases/pubs/crohns>.

Figure 1 shows there was a direct relationship between the QEI and GQS (r = 0.81). There was an unclear relationship between the QEI scores and the Google™ search rank (data not shown).

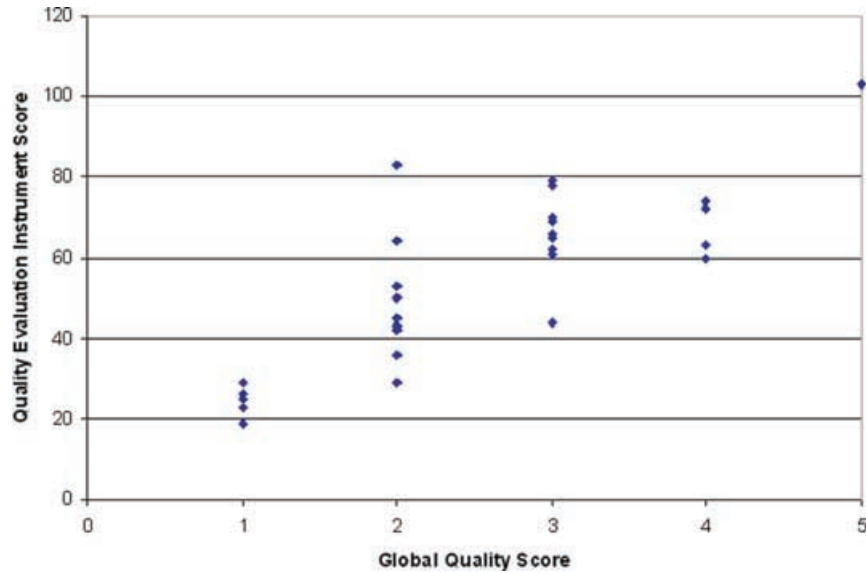
Figure 1 describes the composition of raw scores according to category. The categories dealing with symptoms, diagnosis, and etiology showed the least amount of variability. The average score for each domain was calculated from all

**Table 3.** The Six Points Comprising the Integrity Score Used to Evaluate Web Sites Containing Information on Crohn’s Disease and Ulcerative Colitis

Six Points of Integrity Score
<input type="checkbox"/> Displays name and logo of institution or organization responsible and relevant authors for page content.
<input type="checkbox"/> The dates of the original Web documents and updates are listed.
<input type="checkbox"/> Site shows evidence that it is updated on a periodic basis, according to new evidence.
<input type="checkbox"/> The mission or purpose of the Web site is stated.
<input type="checkbox"/> Sources of funding and sponsorship (or lack thereof) and linkages with third-party organizations are disclosed.
<input type="checkbox"/> The Web site has a privacy statement, which describes how information is used.

**Table 4.** The Crohn's Disease and Ulcerative Colitis Web Sites as Ranked by the Quality Evaluation Instrument. Also Included Are the Global Quality Score and Position the Web Site Appeared in the Google™ Search.

Web Site	Quality Evaluation Instrument	Global Quality Score	Position in Google™ Search
Crohn's & Colitis Foundation of America <a href="http://www.cffa.org">http://www.cffa.org</a>	103	5	8
Crohn's Disease Resource Centre, Healing Well <a href="http://www.healingwell.com/ibd/">http://www.healingwell.com/ibd/</a>	83	2	1
About.com- Irritable bowel/crohn's disease <a href="http://ibscrohns.about.com/">http://ibscrohns.about.com/</a>	79	3	27
Crohn's Disease in the UK/IBD Site <a href="http://groups.msn.com/CrohnsDiseaseintheUK/">http://groups.msn.com/CrohnsDiseaseintheUK/</a>	78	3	30
Crohn's Disease and Ulcerative Colitis Addensbrook/SHS Int'l <a href="http://www.crohns.org.uk/">http://www.crohns.org.uk/</a>	78	3	22
Your Medical Source: Ulcerative Colitis and Crohn's Disease <a href="http://yourmedicalsourc.com/library/ulcerativecolitis/UC`whatis.html">http://yourmedicalsourc.com/library/ulcerativecolitis/UC`whatis.html</a>	74	4	36
MedicineNet.com – UC/Crohn's <a href="http://www.medicinenet.com/ulcerative_colitis/article.htm">http://www.medicinenet.com/ulcerative_colitis/article.htm</a>	72	4	12
Merck Manual – Inflammatory Bowel Disease <a href="http://www.merck.com/mrkshared/mmanual/section3/chapter31/31c.jsp">http://www.merck.com/mrkshared/mmanual/section3/chapter31/31c.jsp</a>	69	3	41
eMedicine – Ulcerative Colitis (adult) <a href="http://www.emedicine.com/med/topic2336.htm">http://www.emedicine.com/med/topic2336.htm</a>	66	3	18
Diseases we treat, University of Chicago Hospitals and Health System <a href="http://gi.bsd.uchicago.edu/diseases/inflambowel/colitis/ulcerativecolitis.html">http://gi.bsd.uchicago.edu/diseases/inflambowel/colitis/ulcerativecolitis.html</a>	66	3	20
MayoClinic.com – Inflammatory bowel disease <a href="http://www.mayoclinic.com/invoke.cfm?id=DS00104">http://www.mayoclinic.com/invoke.cfm?id=DS00104</a>	65	4	0
eCureMe – Crohn's Disease <a href="http://www.ecureme.com/emyhealth/data/Crohn's_Disease.asp">http://www.ecureme.com/emyhealth/data/Crohn's_Disease.asp</a>	64	4	17
Ulcerative Colitis & Crohn's Disease <a href="http://www.digestivedisorders.org.uk/leaflets/colitis.htm">http://www.digestivedisorders.org.uk/leaflets/colitis.htm</a>	63	4	25
National Digestive Diseases Information Clearinghouse <a href="http://digestive.niddk.nih.gov/ddiseases/pubs/crohns">http://digestive.niddk.nih.gov/ddiseases/pubs/crohns</a>	63	4	7
National Society for Colitis and Crohn's Disease <a href="http://www.nacc.org.uk/">http://www.nacc.org.uk/</a>	62	3	2
Jackson Gastroenterology Patient Education <a href="http://www.gicare.com/pated/ecd0001.htm">http://www.gicare.com/pated/ecd0001.htm</a>	61	3	11
Intestinal Disease Foundation <a href="http://www.intestinalfoundation.org/library/ulcerative.shtml">http://www.intestinalfoundation.org/library/ulcerative.shtml</a>	53	2	43
Digestive Disorders Information <a href="http://www.umm.edu/digest/ibdcr01.htm">http://www.umm.edu/digest/ibdcr01.htm</a>	50	2	47
Everybody – New Zealand Consumer Health Info <a href="http://www.everybody.co.nz/docsq_w/ulcercol.htm">http://www.everybody.co.nz/docsq_w/ulcercol.htm</a>	50	2	29
Cincinnati Children's Hospital Crohn's and Colitis <a href="http://www.cincinnatichildrens.org/health/info/abdomen/diagnose/crohns.htm">http://www.cincinnatichildrens.org/health/info/abdomen/diagnose/crohns.htm</a>	50	2	49
Health Concern: Crohn's Disease <a href="http://www.lef.org/protocols/prtcl-132.shtml">http://www.lef.org/protocols/prtcl-132.shtml</a>	50	2	26
Living Better – P & G <a href="http://www.living-better.com">http://www.living-better.com</a>	49	3	9
NHSDirect: Ulcerative Colitis and Crohn's Disease <a href="http://www.nhsdirect.nhs.uk/en.asp?TopicID=140">http://www.nhsdirect.nhs.uk/en.asp?TopicID=140</a>	45	2	50
Jewish Genetic Diseases <a href="http://www.mazornet.com/genetics/ulcerativecolitis.asp">http://www.mazornet.com/genetics/ulcerativecolitis.asp</a>	43	2	34
Ulcerative Colitis/Crohn's Disease <a href="http://www.netdoctor.co.uk/diseases/facts/ulcerativecolitis.htm">http://www.netdoctor.co.uk/diseases/facts/ulcerativecolitis.htm</a>	42	2	40
Vitacost.com – Ulcerative Colitis and Crohn's Disease <a href="http://www.vitacost.com/science/hn/Concern/Ulcerative_Colitis.htm">http://www.vitacost.com/science/hn/Concern/Ulcerative_Colitis.htm</a>	36	2	42
Practice Guideline – Crohn's Disease, March 2001 <a href="http://www-east.elsevier.com/ajg/issues/9603/ajg3671fla.htm">http://www-east.elsevier.com/ajg/issues/9603/ajg3671fla.htm</a>	36	2	39
Mama's Health – UC and Crohn's <a href="http://www.mamashealth.com/stomach/crohn.asp">http://www.mamashealth.com/stomach/crohn.asp</a>	29	2	48
Wikipedia – The Free Encyclopedia <a href="http://en.wikipedia.org/wiki/Ulcerative_colitis">http://en.wikipedia.org/wiki/Ulcerative_colitis</a>	29	1	0
Crohn's Disease Web Site <a href="http://www.angelfire.com/ga/crohns/">http://www.angelfire.com/ga/crohns/</a>	26	3	6
BBC Medical Notes – Crohn's Disease <a href="http://news.bbc.co.uk/1/hi/health/medical_notes/149004.stm">http://news.bbc.co.uk/1/hi/health/medical_notes/149004.stm</a>	25	4	19
Pagewise- What is Crohn's and What is UC? <a href="http://wa.essortment.com/crohnsdiseases_rvw1.htm">http://wa.essortment.com/crohnsdiseases_rvw1.htm</a>	23	1	45
Annie's Crohn's Disease Page <a href="http://mycrohns.freesevers.com/">http://mycrohns.freesevers.com/</a>	19	3	13



**Figure 1.** Relationship of the Global Quality Score and the Quality Evaluation Instrument score used to evaluate Crohn's disease and ulcerative colitis Web sites.

the Web sites. The highest scoring domains were etiology (74% of the possible points achieved), symptoms (62%), defines IBD (60%), treatment (59%), complications (59%), and course (57%). The domains that averaged the worst scores were quality of life (13%), nutrition (36%), and diagnosis (48%).

The average Flesch-Kincaid Grade Level was 11.2 (range 6.7–12.0). The average Flesch Reading Ease score was 35.6 out of 100 (range 15.2–69.4), on a scale where lower scores represent more complicated text. The median integrity score was 3.0 out of a possible six points ( $N = 34$ ). Eleven sites provided information on when the site was last updated. Only five Web sites disclosed the sponsorship or funding of the Web site.

## DISCUSSION

Patient education is important in the management of any chronic disease (19, 20). Disease knowledge can positively impact quality of life, promote treatment compliance, and helps to facilitate that appropriate treatment is used following an approach that is collaborative and patient-centered (21). Greater knowledge may improve quality of life and reduce disease-related concerns (1). The Internet is increasingly used by patients including those suffering from IBD (8, 9). Patients are motivated to use the Internet for a variety of reasons, including seeking second opinions, finding support, helping in the interpretation of symptoms, gaining knowledge about tests and treatments, and identifying questions for doctors (22). There is evidence that the quality of Internet-derived health information varies widely and warnings have been issued that sites may provide misleading and nonevidence-based information (23).

We prospectively evaluated the quality of educational information deemed important by both patients and clinicians

available on Web sites for inflammatory bowel disease. Web sites were identified using Google™, which is by far the most popular search engine used by members of the public (24–26).

The results showed marked variation in the quality of available educational material as covered by the QEI. The QEI covers a wide variety of information that is relevant for IBD patients. There was no clear relationship between the search rank of a Web site returned by Google™ and the QEI. Only two of the 10 highest QEI scoring Web sites appeared within the first 10 Web sites listed by Google™. This is of particular concern considering that most Web users browse only the first 10 Web sites listed in the results (16). This suggests that patients are unlikely to consistently view the most comprehensive Web sites when searching the Internet. The reasons for the poor correlation between Google™ rank and QEI score are unclear but likely are due to the fact that our quality criteria are not the ones that make a Web site rank high on Google™. Google™ ranks a particular Web site based upon the number and importance of other pages, which link to that site. This technology, Pagerank™, has been shown to correlate with Web site quality; however, this may not be specific for the quality of medical information provided, which was the main interest of our study (27).

The GQS like the QEI also demonstrated marked variation in Web site quality, with only one site achieving the maximum score of five and four sites achieving scores of four. There was a direct relationship between the QEI and the GQS ( $r$  of 0.81). The QEI therefore has the ability to discriminate between Web sites that would be of use to patients or not. One Web site, <http://www.healingwell.com/ibd>, received a poor GQS but a high QEI score of 83 because when the Web site was originally reviewed the “frequently asked questions” section, which was very well written, was difficult to locate within the Web site. The reviewers gave this Web site a GQS of 2 due to

“poor flow.” The Web site was reviewed the following year for a different study and at that time the link to the “frequently asked questions” section was easy to locate and was user friendly. If <http://www.healingwell.com/ibd> is not included in the data for calculation of the correlation coefficient, the *r* value increases to 0.87. This underlines the importance of Web sites having a simple and effective format from which the information is easy to derive.

There was a high degree of variability in several of the knowledge categories assessed in this study. The quality of life domain included such issues as sexuality, fertility and pregnancy, costs, insurance, travel, and depression, which are deemed important by many patients. However, only one Web site, <http://www.ccfa.org>, discussed more than half of the eight items in this category. Similarly, information on nutrition was infrequently covered. It is unclear why both quality of life and nutrition received so little attention in the Web sites despite the fact that their importance is generally acknowledged. Perhaps this is explained by the fact that there are no specific treatments or recommendations that specifically target these areas. It has been shown that patients have fears about surgery following a diagnosis of IBD (28), but very few sites addressed this concern adequately with only seven Web sites discussing more than 80% of the items in the surgery category. Four Web sites, <http://www.ccfa.org>, <http://www.healingwell.com/ibd>, <http://groups.msn.com/CrohnsDiseaseintheUK>, and <http://gi.bsd.uchicago.edu/diseases/inflambowel/colitis/ulcerativecolitis.html> achieved satisfactory results scoring over 90% of the items in the surgery category. Prednisone and budesonide, common drugs in the treatment of IBD, were discussed by most sites, though their side effects were not discussed in adequate detail in 50% of sites.

Most Web sites did not provide adequate information about how up to date the Web site was as only eleven sites provided a date of last update. Additionally, only five Web sites had information regarding the sponsorship or funding of the Web site. A study evaluating the quality of Web sites providing information about prostate cancer found that most of the reviewed Web sites did not have information on currency, and other aspects of disclosure such as authorship were often lacking (29). This highlights that these important pieces of information are often missing (30, 31).

The readability assessment showed that most Web sites require an advanced reading level to understand their content. The average reading grade level of the Web sites was 11.2 out of 12. This is well above the recommended grade six reading level (28). It will be interesting to find out whether the high reading-grade level means that the content will not be understood by a substantial number of patients. It is possible, however, that Internet users have a higher education level, making reading grade less of a concern.

In conclusion, we have shown that there is marked variation in the quality, integrity, and how up to date the information is in educational Web sites for IBD patients. The Internet is a vast information resource and the quality of information it

contains varies extensively. Patients use the Internet to learn about their diseases. The information that a patient derives from the Internet has the potential to influence that patient's opinion and ultimately the course of disease and treatment. Ideally, health-care providers should suggest appropriate Web sites and information resources so that patients can make educated decisions based on accurate and complete information. For that reason, it would be helpful that an accreditation system be put in place that would clearly identify Web sites that provide unbiased, evidence-based, and up to date information. Accreditation should be a prominent feature that can be identified by search engines such as Google™.

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### CONFLICT OF INTEREST

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