

# Surfing the Net — Information on the World Wide Web for Persons with Arthritis: Patient Empowerment or Patient Deceit?

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**ABSTRACT.** *Objective.* In the past few years access to the Internet has become readily available. Patients are increasingly seeking and obtaining health information through the Internet, most often the World Wide Web (WWW). We assessed the content, authorship, and scope of the information available on WWW in relation to rheumatoid arthritis.

*Methods.* In an attempt to replicate use by the average person, a broad search of the Internet was conducted for the phrase “rheumatoid arthritis” using WebCrawler, a commonly used search engine. All the “hits” were critically assessed after visiting and collecting information from the respective Web sites in relation to relevance, scope, authorship, type of publication, and financial objectives.

*Results.* The search returned 537 hits. We evaluated 531 — 2 did not exist, 2 could not be contacted, one was not in English, and one required a membership to access. The 531 hits originated from 388 Web sites. Only 198 (51%) were considered to be relevant and 7 (2%) were of doubtful relevance. Thirty-four (17%) were posted by an individual, 57 (28%) by a nonprofit organization, 104 (51%) by a profit industry, and 10 (5%) by universities. Ninety-one (44%) promoted alternative therapies, the most common including cetyl-myristoleate, colloidal minerals, Pycnogenol, shark cartilage, and Tahitian Noni. Of the 107 sites with financial interests, 76 (71%) promoted alternative medicine. The first 100 hits only identified about a third of the nonprofit organizations or university owned Web pages.

*Conclusion.* Many sites easily accessed by consumers appear to be profit based companies advertising an alternative product claimed to be effective for many conditions. These findings emphasize the need for critical evaluation of Web site contents. (J Rheumatol 2001;28:185–91)

*Key Indexing Terms:*

RHEUMATOID ARTHRITIS    WORLD WIDE WEB    INTERNET    ALTERNATIVE THERAPY

In the past few years access to the Internet has become readily available in developed countries. Patients are increasingly seeking and obtaining health information through the Internet, most often the World Wide Web (WWW). The advantages of disseminating information via the Internet are obvious. The Internet has doubled in size annually for the past 11 years. It is estimated that it is accessed by 150 million users<sup>1</sup>. Consumers and health professionals are using the Web in

increasing numbers to locate and purchase goods, and also to access health information to assist them in medical decisions. For the provider of information the use of this medium is expedient, powerful, and inexpensive, and allows for change or substitution of contents on an ongoing basis. For consumers, access to the Web is also relatively inexpensive if they own a computer and user friendly, even for those with limited computer skills. Access to information can theoretically provide patients with enhanced skills for decision making processes and preference based choices. On the other hand, misleading or untruthful information can result in a false sense of knowledge and control.

According to a recent study by the Office of Research of the Online Computer Library Center (OCLC), it is estimated that there are about 3.6 million sites on the Web, with 2.2 million offering publicly accessible content<sup>2</sup>. Another recent study indicates that the publicly accessible Web contains roughly 800 million pages on more than 3 million servers<sup>3</sup>. Independent parties have seldom critically appraised health related contents. Nevertheless, the little information available suggests that the quality of health related Web sites is highly variable<sup>4-6</sup>.

Patients with rheumatic disorders are among the most frequent seekers of alternative therapy<sup>7-12</sup>, perhaps because of the

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chronic nature of their illness and the lack of curative therapies. These traits may also result in behaviors related to the retrieval of information other than that provided by “conventional” health professionals. We assessed the content, authorship, and scope of the information available on the Web for patients with rheumatoid arthritis (RA) by replicating a simple search strategy that a patient may use.

## MATERIALS AND METHODS

An electronic search was conducted using WebCrawler, a commonly used search engine that allows natural language searching. WebCrawler was America Online’s preferred search engine until November 1996, when it was bought by Excite, which runs it now as an independent engine. We selected WebCrawler for the study because it has a smaller index than other search engines, and provides less overwhelming results in general searches<sup>13</sup>. The search was broad in an attempt to replicate use by a typical patient: The phrase “rheumatoid arthritis” was searched with no restrictions or filters applied. All of the “hits” (Web pages) obtained with the search were critically assessed. Often several different Web pages from a single Web site were accessed. We assessed the page after visiting and collecting information from the associated site. The assessments were made by one author (CJK), and were crosschecked by another if the assessment was considered unclear (MSA). The following items were included in the review:

1. Relevance to patients with RA. We considered relevant those sites that included information about the clinical aspects of RA — signs and symptoms, etiology, diagnosis, treatment, or prognosis. Relevance was not judged in relation to the quality or accuracy of the data presented, only in relation to whether the information could potentially change the patients’ perceptions, attitudes, and knowledge about their disease. Sites presenting only basic research facts with little clinical content were considered to be not relevant or of doubtful relevance. A limitation of this approach was that the relevance of the information was established by the authors and does not represent patient views. However, this first step was considered necessary since many of the sites were obviously unrelated to arthritis or clearly targeted a scientific audience.
2. Authorship (e.g., individual, organization, industry).
3. Type of publication (e.g., news, advertisement, research paper).

4. Scope and contents (e.g., disease targets, interventions). We categorized interventions into conventional or alternative based on the definition by Eisenberg<sup>14</sup> — “Medical interventions not taught widely at U.S. medical schools or generally available at U.S. hospitals”.

5. Commercial/financial interests. We considered as financially driven those sites advertising or offering products for sale, or requesting unrestricted funds (e.g., donations).

Results were analyzed both for single hits (Web pages) and Web sites. Only English language sites were included. The search was conducted in May 1998, and the sites reviewed between May and September of the same year.

We also examined the order or rank of the hits in the search retrieval, comparing the median rank for the various features of interest such as authorship or financial interest. We also arbitrarily categorized the order of retrieval of the Web pages into 4 categories: (1) the first 20 hits; (2) hits 21 to 100; (3) hits 101 to 200; and (4) hits 201 to the end of the search. The purpose of this categorization was to examine the features of the most accessible sites compared to others retrieved at later stages. The frequency of specific characteristics such as authorship or content was examined for each category. In WebCrawler, as in other search engines, the ranking of the hits is based on indexing/relevance algorithms that consider a number of criteria such as whether the search terms are together or not, how early and how often they appear, whether they are in the title, links, etc.

## RESULTS

The WebCrawler search resulted in 537 hits. Of these, 531 (99%) were evaluated, 2 did not exist, 2 could not be contacted, one was not in English, and one required a membership to access. The 531 hits were posted on 388 different Web sites. Of the 388 sites, 198 (51%) were considered to be relevant, 183 (47%) not relevant, and 7 (2%) of doubtful relevance. We considered for the assessment only the 286 Web pages and 205 Web sites classified as relevant or of doubtful relevance.

Table 1 shows the characteristics of the Web pages in relation to type of publication, diseases discussed, and content topics. One hundred thirty-seven pages (48%) were considered to be advertisements. Examining the diseases discussed

Table 1. Characteristics of the Web sites.

Web Pages (N = 286)*	n (%)	Web Sites (N = 205)	
Type of publication		Authorship	
Advertisements	137 (48)	Profit industry	104 (51)
Information sites	103 (36)	Nonprofit organization	57 (28)
Link pages	29 (10)	Individuals with no clear affiliation	34 (17)
News articles	22 (8)	Universities	10 (5)
Posting of research results	14 (5)	Financial Interest	
Recruiting sites for research	4 (1)	Primarily sold products	87 (42)
Chat locations	2 (< 1)	Sold products indirectly	16 (8)
Case study	1 (< 1)	Sought paid memberships	2 (1)
Site for support group	1 (< 1)	Asked for donations	2 (1)
Diseases discussed			
Rheumatoid arthritis only	23 (8)		
Arthritis	65 (23)		
Autoimmune disorders	6 (2)		
Various (arthritic and nonarthritic)	192 (67)		
Contents			
General information	124 (43)		
Conventional therapy	23 (8)		
Alternative therapy	131 (45)		
Uncertain	8 (3)		

\* Total exceeds 286 — some Web pages were categorized under more than one type of publication.

in the Web pages, two-thirds covered a variety of arthritic and nonarthritic disorders and one-third contained information on arthritis or related diseases exclusively. Fifty-one percent of the pages offered general information or information on conventional therapies. Forty-six percent of the pages discussed only alternative therapies. Authorship and financial interests of the Web sites are also shown in Table 1. Profit driven industries or companies owned more than half the identified Web sites. About a third of the sites were posted by nonprofit organizations or universities. Individuals with no clear affiliation posted the additional sites (17%). Two-thirds of the sites had information about other diseases (arthritic and nonarthritic), and this was most common in sites discussing alternative therapies and those with clear financial interests.

Of 107 Web sites with financial requests, 87 (81%) sold products directly (overall, 42% of the sites were vendors); 16 (15%) promoted sales indirectly; the remainder requested memberships or donations. Figure 1 shows the proportion of Web sites with financial aims according to selected features. Seventy-two percent of the Web sites that had overt profit interests sold or advertised alternative therapies; of the sites discussing alternative therapies, over 80% had clear financial aims. The most common therapies promoted included cetylmyristoleate, shark cartilage, colloidal minerals, Tahitian Noni, Pycnogenol, and a variety of nutrients. About half the Web sites discussing conventional therapies also had financial aims such as promoting, advertising, or selling products.

We examined the order of presentation (ranking) of the hits in relation to the various characteristics of interest to examine what types of Web pages would be more readily retrieved. As expected, more relevant results were found earlier in the search. The median rank for relevant pages was 236, compared with 316 for nonrelevant hits. Examining authorship, there was a trend for nonprofit and schools sites being

retrieved earlier — median rank respectively 174 and 154, compared with industries — median rank 239, and pages “authored” by individuals. When examining the rank according to contents, the lowest median rank was observed for pages discussing conventional therapies (median = 141), compared to a median rank for alternative therapies of 252 and for general information pages 235. No major differences were observed in the rank of hits with or without a financial interest — median rank for profit pages 229, and median rank for nonprofit pages 238. Figure 2 shows the relevance, authorship, financial interest, and contents of the hits categorized according to their rank in the search using the categories described in Materials and Methods (hits 1 to 20, hits 21 to 100, hits 101 to 200, and hits 200+). Although the majority of the sites posted by schools and nonprofit organizations were included within the earlier hits, many of these sites were retrieved in the bottom half of the search.

Figure 3 shows how many sites were retrieved or missed in the first 100 hits. We examined the first 100 hits under the assumption that most patients accessing the Web would only open a limited number of pages, and not all of those retrieved, since they exceeded 500. About 40% of the sites discussing conventional therapy and a third of the sites posted by nonprofit organizations or schools were identified in the first 100 hits.

## DISCUSSION

We assessed the general features of Web sites that are readily available to patients with rheumatoid arthritis who access the World Wide Web through a commonly used engine. We tried to replicate access by a typical consumer, using a very broad search with no filters or restrictions. A more detailed and confined search strategy may have yielded different results. However, we hypothesized that most individuals probably use relatively simple terms when seeking information on the Net.

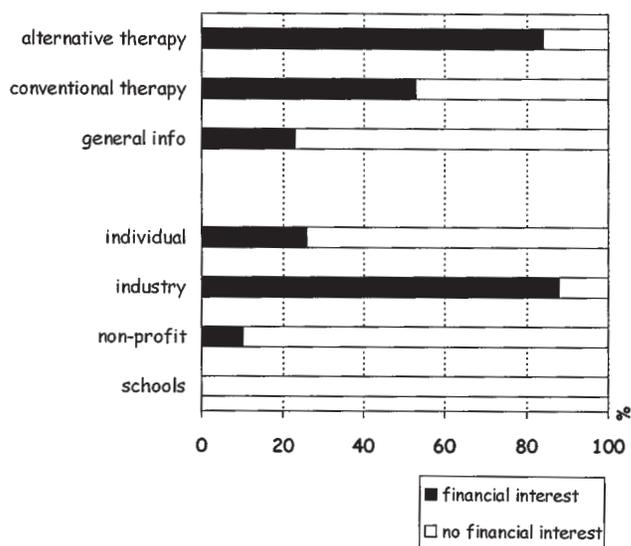
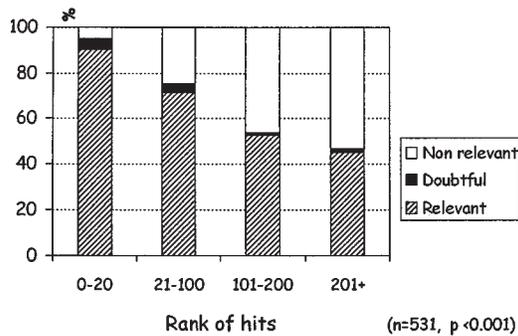
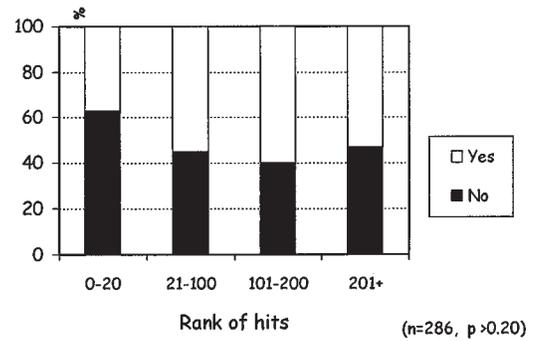


Figure 1. Web sites with commercial advertising or financial requests.

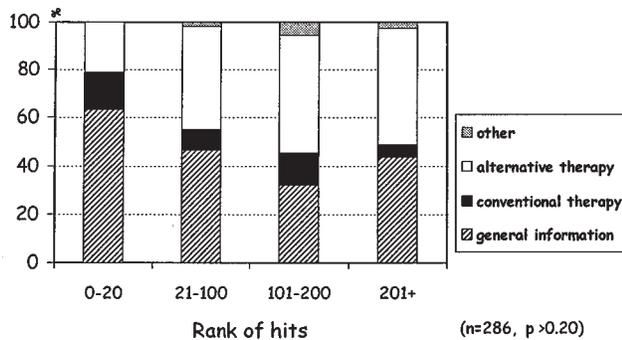
### Relevance



### Financial interests



### Content of Webpages



### Authorship

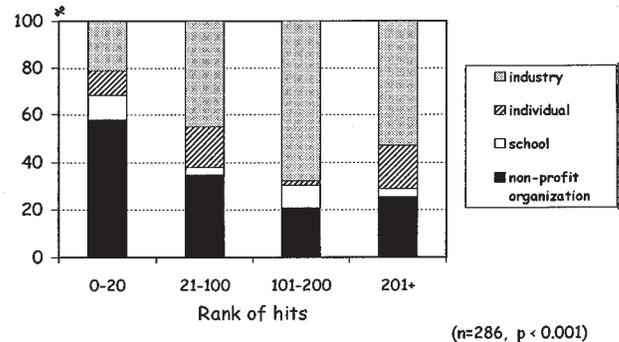


Figure 2. Relevance, contents, commercial interest, and authorship according to the ranking of hits.

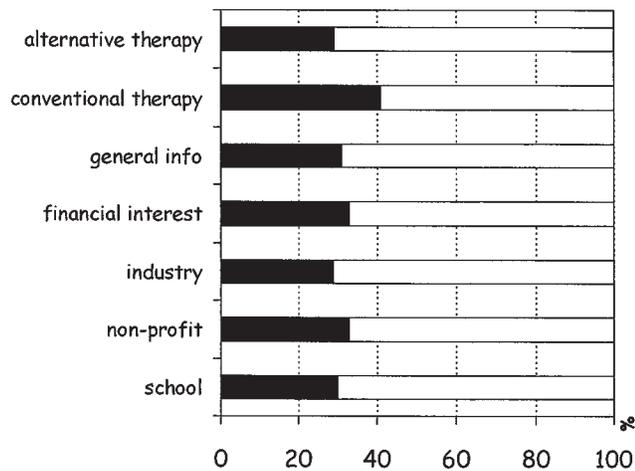


Figure 3. Proportion of sites retrieved in the first 100 hits according to selected features.

The first finding of interest was that about half the sites retrieved were judged to be of little relevance from a patient's perspective (low specificity). Hersh, *et al* examined the applicability and quality of the information on the Web to

answer clinical questions, albeit from a clinician's perspective<sup>15</sup>, and found that 89% of the retrieved pages were not relevant to the questions asked. In our study, although most of the relevant pages were retrieved in the first half of the search, a significant number of nonrelevant pages (about 25%) were found in the first 100 hits. The specificity of retrievals could probably be improved with a more restricted strategy, but this may result in a decrease in sensitivity with some relevant informative sites being missed. Sacchetti, *et al* compared search engines for the retrieval of urology related topics<sup>16</sup>. Yahoo identified 51 sites and Hotbot over 15,000. Although Yahoo reduced the number of irrelevant sites, it missed important sites, which were identified by HotBot, illustrating the tradeoff between sensitivity and specificity that can be expected. Our objective was not to evaluate the efficiency of alternative strategies or search engines and this point was not assessed any further.

A major concern with the information posted on the Web relates to the quality and accuracy of the data and recommendations provided. Impicciatori, *et al* assessed the reliability of 41 Web pages relating to the management of febrile children and compared the recommendations to published guidelines<sup>4</sup>. Only a few of the sites provided complete and accurate information. In a Web search on vascular surgery<sup>17</sup>, most sites had

non-useful or inaccurate information; moreover, the Joint Vascular Societies page was only identified as a tertiary link. Even more worrisome, McClung, *et al* reviewed 60 articles published by traditional medical sources on the treatment of childhood diarrhea and found that only 20% conformed to recommendations from the American Academy of Pediatrics<sup>18</sup>. On the bright side, a study evaluating 75 Web sites providing information on urinary incontinence found excellent information, and the most informative site was retrieved with several search engines<sup>19</sup>. In our review, only about a third of the sites were posted by nonprofit organizations or universities. Many nonprofit organization Web sites were retrieved early in the search, but many other sites were missed by the first hits, suggesting that patients may not access useful and informative sites if they fatigue after the first hits. As an example, The Arthritis Society site in Canada was retrieved 8th, the Arthritis Foundation 13th, the National Institute of Arthritis and Musculoskeletal and Skin Diseases of the National Institutes of Health 26th, the Cochrane Library 478th. A limitation of our study is that we did not critically appraise the content of the Web pages and we can only assume that the quality of the information in nonprofit sites is better than that provided by industry or individuals.

We found that over half the identified Web sites were owned by industries or companies that primarily sold products directly to the public. Nogler, *et al* reported similar results when attempting to obtain information specific to ankle and foot orthopedics<sup>20</sup>: 41% of the identified sites were commercially oriented and included advertisements. Another study using the word “rheumatology,” which is more likely to be used by health professionals than patients, also found that of the sites directed to patients — only 16% of the total — about half contained advertisements<sup>21</sup>. In our study, over two-thirds of the sites with overt financial aims promoted the use of alternative therapy, often claiming that their products were effective for arthritis and other conditions. The use of alternative therapies has markedly increased in the past few years<sup>3,13</sup>. In the US, in 1990, alternative therapy expenditures reached \$13.7 billion, exceeding hospitalization costs at \$12.8 billion<sup>14</sup>. Many Web sites promoting conventional therapy also had financial interests in given products, or offered sales, which is an increasing trend, with both nonprescription and prescription therapies being sold through the Internet. About one-third of the general population and two-thirds of patients with chronic diseases use alternative therapies<sup>7,8</sup>. Most typically, in North America, Europe, and Australia, these individuals are Caucasian, female, 30 to 50 years old, and have higher education levels than nonusers. It could therefore be expected that many of them will have access to the Internet. Although some alternative therapies may be efficacious<sup>22,23</sup>, most have not been adequately studied, and often, positive studies have major methodological flaws<sup>23,24</sup>. In rheumatic diseases, the few well conducted trials and systematic reviews have not shown clear efficacy<sup>25-28</sup>. The most common thera-

pies advertised in the sites retrieved by our search included cetyl-myristoleate, shark cartilage, colloidal minerals, Tahitian Noni, and Pycnogenol. None of these substances has been proven to be beneficial for the treatment of arthritis. Most of these therapies may be innocuous in their biological actions, but there are some concerns about overall safety, in relation both to the expected contents of the product and to undeclared substances<sup>29,32</sup>. Interestingly, there is a report of acute renal failure from wormwood oil purchased through the Internet<sup>33</sup>.

The Web provides an easy, accessible medium for a substantial proportion of patients with chronic disease to access health information. One study evaluating the motivation and expectations of patients seeking tele-advice through a university hospital dermatology Web site found that most patients had chronic disease, and were seeking a second opinion; 17% were unsatisfied about previous encounters with live physicians<sup>34</sup>. As an additional concern, a review of the readability levels of selected patient education material on the Web showed an average reading level at 10th grade (Flesch-Kinkaid), which is considered too difficult for a large proportion of the population<sup>35</sup>. If accurate information provided in a Web site is not comprehensible, it will not conform to patients' expectations. In our study, a substantial number of sites (17%) were posted by individuals with no clear affiliation. Often these sites were patient based, with individuals recounting their experiences with arthritis. Culver, *et al* reported that in an online discussion group for sufferers of painful arm and hand conditions, 89% of the messages providing medical information were authored by individuals without professional medical training, and about a third provided “unconventional” information<sup>36</sup>. It is unknown whether this sharing and exchange of information may result in any beneficial outcomes. It can be theorized that positive, personal information from their peers can perhaps improve patient's self-efficacy by providing social support<sup>37,38</sup>. A randomized controlled trial compared HIV positive patients who were provided in-home access to a computerized system (CHESS) with a control group<sup>39</sup>. CHESS provided information, decision support, and access to experts and other patients. Users reported an improvement in quality of life, less time spent in ambulatory visits, fewer and shorter hospitalizations. Whether the benefits were related to increased information, expert access, or peer support cannot be clearly established. Patients and health care providers should also be aware that the Internet provides fertile grounds for individuals with “Munchausen” type disorders who imagine fictitious illnesses in order to gain attention and sympathy from others<sup>40,41</sup>.

Most of the larger search engines such as AltaVista, Northern Light, Excite, and Google include a ranking of relevance or quality. Jadad, *et al* identified and reviewed rating instruments to evaluate Web sites providing health information<sup>6</sup>. Although a number of instruments were found, none of them provided information on their performance as measured

by their reliability and validity. Many of these scales feature sites with “seals of approval,” “best of the Web,” etc., often with visual ordinal scales — for instance 0 to 3 stars. Consumers may place faith in these assessments but it is unclear how many of these are derived, and whether they are performed by independent third parties<sup>6</sup>. Many of these ratings are based on graphic quality, ease of use, and interactivity, but it is otherwise unclear how the health contents are assessed. Several methods have been proposed to improve the accuracy and quality of health information in the Net including better labeling, creation of directories, and filtering<sup>42-44</sup>. Since the Web allows easy posting of information by individuals, it may be impossible to monitor the quality of new sites on an ongoing basis without substantial resources. Nonprofit organizations have started to provide lists of reliable sites that can be made readily available.

Our findings suggest that most of the health information on the Web available to patients with arthritis about their disease is profit driven, and produced by companies or individuals with no clear affiliation. These findings emphasize the need for critical evaluation of health information in the Internet. We encourage physicians to openly discuss Web contents and specific sites with their patients, and to provide addresses of Web sites with reliable, evidence based data. Additional research is required to explore the effects of exposure to this information on patients’ attitudes, expectations, behaviors, and outcomes.

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