

Crawling Through the Web: What Do Our Patients Find?



In this edition of *The Journal* the article by Suarez-Almazor, *et al*¹ investigates the information available to patients on the World Wide Web when they enter the 2 words “rheumatoid arthritis.” The authors discuss whether there is deceit or patient empowerment disseminated with the information obtained. The message seems clear; websites on RA found with a standard Web search engine are very likely to have a profit motive, or be linked to a company that does. Either that, or the page is one person’s view of their disease, with unconventional and alternative treatments being the primary message. In other words, the spider spinning the Web has an eye on catching a good meal and evidence based medicine has not learned how to spin. Or at least it would seem to be so.

The search for websites was conducted in 1998 using the search engine Webcrawler (www.webcrawler.com). Of course, there are many other search engines, and more sophisticated means of searching, but this provides a robust example of what type of search results your patients might be coming to the office with. Of the 388 websites, with 531 Web page hits, the authors found only 205 of possible relevance, of which 68% were sponsored either by for-profit industry or by individuals with no professional affiliations.

Out of curiosity I performed the same search in September 2000 and found 5380 hits, a 10-fold increase in 24 months, which is almost equivalent to the growth in some of the e-commerce stock prices over the same period. Needless to say, industry and commercial organizations ranked high on the list. The number one spot was “Doctor’s Guide to the Internet,” which is sponsored by industry and had the heading “The latest medical news and information for patients or friends/parents of patients diagnosed with arthritis.” Using Excite as the search engine I found a banner ad for “The New Arthritis Breakthrough” hotlinked to Enbrel, with information for health professionals, but of course available to any Web browser. The 24th site listed was the “Road Back Foundation,” developed to promote McPherson Brown’s thesis on antibiotic therapy. I also

found that with one click I could drop into an Internet book publishing site and for \$14.95 buy “The Arthritis Breakthrough,” by Henry Scammell, with Thomas McPherson Brown. No wonder many patients in the past months have been asking to be given antibiotics, or are wondering why the new tumor necrosis factor-alpha blockers aren’t covered by provincial drug plans.

Nevertheless, it was helpful to see that The Arthritis Society site in Canada, with material largely contributed by rheumatologists and allied health professionals, was still 8th on the list, and that The Arthritis Foundation was noted in several of the top 25 spots.

INFORMATION AS THERAPY

In selecting the sites, the authors sought relevance only “in relation as to whether the information could potentially change the patients’ perceptions, attitudes, and knowledge about disease. Sites presenting only basic research facts with little clinical content were considered to be not relevant or of doubtful relevance.” The authors found that many of the sites in the top 100 citations portrayed alternative therapy as useful for arthritis, where the definition of alternative medicine comes from Eisenberg, *et al*² — “Medical interventions not taught widely at US medical schools or generally available at US hospitals.” The operative approach of many sites is to change perceptions and attitudes, with little attention to the scientific methodologies employed by clinical scientists. For example, a general perception portrayed is that alternative medicines are beneficial and much safer than conventional therapy, without attention to the rigorous assessment of studies with placebo controls, clinical outcomes, and blinded assessments. No doubt the costs associated with rigorous assessments and criteria for approval would be a bitter pill for shareholders in these companies to swallow.

The title of Dr. Suarez-Almazor’s article portrays the dilemma we face as clinicians. Is this new technology

See Surfing the Net — Information on the World Wide Web for persons with arthritis, *page 185*

leading to “patient empowerment or patient deceit”? There is no question that information can be powerful, no matter what the quality, validity, or reliability. As rheumatologists we deal with information day in and day out. What is disconcerting about the present study’s findings is that information about alternative therapies such as shark cartilage, colloidal minerals, Tahitian Noni, and pycnogenol comes directly to the attention of patients, largely with anecdotes and promotional literature. We are then faced on the front line at our office with questions about antioxidants, commercially prepared products in other countries, and anecdotal claims about magnet therapy. If the physician does not attempt some explanation, patients leave with the subliminal message either that the physician doesn’t care about their arthritis, or that we aren’t the experts in arthritis care that we say we are.

CHALLENGES TO THE PROFESSION

Clearly, patients are looking for information beyond that we learn, and teach, in medical school. The Web, as an information source, will not go away. Webcrawlers will become more prevalent as our society engages extensively in this form of communication and commercialization. Moreover, patients with RA are often in desperate straights, which friends and family try to help by providing their own Web informed diagnosis and treatment plan. Our current manpower crisis, with long waiting lists and frustrated referring doctors, provides another factor pushing patients to seek alternative sources of information. A direct effect on the physician’s office, if the patient’s Web information is addressed, is a decrease in the amount of time available for patients who do not surf the net. What should our response be?

We know that the side effects from this information can be excessive expenditures on unproven products, distraction from continuing proven therapies, and disruption of the trust in conventional health practitioners. Therefore, we could restrict our patients to those without Web access, or put signs at the front door indicating “No Internet Searches Allowed.” Or, as information specialists in our own right, we could begin to take advantage of this new medium. For example, a tool for arthritis content could help patients decide on the value of the websites they are visiting. A list of excellent patient websites could be posted in the front office. Rheumatologists’ perspectives on arthritis care for local communities could be posted on national websites. Search engines could be notified of the key sites we recommend, and the websites could be encouraged to “fly their banner” in keeping with the current practice of private industry. Patients could be told a few simple techniques for advanced searching with key words like “rheumatoid

arthritis” and “patient information” in Canada. By conducting this additional search strategy I was able to reduce the “hits” to 800 from 5000 (greater specificity), and the top 3 sites were The Arthritis Society, the Cochrane Collaboration, and Doctor’s Guide to the Internet, suggesting greater credibility.

Perhaps we also need a new elective, in rheumatology training programs, which will allow fellows to give input to Web design teams in a constructive fashion. Such items as graphic quality, ease of use, interactivity, and valid content could be stressed to the design teams that are reshaping our world.

SUMMARY

Webcrawling, like pubcrawling, can be dangerous for the uninitiated. Most of the health information on the Web available to patients with arthritis about their disease is profit driven, produced by companies selling product or by individuals with no clear affiliation with a knowledge organization such as a university or a rheumatology association. The potential for patient deceit, bias, or distraction is high. The authors emphasize the need for critical evaluation of health information on the Internet and encourage physicians to openly discuss Web contents and specific sites with their patients. They stress that additional research is required to explore the effects of exposure to this information on patients’ attitudes, expectations, behaviors, and outcomes. Patient empowerment, when set in the right direction, is known to be a useful tool. The problem remains, however, in setting the right direction. Rheumatologists, as information providers, can play a pivotal role in choosing this direction.

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