# Black Holes on the Web:

## **Avoiding the Pitfalls of Online Misinformation**



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RN, ET, is the Eastern WOCN consultant for Saint Elizabeth Health Care as well as the Regional Director (Ontario) for the CAET, a peer reviewer for Ostomy/ Wound Management and Advances in Skin and Wound Care, a member of the CAWC Research Committee and an Academic Advisor with the CAET-ETNEP program. hen Captain James Kirk and his crew boarded their starship, *Enterprise*, to "boldly go where no one has gone before" they were certain that space was, in fact, the final frontier. How wrong they were!

Welcome to the 21<sup>st</sup> century, the age of information technology. Enter the ever-expanding universe of the World Wide Web. As health professionals, we navigate this universe with our personal computers using many different search engines to seek data, information and knowledge. There are virtually millions of planets (Web sites) to land on and explore. There are literally thousands of health-related Web sites, including those that contain wound management information.

A recent study completed by IBM suggests that the Internet has become the main source of health information for approximately three in 10 Canadians. It further states, "In 2003, the Internet surpassed the physician as Canada's primary source for health information. While more Canadians are using the Internet for diagnostic purposes, the vast majority feel it is difficult to determine which information found online can be trusted and that the quality of medical information on the Internet needs to be improved."1 As the Internet's audience continues to grow, understanding how people use it to obtain medical information becomes more important to both users and providers. Presently, the health care community has become increasingly aware of and concerned about the credibility of health information available on the Internet.<sup>2</sup>

As health professionals and wound-care specialists, we must learn how to use the Web to provide ourselves, patients, their families and other health-care providers with accurate, timely and complete health information regarding different wound etiologies and treatment options. How can we determine the value of the information we find? How can we differentiate trustworthy information from those "black holes" full of information "pretending to be objective but possessing a hidden agenda of persuasion or hidden bias?"<sup>3</sup>

Health professionals, especially wound-care practitioners, are subject to a great deal of marketing pressure to recommend specific treatments or products.<sup>4</sup>

Marketing information sometimes looks like "best practice" information; therefore, health professionals require highly developed critical-thinking skills to ensure that the information they provide patients is accurate and truthful. Critical thinking is not regular or normal thinking, nor is it emotional or judgmental. It is selfdirected, self-disciplined, self-monitored and selfcorrective thinking.<sup>5</sup> When using the Internet as a source of information, a professional may find the following definition of critical thinking to be helpful: "The propensity and skill to engage in an activity with reflective skepticism."<sup>6</sup>

As the number of health-related Web sites increases, so too does the need for all health professionals to use "reflective skepticism" when using this information for informing professional practice. There has been a marked increase in the number of organizations attempting to increase the reliability of health information found on the Internet. Consumer-protection advocates, led by Ralph Nader in the 1960s, started a worldwide movement toward protecting consumers and workers from unsafe products and misleading advertising. In today's technological world, many consumer-protection advocates use their Web sites to assist consumers of health information in ascertaining

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the credibility of the information they find on the Web. This article will briefly introduce three of these sites. Readers are encouraged to search them out and, using their own critical-thinking skills, formulate opinions as to how these sites and the information contained therein will impact their practice.

#### **Credibility on the Web**

To determine the credibility of Web site content and to make reasonable decisions about what health information we will trust or what products or services we will use or recommend, health-care professionals should know what standards a site employs in developing content. Like accreditation for health-care facilities, there are accreditation processes for health-related Web sites to ensure that content achieves a minimum standard of credibility.<sup>7</sup>

Using a Web site critique template will enable the practitioner to ensure that they have comprehensively assessed the quality and reliability of the site from which they are accessing information. The Health on the Net Foundation (HON) has published a code of conduct that can be used as just such a template. Using this template regularly when "surfing the net" will ensure that clinicians are asking the right questions and

not mistakenly integrating misleading information into their practice.

### **Health on the Net Foundation**

HON is an organization promoting and guiding the deployment of useful and reliable online medical

and health information. It can be found at www.hon.ch/ visitor.html. Created in 1995, HON is a non-profit, nongovernmental organization accredited to the Economic and Social Council of the United Nations. Its mission is to "guide the growing community of health-care consumers and providers on the World Wide Web to sound, reliable medical information and expertise."<sup>7</sup>

HON does not rate the quality of the content, but rather articulates a set of rules to hold content developers to basic ethical standards in the presentation of the information so that readers can be sure of the source and purpose of the information they are reading.

Accreditation is free and voluntary. The process has

been clearly outlined on the HON Web site, and the publishers of any health-related Web site may apply for accreditation, and, if successful, post the HON logo. Successful accreditation is determined by meeting the following code of conduct standards. Readers can also use these standards to assess Web sites they use.

The Web site must demonstrate

- authority. This means the qualifications of the authors are clearly indicated and ensures that "any medical or health advice provided and hosted on this site will only be given by medically trained and qualified professionals unless a clear statement is made that a piece of advice offered is from a nonmedically qualified individual or organization."
- 2. complementarity. This ensures that "the information provided on this site is designed to support, not replace, the relationship that exists between a patient/site visitor and his/her existing physician" or health professional.
- 3. privacy. This ensures the website respects the "confidentiality of data relating to individual patients and visitors to a medical/health Web site, including their identity ... The Web site owners undertake to honour or exceed the legal requirements of medical/health



information privacy that apply in the country and they will state where the Web site and mirror sites are located."

 attribution. This ensures where appropriate, "the information contained on this site will be

supported by clear references to source data and, where possible, have specific HTML links to that data. The date when a clinical page was last modified will be clearly displayed (e.g., at the bottom of the page)."

- **5. justifiability.** "Any claims relating to the benefits/ performance of a specific treatment or commercial product or service will be supported by appropriate, balanced evidence in the manner outlined above in principle four."
- 6. transparency. This ensures designers of the Web site "will seek to provide information in the clearest continued on page 34







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possible manner and provide contact addresses for visitors that seek further information or support. The Webmaster will display his/her e-mail address clearly throughout the Web site."

- 7. financial disclosure. Clearly identifies support for the Web site "including the identities of commercial and non-commercial organizations that have contributed funding, services or material for the site."
- 8. advertising policy. This ensures that readers can "clearly distinguish advertising from editorial content. ... If advertising is a source of funding it will be clearly stated. A brief description of the advertising policy adopted by the Web site owners will be displayed on the site. Advertising and other promotional material will be presented to viewers in a manner and context that facilitates differentiation between it and the original material created by the institution operating the site."<sup>6</sup>

Dr. Peter Mansfield, Director of Healthy Skepticism (see below), reminds us conversely, "just because a site has the HON logo does not mean the information it provides is reliable since HON does not check the quality of the content. It is also possible that Web sites might use the logo without authorization. Consequently, it is important to remain skeptical of *all* information regardless of whether the source has the HON logo or not."<sup>9</sup>

Health professionals have a role to play in increasing the reliability of information on the Internet. By regularly using the eight HON principles as a template for assessing Web sites they use regularly, and contacting Web site masters/owners when they find Web sites deficient, they can actively improve content reliability on these sites.

#### Quackwatch

HON encourages Internet consumers to contact them and report fraud. They also work with other



organizations to monitor health-related Web-site credibility. If you come across a health-care Web site that you believe is either possibly or blatantly fraudulent that displays the HON Logo, please contact them immediately. If the site does NOT display the HON code you should alert Quackwatch, an HON partner, at www.quackwatch.org.

Quackwatch, with a worldwide network of volunteers, is a not-for-profit organization committed to combating health-related frauds, myths, fads, fallacies and misconduct on the Internet. Dr. Stephen Barrett, a "Ralph Nader" of the Internet, is a retired psychiatrist who has become a renowned author, editor and consumer advocate. As the Vice President of the National Council Against Health Fraud, his activities include "investigating questionable claims, answering inquiries about products and services ... debunking pseudoscientific claims ... improving the quality of health information on the Internet and attacking misleading advertising on the Internet."<sup>10</sup>

### Healthy Skepticism

The pharmaceutical industry has a strong presence in health research and health



information available on the Internet. It can be difficult for consumers to disentangle advertising claims from scientific research or to understand the validity/reliability of claims made about the research supporting a specific product or treatment. Treatment recommendations to patients must be based on the best possible scientific evidence.

"Healthy Skepticism is an independent, international, not-for-profit organization for people with an interest in improving health." Specifically, Healthy Skepticism works to reduce the potential harm resulting from misleading drug promotions because "misleading drug promotion wastes money and harms people's health."<sup>11</sup> The Healthy Skepticism Web site can be found at www.healthyskepticism.org.

The Healthy Skepticism Web site articulates seven goals:

- Improving health by reducing harm from inappropriate, misleading or unethical marketing of health products or services, especially misleading pharmaceutical promotion.
- **2.** Investigating and communicating about marketing practices.



Users of healthrelated Web sites should look for the HON logo.

- **3.** Promoting healthy skepticism about marketing practices via advocacy, research and education.
- **4.** Developing, supporting and evaluating initiatives to reduce harmful marketing practices, including reform of regulations and incentives.
- **5.** Developing, implementing and evaluating educational strategies to improve health-care decision-making, including evaluation of drug promotion.
- **6.** Supporting compassionate, appropriate, sustainable, evidence-based health care provided according to need, for optimal health outcomes.
- **7.** Providing practical opportunities to advance the aims of Healthy Skepticism Inc.<sup>12</sup>

To achieve these aims, the Healthy Skepticism Web site includes a variety of services. There is a free monthly e-mail update service and an active e-mail discussion list for members. There is an international news section and an online library listing of articles relevant to drug promotion from medical journals,

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newspapers and other sources. Many of these are offered free as full-text articles. The Healthy Skepticism authors feel "misleading drug promotion is more common, more influential and more harmful than is generally realized." And because consumers and health-care professionals find it difficult to decide which claims about drugs to accept and which claims to resist," the site offers an advertising "watchdog" service called "Ad Watch" that provides examples of false and misleading advertisements critiqued to illuminate for consumers *continued on page 40* 

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