

A B S T R A C T

The Internet is a powerful tool for accessing information about complex health topics. The purpose of this study was to evaluate breast cancer Internet sites using published criteria about website structure. Two searches were undertaken (November 1998 and June 1999) using the Yahoo search engine, providing a sample of 136 unique addresses. The results showed 1) owner's credentials were identified in 31.6% of sites, 2) financial charges were stated in 10.3% of sites, 3) less than 14.0% identified site creation date, 4) 33.1% identified content posting update, 5) 30.1% identified information sources, and 6) just under 88% of sites provided e-mail interactivity. The results indicate variability in breast cancer Internet sites with respect to framework criteria of accountability. We suggest that websites that lack fundamental indicators (such as dating and sources) do not provide the user with fundamental information that could enable informed decision making about site quality.

A B R É G É

Internet est un outil puissant permettant d'accéder à des informations relatives à des sujets médicaux complexes. L'objectif de cette étude est d'évaluer les sites Internet liés au cancer du sein à l'aide des critères publiés en matière de structure des sites Web. Deux études ont été entreprises (novembre 1998 et juin 1999) à l'aide du moteur de recherche Yahoo, qui ont donné lieu à un échantillon de 136 adresses différentes. Les résultats ont démontré ce qui suit : 1) les qualifications du propriétaire étaient précisées dans 31,6 % des cas, 2) les frais étaient indiqués dans 10,3 % des sites, 3) moins de 14,0 % des sites indiquaient la date de création, 4) 33,1 % des sites indiquaient que de nouvelles informations avaient été affichées dans le cadre de mises à jour, 5) 30,1 % désignaient leurs sources de renseignements, et 6) près de 88 % des sites faisaient preuve d'une certaine interactivité au moyen du courriel. Les résultats révèlent une certaine variabilité dans les sites Web consacrés au cancer du sein du point de vue des critères fondamentaux de responsabilité. Nous suggérons que les sites Web qui ne disposent pas de certaines indications fondamentales (comme la date et les sources) ne fournissent pas d'informations fondamentales dont l'utilisateur pourrait se servir pour prendre une décision éclairée au sujet de la qualité du site.

Quality of Breast Cancer Sites on the World Wide Web

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The Internet, a worldwide web of interconnected computer networks, is a powerful global health information resource. Health information obtained through the Internet can contribute to user education about self-care in chronic conditions, health and medical treatment options, and correct use of pharmaceuticals.¹ With over 300 million health-related web pages posted in 1997,² an estimated 37.4 million North American users of the Internet,³ and expansion estimated at the rate of doubling of new users per year,⁴ the Internet has the potential to shape health care delivery and policies.⁵

There is little systematic information about the epidemiology of Internet health informatics.⁶ One recent study suggests that use of electronic media for self-help information is not associated with negative health outcomes. Alemi et al.⁷ examined the impact of a voice-electronic bulletin board on the utilization of healthcare services and health status of 53 pregnant women who abused drugs. A lower use of outpatient clinic visits for women using the electronic bulletin board was reported and this was not associated with higher self-reported use of alcohol.

Empirical studies evaluating Internet sites suggest that misleading and inaccurate health information is prevalent. For exam-

ple, a site promoting the use of BioResonance Therapy, an alternative cancer therapy combining information about the *p53* tumour suppressor gene with folk concepts of vitalism, can be readily accessed by net surfers.⁸ Biermann and colleagues² undertook an evaluation of Internet sites on Ewing sarcoma to assess the accuracy, ease, and variability of information retrieval from a patient's perspective: 6% of the non-peer-reviewed sites contained erroneous information. Impicciatore et al.⁹ evaluated websites on advice regarding fevers in children: less than 10% of sites adhered to the main recommendations found in the accepted, published medical literature. Culver et al.¹⁰ investigated the consistency of the information at an electronic bulletin board dedicated to discussion about painful hand and arm conditions with standard medical practice: about one third of the messages posted included unconventional or erroneous medical information.

Despite the wealth of health information on the Internet, the issue of quality remains problematic. As one researcher noted "the problem [with the Internet] is not too little information but too much, vast chunks of it incomplete, misleading, or inaccurate, with a potential to become the world's largest vanity press."^{11, p1244} Pool¹² suggests we are already experiencing an Internet "info glut".

A first step in enabling the user to evaluate websites for credibility would be the development of accountability standards. There are clear criteria for judging the quality of information in medical journals. Empirical findings submitted for review must conform to a presentation that allows replication and evaluation of authors' conclusions. Because health information on

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the Internet is not usually original research, peer review is not common.¹³ Researchers^{11,14} and policy groups^{15,16} alike have advocated the development of assessment criteria to improve the accountability of health information posted on the Internet.

The purpose of this study was to evaluate the accountability of breast cancer sites on the Internet. We used the criteria of Silberg and colleagues¹¹ which have been incorporated into policy documents on health informatics.¹⁵ These criteria include information about site ownership, source attribution, financial disclosure and site currency. Analogous to the peer-review process, these criteria are meant to provide a minimum framework for assessing the quality structure of Internet health information sites.

METHODS

The study was performed between November 1998 and June 1999. The variable of interest was English language breast cancer Internet sites. To evaluate breast cancer sites on the basis of accountability, we performed a systematic study using Yahoo, a subject guide search tool at <http://www.yahoo.com> available on the homepage of the Internet browser Netscape.TM We retrieved 310 universal resource locators (URLs) from Yahoo in 1998 using the term 'breast cancer' of which we selected a random 1 in 3 sample (n=100). In 1999, we retrieved 312 URLs and randomly selected an additional 36 non-overlapping sites. For analysis, we combined the two searches for a total sample of 136 websites.

We developed an instrument to abstract breast cancer information from Internet addresses. The instrument was based on Silberg and colleagues' accountability criteria¹¹ which included: *site disclosure* (credentials of site owner; copyright information; financial charges for services), *site currency* (date contents posted and updated), *source attribution* (identification of references or sources for content), *site authorship or ownership* (individual, group, government or not-for-profit organization, commercial organization, not identified) and *user interactivity* (e-mail, links to other sites). In

addition, we collected information about *privacy protection* (security and disclaimer) and the *type of site* (news or support groups; chatrooms; government or not-for-profit organization information sites; commercial sites; other groups such as health maintenance organizations; individual or personal sites; or sites that could not be classified into the above categories). At this point we did not evaluate the scientific or medical merit of the information in the sites. Nor did we examine the possibility of a correlation between the attainment of core accountability and the quality of the actual information.

To assess coding reliability, we separately coded a small selection of consecutive sites listed using the Yahoo search engine during November 1998. There was perfect agreement for criteria of currency, attribution, interactivity, and privacy protection. There was good agreement for site disclosure, type and ownership of site. Although kappa scores were not tabulated, the authors extensively discussed each criterion where the coding differed until agreement was reached. Descriptive statistics (frequencies and cross-tabulations) and chi-square analyses were performed using SPSS, version 8.0.

RESULTS

Site disclosure: Criteria to assess site disclosure included information about credentials of site owner, copyright information and financial charges for site services. Credentials of the site owner(s) could be identified in 31.6% of the pages (43 of 136 pages) on breast cancer. Copyright was indicated for 81 of 136 sites (59.6% of sites). Few sites contained information about financial charges associated with products or services from the site (14 of 136 pages or 10.3%).

Source currency: Assessment of site currency used the criteria of date created and date posting updated as measures of timeliness. Less than 14% of the sites indicated when the page was created (19 of 136 sites). One third of the sites included information about when the posting was updated (45 of 136 sites, or 33.1%).

Source attribution: Identification of references was used to assess source attribution.

Less than one third of the 136 sites clearly identified sources for information cited in the web page (41 sites had identified experts with credentials).

User interactivity: Most websites provided feedback from users to site owner/provider through e-mail (119 sites or 88%). Of the web pages which did not provide e-mail communication, other feedback was used (e.g., telephone). Most web pages provided some type of link: external sites (36 sites or 27%), internal sites (35 sites or 26%), or both (41 sites or 26%). In about one fifth of the sites, there were no links (29 sites or 21%).

User privacy protection: Less than 6% of sites (7 of 136 sites) indicated that information sent by the user would be a secure transmission or had a disclaimer indicating that messages sent would not be secured.

Type of site: We categorized websites as news/support groups, chatrooms, individual or personal pages, government or not-for-profit agency information sites, commercial sites, other group information and service sites, and sites which did not fit these standard groupings. Fifty-six percent of the sites were news/support groups (35 of 136 sites) or information sites (42 of 136 sites). Less than 17% were commercial sites and 7% were personal pages. Table I lists URLs of representative breast cancer websites by type of site.

Because commercial sites marketing products and services have different agendas than government information sites, we used the accountability criteria (interactivity, disclosure, etc.) to assess differences by type of website (Table II). Inclusion of site creation date differed from chance alone as a function of the type of website ($\chi^2=13.12$, $df=6$, $p<0.05$). Breast cancer information sites were more likely to report date site was created relative to other sites. The likelihood of a site presenting information about attribution differed from chance alone by the type of website ($\chi^2=21.54$, $df=6$, $p<0.001$). Government or not-for-profit organization information sites were about equally likely to give source attribution (23 of 42 sites indicated source) compared with other types of sites. There were significant differences in indication of credentials of site owner by type of website ($\chi^2=12.71$, $df=6$, $p<0.05$). There

TABLE I
Examples of URL Addresses Evaluated for Internet Study on Breast Cancer

Type of Site	Name of Site	URL Address
Support or news group	Mothers supporting daughters with breast cancer	http://www.azstarnet.com/~pud/msdbc/
Information site	Breast cancer action Nova Scotia	http://bcans.org/
Commercial site	Breast cancer survivor's rehabilitative exercise	http://www.breastfit.com/
Information site	Komen St. Louis	http://www.stlouisraceforthecure.com/
Support or news group	Bosom buddies: survivors helping survivors	http://www.bosombuddies.org/
Information site	Breast cancer: ask NOAH	http://www.noah.cuny.edu/cancer/breastcancer.html
Support or news group	Breast cancer survivors' club	http://www.azstarnet.com/~pud/book/
Other groups	North shore medical accelerator, P.C.	http://www.cancer-radiation.com/
Other groups	Eastbay cancer center	http://www.eastbaycancercenter.com/
Other groups	California endocrine therapy cancer center	http://www.cetmc.com/
Commercial site	Bras for body and soul	http://www.bralady.com/
Information site	Canadian breast cancer research initiative	http://www.breastcancer.ca/
Support or news group	Living beyond breast cancer	http://www.lbbc.org/
Individual site	Sooner or later breast cancer affects us all	http://www.mindspring.com/~bteater
Commercial site	Fine black lines	http://www.bookzone.com/bookzone/10000938.html
Individual site	Info breast cancer - Stan and Carol's website	http://www.intranet.ca/~stancar/
Other groups	Temple B'nai Sholom - Breast cancer awareness	http://www.hsv.tis.net/~tbsholom/awareness.html
Individual site	Alice's breast cancer info and links	http://www2.cybernex.net/~sune/
Commercial site	Beautiful shapes by OLGA's	http://www.beautifulshapes.com/

TABLE II
Number of Websites that Met Accountability Criteria by Type of Website

Criteria	Type of Website						
	News Group (n=35)	Chatroom (n=1)	Other Group (n=20)	Information Site (n=42)	Commercial Site (n=23)	Individual Site (n=9)	Not Determined (6)
Creation Date Indicated	3	0	1	11	1	3	0
Posting Update Indicated	12	0	4	20	6	2	1
Source Attribution	7	0	7	23	2	1	1
Credentials Indicated	4	0	9	19	7	2	2
Medical Services Offered	2	0	6	2	5	1	0
Security of Information	2	0	1	3	1	0	0
E-mail Available	29	1	16	40	20	8	5
Links Present	33	1	16	33	16	4	4
Copyright Indicated	17	0	12	25	16	5	6

was no difference in whether a site provided e-mail by type of site. There were, however, significant differences from those expected from chance alone in the type of links provided (internal, external, both, none) by type of website ($\chi^2=41.71$, $df=18$, $p<0.001$). Information sites and news groups were more likely to provide both internal and external links (15 of 42 sites and 13 of 35 sites, respectively) and commercial sites were more likely to provide internal links only (13 of 24 sites).

Ownership of site: Ownership was grouped using the following categories: individual; group; government or not-for-profit organization; commercial ownership; not identified. Two categories accounted for two thirds of the ownership: groups (43 of 136 sites) and government or not-for-profit organizations (45 of 136 sites). Just under 20% of ownership was by individuals (27 of 136 sites). Commercial organizations accounted for less than 15% of the site ownership (18 of 136 sites) in this survey.

DISCUSSION

The results suggest that breast cancer sites available on the Internet vary with respect to the criterion of accountability. Many sites lacked information which would allow the user to assess the credibility of the owner. Less than one third of the sites identified references or sources for information cited at the site. Information sites (e.g., those maintained by government) had a higher proportion reporting source attribution than the other website types. Regardless of the type of website, without clear identification of sources, it would be difficult for the user to take the next step in determining the accuracy of the scientific content.

Less than half of the sites provided indicators of currency of the information. Listing a date when the site was updated does not guarantee the information is either correct or up to date. However, it can serve as an initial screen for users to assess the information against current best

practice. One of the advantages to posting information on the Internet is that it allows frequent updating of information in contrast to traditional print media.

Most sites provided opportunities for user feedback through e-mail. This feature allows users to provide comments, suggestions, corrections, criticisms and to ask questions about information posted. E-mail interactivity provides one measure of site accountability. However, one recent report¹⁷ raises disturbing questions about whether e-mail interactivity actually provides site accountability. E-mails on behalf of a fictitious patient were sent to 57 websites that professed some knowledge of medicine and dermatology, in particular, and only one half of the e-mails received a response within 1-10 days.

Links are "connections to other internal pages or to external sites that form the web-like structure of information searches within and among sites."^{15, p5} This study found that most sites had some type of link, although the link structure (internal,

external) varied by type of website. Commercial sites were more likely to provide internal links only and individuals seeking information about breast cancer could spend valuable time sifting through dead ends.

Despite the openness of the Internet, health care practitioners,^{18,19} health researchers^{11,14,20} and policymakers^{15,16} advocate the development of specific standards to protect public health. Such criteria are relevant given high profile health websites which have been criticized for failure of financial disclosure.²¹ In this study, we applied published, peer-reviewed indicators of website accountability¹¹ to breast cancer websites and found gaps with respect to currency, attribution and disclosure. We argue that websites that lack essential indicators, such as dating, do not provide the user with even the fundamental information that would enable the user to make an informed judgement about the quality. Additional research on the quality of the content information, the development of accountability criteria that are widely accepted, and application to consumer expectations for healthcare, needs to be done.

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REFERENCES

1. Coulter A. Evidence-based patient information. *BMJ* 1998;317:225-26.
2. Biermann JS, Gooladay GJ, Greenfield MLVH, Baker LH. Evaluation of cancer information on the Internet. *Cancer* 1999;86:381-90.
3. Wootton JC. The quality of information on women's health on the internet. *J Women Health* 1997;6:575-81.
4. Lowes RL. Here come the patients who've studied medicine on-line. *Med Econ* 1997;32:612-14.
5. Kassirer JP. The next transformation in the delivery of health care. *New Engl J Med* 1995;332:52-54.
6. Coiera E. Information epidemics, economics, and immunity on the internet. *BMJ* 1998;317:1469-70.
7. Alemi F, Mosavel M, Stephens RC, et al. Electronic self-help and support groups. *Med Care* 1996;34:OS32-OS34.
8. Larkin M. Internet accelerates spread of bogus cancer cure. *Lancet* 1999;353:331.
9. Impicciatore P, Pandolfini C, Casella N, Bonati M. Reliability of health information for the public on the world wide web: Systematic survey of advice on managing fever in children at home. *BMJ* 1997;314:1875-81.
10. Culver JD, Gerr F, Frumkin H. Medical information on the internet. A study of an electronic bulletin board. *J Gen Intern Med* 1997;12:466-70.

11. Silberg WM, Lundberg GD, Musacchio RA. Assessing, controlling, and assuring the quality of medical information on the Internet. *JAMA* 1997;277:1244-45.
12. Pool R. Turning an info-glut into a library. *Science* 1994;266:20-22.
13. Glowniak JV. Medical resources on the Internet. *Ann Intern Med* 1995;123:123-31.
14. Wyatt JC. Commentary: Measuring quality and impact of the world wide web. *BMJ* 1997;314:1879-80.
15. Health Summit Working Group. Criteria for assessing the quality of health information on the Internet. Policy Paper. <http://hitweb.mitretrek.org/docs/policy.pdf> accessed August 11, 1999.
16. *Canada Health InfoWay. Paths to Better Health: Final Report.* Advisory Council on Health Infrastructure. Ottawa: Health Canada Publication. February 1999. (Also available online at <http://www.hc-sc.gc.ca/ohih-bsi>)
17. Rutter F. Doctors learn of the dangers of the Internet. *BMJ* 1998;317:1103.
18. Gardiner PV. Evidence based patient information. Doctors should be encouraged to develop information resources on the internet (letter). *BMJ* 1999;318:461.
19. Mack J. Quality of medical information on the internet (letter). *JAMA* 1997;278:632.
20. Eysenbach G, Diepgen TL. Towards quality management of medical information on the Internet: Evaluation, labelling, and filtering of information. *BMJ* 1998;317:1496-502.
21. Noble HB. Hailed as a Surgeon General, Koop criticized on web ethics. *The New York Times* 1999 Sept 5;Sect. National:1 (col.1-2), 17 (col. 3-6).

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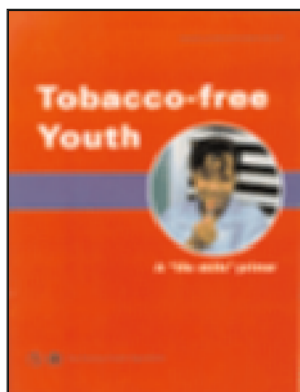
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