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## Consumer health information seeking on the Internet: the state of the art

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### Abstract

Increasingly, consumers engage in health information seeking via the Internet. Taking a communication perspective, this review argues why public health professionals should be concerned about the topic, considers potential benefits, synthesizes quality concerns, identifies criteria for evaluating online health information and critiques the literature. More than 70 000 websites disseminate health information; in excess of 50 million people seek health information online, with likely consequences for the health care system. The Internet offers widespread access to health information, and the advantages of interactivity, information tailoring and anonymity. However, access is inequitable and use is hindered further by navigational challenges due to numerous design features (e.g. disorganization, technical language and lack of permanence). Increasingly, critics question the quality of online health information; limited research indicates that much is inaccurate. Meager information-evaluation skills add to consumers' vulnerability, and reinforce the need for quality standards and widespread criteria for evaluating health information. Extant literature can be characterized as speculative, comprised of basic 'how to' presentations, with little empirical research. Future research needs to address the Internet

as part of the larger health communication system and take advantage of incorporating extant communication concepts. Not only should research focus on the 'net-gap' and information quality, it also should address the inherently communicative and transactional quality of Internet use. Both interpersonal and mass communication concepts open avenues for investigation and understanding the influence of the Internet on health beliefs and behaviors, health care, medical outcomes, and the health care system.

### Introduction

Increasingly, professionals and consumers engage in interactive health communication. Robinson *et al.* define 'interactive health communication' as 'the interaction of an individual—consumer, patient, caregiver or professional—with or through an electronic device or communication technology to access or transmit health information or to receive guidance and support on a health-related issue' [(Robinson *et al.*, 1998), p. 1264]. Perhaps the most common and influential function of interactive health communication today is health-information seeking by consumers. Concerns about the quality of health information found on the web led to the focus of one *Healthy People 2010*'s health communication objective, 'quality of Internet health information sources', as public health officials recognize that 'the potential for harm from inaccurate information...is significant' [(Office of Disease Prevention and Health Promotion, 2000), pp. 11–16]. This state-of-the-art review focuses on consumer online health-information seeking.

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Reviewing literature identified via Medline, Psych-Info and web searches, the report argues why public health professionals should be informed and concerned about consumers' Internet health-information seeking, considers potential benefits, synthesizes quality concerns, identifies criteria for evaluating websites, and concludes with a commentary about the nature of the literature.

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### **Public health interest in consumer health-information seeking via the Internet**

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Public health professionals need to focus on health-information seeking via the Internet for a variety of reasons. These include magnitude and diversity of use; diversity of users; and, ultimately, implications for the health care system, in terms of structure, health care interaction and quality of medical outcomes.

#### **Magnitude of use**

As the Internet has grown, so too have health-related purposes. Perhaps most common is consumer health-information seeking.

#### **Internet use**

The Internet's rapid growth triggered an 'information revolution of unprecedented magnitude' [(Jadad and Gagliari, 1998), p. 611]. The movement began with widespread diffusion of personal computers; Internet use 'exploded' in the fall of 1994 [(Breeck, 1997), p. 1032]. Households with personal computers grew from 8% in 1984 to more than 50% by 2001 (Eng *et al.*, 1998; Pew Internet and American Life Project, 2001). Although only 1000 computers were linked to the Internet in 1985, by 1998, 4 million were (Eng *et al.*, 1998). Recent estimates place from 90 million (The Associated Press, 2000a) to 120 million (Reuters, 2000) Internet users in the US.

#### *Consumers seeking health information*

Consumer use of the Internet for health information is large and growing; more than 70 000 websites provide health information (Grandinetti, 2000).

Estimates of Internet health-information seeking vary widely, but are uniformly high, evidencing 'exponential' growth [(Lacroix *et al.*, 1994), p. 417]. By 1997, nearly half of Internet users in the US had sought health information [(Find/SVP, 1998), as cited by (Eng *et al.*, 1998)]. Annual estimates grew from 43% in 1997 [(Find/SVP, 1998), as cited by (Chi-Lum, 1999)] to 63% in 2000 (Pew Internet and American Life Project, 2001). Expressed in raw numbers, an estimated 18 million adults in the US sought health information online in 1998 (Cyber Dialogue, 1998). Recent estimates range from 60 to 100 million people doing so (Louis Harris and Associates, 1999; Grandinetti, 2000; Harris Interactive, 2001; Pew Internet and American Life Project, 2001), most at least once a month (Pew Internet and American Life Project, 2000c).

An example illustrates the growth. When the National Library of Medicine (NLM) made Medline available to the public via the Internet, use exploded to more than 250 000 inquiries a day (Pathfinder, 1998). Searches increased from 7 million in 1997 to more than 120 million in 1998; more than one-third of the latter were consumers (Louis Harris and Associates, 1999). In response, NLM developed a site designed specifically for consumers, MedlinePlus.

Reasons for the growth of consumers' online health-information seeking include the development of participative or consumer-oriented health care models, the growth of health information that makes any one clinician incapable of keeping pace, cost-containment efforts that reduce clinicians' time with patients and raise concern about access to 'best' care, emphasis on self-care and prevention, an aging population with increased health-care needs, and increased interest in alternative approaches to health care (Eng *et al.*, 1998; Gallagher, 1999). In addition, consumers report convenience, anonymity and diversity of information sources as attractions (Pew Internet and American Life Project, 2000c).

#### **Diverse purposes**

The scope of the health-related Internet applications is 'as broad as medicine itself' [(Sonnenberg,

1997), p. 151]. Consumers access online health information in three primary ways: searching directly for health information, participating in support groups and consulting with health professionals.

#### *Health web pages*

Consumers can access online health information directly from credible scientific and institutional sources (e.g. Medline, Healthfinder) as well as unreviewed sources of unknown credibility (e.g. well-informed individuals along with quacks and charlatans) (Gregory-Head, 1999). The majority of consumers (77%) seeking health information for themselves want disease information for consultation with their physicians [(Find/SVP, 1998), as cited by (Chi-Lum, 1999)]; many (54%) seek information for others (Pew Internet and American Life Project, 2000c). Searches often are triggered by a diagnosis and desire for treatment information (Boyer *et al.*, 1999), as more than 90% of health-information seekers search for material related to physical illnesses (Pew Internet and American Life Project, 2000c). In turn, information found may influence medical decision making and help consumers to manage their own care (Wilkins, 1999; Pew Internet and American Life Project, 2000c). About 47% of those seeking health information for themselves reported that their findings influenced treatment decisions (Pew Internet and American Life Project, 2000c). The most common topics are the leading causes of death (heart disease and cancer); children's health also is a common topic (Cyber Dialogue, 1998).

Consumers also use the Internet to access performance reports regarding providers and hospitals (Green 1996; Anonymous, 1997), and information about managed care organizations (Williams, 1999). Information may be used to select providers (Coile and Howe, 1999), identify specialists (Williams, 1999) and make decisions regarding employment-related health care benefits (Cronin, 1998). In addition, the Internet may be used to complement school health education (Roffman *et al.*, 1997; Cox, 1998).

#### *Online support groups*

An estimated one in four health-information seekers joins a support group (Anonymous, 1998; Cyber Dialogue, 1998). Social support groups abound offline and online for an array of reasons (Cline, 1999). Like face-to-face groups, online groups offer an alternative to professional care; provide social support, information, shared experiences and behavioral models; and empower participants, fulfilling the functions of a community (Sharf, 1997; King and Moreggi, 1998; Nochi, 1998).

One study found that users rated online support groups more helpful than physicians in numerous ways (e.g. convenience, emotional support, cost-effectiveness and in-depth information) (Grandinetti, 2000). Relative advantages of online groups are their 24-h availability, anonymity, selectivity in responding, capacity for immediate and time-delayed reactions, unlimited volume of participants (including professionals), and exposure to an increased number of opinions, expertise and experience (Sharf, 1997; Haythornwaite *et al.*, 1998; King and Moreggi, 1998). The lack of non-verbal cues and potential for anonymity create a level playing field with regard to status (King and Moreggi, 1998). Because many demographic and physical differences are obscured, a sense of 'groupness' may evolve more readily.

#### *Online interaction with health professionals*

Increasingly, consumers use the Internet to consult with health professionals. Touted only a short time ago as a 'future development', today, many patients maintain E-mail contact with physicians. About one in five physicians E-mail patients (Cyber Dialogue, 2000b) and 3.7 million patients E-mail their doctors (Cyber Dialogue, 2000a); however, as many as 33.6 million would like to do so. Patients also use E-mail to interact with 'cyber-docs'—interactive virtual doctors' offices (Bader and Braude, 1998; Oravac, 2000).

A more controversial development is fee-based psychotherapy via E-mail. King and Moreggi contend this application may be most useful for problems with 'everyday living' [(King and

Moreggi 1998), p. 94]; disorders involving distortions of reality may be difficult to detect. Online therapy raises ethical questions and legal concerns (King and Moreggi, 1998) related to diagnosis by E-mail alone (Buhle, 1996), given the potential for misrepresentation and deception (McLellan, 1998), and unclear care standards (with regard to record keeping, outcome expectations, billing and confidentiality) (Shapiro and Schulman, 1999).

### **Diverse users**

Early Internet users were likely to be white male professionals. Today's health-related use tends to defy stereotypes and increasingly reflects the population's composition.

Initially men tended to use the Internet more than women, but women constituted 50% of Internet users for the first time in 1999 (Reuters, 2000). The number of women online grew by 32% in 1999 compared to 20% among men. However, any gender difference may be mediated by race; one study found that women make up 56% of the black population using the Internet, compared to an even gender split among whites (The Associated Press, 2000b). Women, more than men, tend to prefer health sites, in part because of care-taking roles. A Health on the Net Foundation (HON) survey (Health on the Net Foundation, 1999a) found that 60% of respondents using the net to locate health information were women [see also (Pennbridge *et al.*, 1999; Pew Internet and American Life Project, 2000b)].

More whites than blacks have Internet access in the US (57 versus 43%), a gap largely a function of income (Pew Internet and American Life Project, 2001). On a typical day, one-third of blacks with Internet access go online compared to 56% of whites with access (Pew Internet and American Life Project, 2000b). However, blacks, more than whites, rely on the Internet as an informational tool, including for health information (45 versus 35% of Internet users) (Pew Internet and American Life Project, 2000b). Popularity of using the Internet for health information among African-Americans continues to grow, with a 6% increase over a 6-month period in 2000 (Pew Internet and

American Life Project, 2001). This popularity may reflect blacks' lesser access to traditional health information sources.

Internet use spans generational lines. An estimated 45% of children in the US (30 million) have Internet access (Pew Internet and American Life Project, 2001). Izenberg and Lieberman identified health websites specifically designed for children (Izenberg and Lieberman, 1998). An HON survey (Health on the Net Foundation, 1999a) found the largest age group of health users to be baby boomers entering middle age, with 60% of users over age 40 and 8% over age 60. Many of the latter were ill or had ill spouses. The Pew Internet and American Life Project found only 15% of those over age 65 use the Internet (The Pew Internet and American Life Project, 2001). Despite what is labeled a 'gray gap' (Pew Internet and American Life Project, 2000a), some research promises significant value for the elderly; a 1999 study found that Internet can be used effectively by nursing home residents for E-mail and other access, combating the 'four plagues of institutionalized elders: loneliness, boredom, helplessness and decline of mental skills' [(The Associated Press, 1999), p. 2A]. Confidence in learning E-mail spread to other aspects of residents' lives, thereby reducing depression. Major barriers to elders' Internet use relate to economics, lack of contact with computers and privacy concerns (Pew Internet and American Life Project, 2000a).

### **Collaborations or collisions ahead? Implications for the health care system**

Increased consumer participation in interactive health communication is likely to influence the health care system due to its information dissemination, health promotion, social support and health services functions (Robinson *et al.*, 1998). A PricewaterhouseCoopers (PricewaterhouseCoopers, 1999) global survey of health industry thought leaders yielded the expectation that the Internet will create massive changes in health care.

However, critics disagree about the valence of consequences. Optimists anticipate better-informed decisions by consumers, better and more tailored

treatment decisions, stronger provider–client relationships, and increased patient compliance and satisfaction (Ayonride, 1998; Wilkins, 1999), resulting in better medical outcomes (Bader and Braude, 1998; Wilkins, 1999) and more efficient service (PricewaterhouseCoopers, 1999). Pessimists contend that interactive health communication will not enhance physician–patient communication, with physicians likely to balk at the added responsibilities (Appleby, 1999; Baur, 2000). Medical outcomes could be diminished by consumers who lack technical background, interpret information incorrectly and try inappropriate treatments (LaPerrière *et al.*, 1998).

Among the ways that interactive health communication is forecast to affect health care include: replacing traditional information, care and community resources with online information, consultations and social support networks (Simpson, 1996; LaPerrière *et al.*, 1998; Gregory-Head, 1999; Oravec, 2000). As consumers increasingly use the Internet to more actively and independently manage their health care, they are likely to take this active role into encounters with providers. One survey found that 67% of physicians report having patients who discuss with them information retrieved from the Internet (Neff, 1999).

This emerging consumer role has implications for health care relationships. Consumers may confront providers who are unprepared to deal with the magnitude of available information (Coiera, 1996), with patients sometimes having greater information access than their providers. Providers may be stressed by added responsibilities for information seeking and clarification, and become frustrated and resistant due to time costs in correcting inaccuracies (Ayonride, 1998; Appleby, 1999; Lincoln and Builder, 1999). Conflicts between provider and client may be likely as consumers locate information that leads them to challenge, question or ‘second-guess’ providers, indicating diminished trust in their physicians (Robinson *et al.*, 1997; Bader and Braude, 1998; Pereira and Bruera, 1998; Eng and Gustafson, 1999; Lamp and Howard, 1999).

The shifting balance of informational power

functions to erase prior exclusivity of access to information (Coiera; 1996; Wilkins, 1999), treating everyone as a ‘peer’ [(Buhle, 1996), p. 624]. Some applaud this shift as an opportunity for partnerships in health care (Thomas, 1998) and greater use of the consumer as a resource (Wilkins, 1999), while others see a Pandora’s box of ‘unmanageable problems’ [(Mayer and Till, 1996), p. 568]. Many providers are threatened by their loss of power and fear damage to physician–patient communication (Anonymous, 2000). Anticipated changes highlight the need to integrate interactive health communication into medical and health professional curricula (Aschenbrener, 1996; Kaufman *et al.*, 1997; Khonsari and Fabri, 1997; Lunik, 1998), continuing medical education (Doyle *et al.*, 1996), and patient education and provider–client interactions, in order to facilitate clients’ access to information they trust (Lamp and Howard, 1999; Grandinetti, 2000).

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### Potential benefits of consumer online health-information seeking

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From the Internet’s inception, health care was understood to be ‘a major potential beneficiary’ [(Lindberg and Humphreys, 1995), p. 158]. *Potential* benefits to consumers are many.

### Widespread access to health information

The Internet ‘created an avalanche of easily accessible information’ [(Appleby, 1999), p. 21]. Exponential growth of access to health information offers, ‘seemingly endless opportunities to inform, teach, and connect professionals and patients alike’ [(Silberg, *et al.*, 1997), p. 1244]. Breaking the space and time barriers of traditional information-seeking processes, the Internet offers widespread dissemination, high volume and currency (Eng and Gustafson, 1999; Gregory-Head, 1999; McKinley *et al.*, 1999). Theoretically available worldwide, at the price of a local telephone call, 24 h a day (LaPerrière *et al.*, 1998; McKinley *et al.*, 1999), the Internet has the potential to increase health information access in remote areas and to otherwise under-served populations (LaPerrière *et al.*, 1998; McGrath, 1997). As a result, the Internet offers

the potential for greater equity in access to health information (Morris *et al.*, 1997). In some cases, websites are developed specifically for otherwise hard-to-reach audiences (e.g. NetWellness, a consumer health library, developed for a rural population) (Guard *et al.*, 1996).

### **Interactivity**

A major potential benefit of the Internet is its capacity for interactivity, emphasizing transactional rather than linear communication processes (Pereria and Bruera, 1998; McMillan, 1999). Interactivity is reflected in complexity of choice, responsiveness or conversationality and interpersonal communication (McMillan, 1999). Interactivity further promotes tailoring of messages and facilitates interpersonal interaction.

### **Tailoring of information**

In contrast to traditional sources of health information (e.g. print), interactive health communication offers the potential for more individually tailored messages in a variety of formats (Robinson *et al.*, 1998; Eng and Gustafson, 1999). Consumers can select sites, links and specific messages based on knowledge, educational or language level, need, and preferences for format and learning style, often at lower cost than conventional methods (Pereira and Bruera, 1998). At the same time, traditional health information and patient education materials and messages can be placed on the Internet inexpensively (Richards, *et al.*, 1998).

### **Potential to facilitate interpersonal interaction and social support**

The Internet offers opportunities for consumers to interact interpersonally with health professionals and peers. Research consistently indicates that health behavior change typically results more from interpersonal than mass communication [e.g. (Piotrow *et al.*, 1997)]; thus, the Internet may be used to promote health behavior change.

### **Potential for anonymity**

Relative to face-to-face interaction, interactive health communication offers potential anonymity (Robinson *et al.*, 1998). Consumers may access

information on sensitive topics, and the stigmatized may interact without the predictable disconfirmation of face-to-face interaction. Those who have difficulty communicating face-to-face may be able to engage in interactive health communication (LaPerrière *et al.*, 1998).

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### **Roadblocks, bumpy roads and hazards on the information superhighway**

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Despite potential benefits of interactive health communication, limitations and cautions abound. Roadblocks to access, navigational difficulties and quality concerns constitute potential downfalls of relying on the Internet for health-related information.

#### **Roadblocks to access**

Claims that 'the Internet is inherently democratic' by having information for everyone [(Wootton, 1997), p. 576] are countered by evidence of inequitable access. Those in greatest need are least likely to have Internet access (Eng *et al.*, 1998). Havenots include rural, isolated and traditionally underserved populations (e.g. inner city and low socioeconomic status neighborhoods; the elderly) (Eng and Gustafson, 1999; Gallagher, 1999). Barriers to online health information include cost, geographic location, literacy, computer skills and institutional policies (Eng *et al.*, 1998; LaPerrière, *et al.*, 1998; Gallagher, 1999).

Disparities in access to both computers and the Internet are growing (Chapman, 1999). A Department of Commerce study reported that 40% of US households have personal computers (Chapman, 1999); however, data indicate a growing divide based on both education and income levels. Although 82% of US households with incomes in excess of \$75 000 have Internet access, only 38% of those with incomes below \$30 000 do so (Pew Internet and American Life Project, 2001), figures that translate to about 20 times greater likelihood of access among the higher than the lower income group (Chapman, 1999). Both consumers' and professionals' (e.g. rural and urban community

health providers) access can be bounded by cost (Martin *et al.*, 1997). Access is defined not simply as having a computer, but also in terms of 'affordability, accessibility, availability, acceptability and accommodation of Internet connections' [(Wilkins, 1999), p. 31].

Cost often correlates with geography. The worldwide picture is dismal. Only 10% of the 55 billion US\$55 spent globally on health research addresses the needs of poor countries (World Health Organization, 1995). In the US, one in six people use the Internet, but in Africa (excluding South Africa), one in 5000 uses the Internet (Lown *et al.*, 1998). In Africa, Internet service providers are increasing, but most health professionals and hospitals cannot afford hook-up and access fees; these same countries often lack textbooks for medical and nursing students, and have little access to medical journals (Lown *et al.*, 1998). Internet access is prohibitively expensive for many developing countries (Pereira and Bruera, 1998). The role of poverty versus affluence in accessing the Internet is obvious: 'While the affluent travel at greater speed on the information superhighway, a majority of the world's population has never even made a telephone call' [(Lown *et al.*, 1998), p. SII36]. At the same time that analysts fear information overload regarding HIV treatments [e.g. (Green, 1999)], 95% of HIV cases occur in the developing world where few doctors can access the Internet and for whom few sites exist in local languages. Thus, little attention is paid to making information accessible to those in greatest need.

Computer, English language and health literacy constrain Internet use. People may not know how to access the Internet or be afraid of the technology (Wilkins, 1999). People unable to speak, read or understand English are disadvantaged as English is the dominant online language (Pereira and Bruera, 1998). NOAH (New York Online Access to Health) was one of the first websites developed to address consumer health information needs in both English and Spanish (Voge, 1998). People with the greatest health care needs often have low information access due to lower health literacy levels (American Medical Association, 1999).

Eng *et al.* advocate universal access to health information (Eng *et al.*, 1998). They challenge both public and private stakeholders to collaborate to reduce the gap between 'haves' and 'have-nots', by supporting access in homes and public places (e.g. public libraries, schools, malls, community centers, health care facilities, places of worship), developing applications for diverse users, supporting access-related research, addressing quality of information issues and training health information specialists to function as intermediaries (Eng *et al.*, 1998).

Arguments for universal access are 3-fold: philosophical, public health and economic. Philosophically, the majority of health information was developed from publicly funded research and should be accessible to all. The authors' views parallel the egalitarian philosophy about public libraries, i.e. 'encouraging an informed citizenry and a vibrant democracy' [(Eng *et al.*, 1998), p. 1373]. Greater access to health information may improve health status by enhancing the quality of health-related decisions; in turn, health care costs may be reduced.

### **Bumpy roads: navigational difficulties**

Internet users may find health information functionally inaccessible due to design features resulting in difficulty of use.

#### *Information overload*

Analysts recognize online health information overload as a problem [e.g. (LaPerrière *et al.*, 1998)], characterizing it as a 'disease' [(Morris, 1998), p. 1866] or a 'traffic jam' [(McGrath, 1997), p. 90]. Wootton likens the Internet to a vast library in conjunction with a giant set of Yellow Pages (Wootton, 1997). A spokesperson for the US Department of Health and Human Services warned, 'Trying to get information from the Internet is like drinking from a firehose, and you don't even know what the source of the water is' [(McLellan, 1998), p. SII39]. One physician complained of 'an information glut to the point that people get all balled up' [(Appleby, 1999), p. 21]. The speed and uncontrolled manner of Internet growth and

information accumulation make locating valid information more difficult (Jadad and Gagliari, 1998).

#### *Disorganization*

Not only is the Internet overloaded, it is disorganized (McKinley *et al.*, 1999). The Internet is like [(Jacobson, 1995), pp. A29–A30]:

...a library where all the books have been donated by patrons and placed randomly on shelves. There are no call numbers or other classification schemes, and people can move books around from shelf to shelf whenever they wish. Moreover the library is expanding rapidly, with new collections arriving every day and thousands of additional people signing up every week to roam through the stacks...It is an unorganized mass of material—some of it wonderful, some of it awful.

#### *Searching difficulties*

Even Internet literate users may not be skilled in locating health information. Searching can be difficult both for consumers and professionals (DeGeorges, 1998; Pereira and Bruera, 1998). Users may find that search engines locate too many or too few sites (Chi-Lum, 1999); target audiences often are unspecified. Availability of information on the web is subject to the same disparities as traditional sources. For example, although many sites contain HIV/AIDS information, few are designed for women (Mallory, 1997), mirroring offline discriminating factors in attending to the disease [see, e.g. (Cline and McKenzie, 1996)].

#### *Inaccessible or overly technical language*

Beyond inaccessibility to material in one's native language, users may find much health information presented in jargon or highly technical language. Despite their training, 48% of nurses studied indicated that they found Internet-based health information unclear (AWHONN, 1997). Much health information is presented at a high reading level; overuse of textual formats may exacerbate language problems (McGrath, 1997). However,

graphic formats pose their own problems, often in the form of slowness in downloading graphics (McGrath, 1997).

#### *Lack of user friendliness*

Once located, health sites may be difficult to use due to confusing layering, difficult-to-follow linkages and lack of searchability. Difficult to use or weak browsers and search engine technologies may challenge users (Pennbridge *et al.*, 1999). Consumers unfamiliar with the technology may be intimidated and retreat both from the Internet and from the health care system (Gallagher, 1999).

#### *Lack of permanence*

The Internet is fluid rather than permanent. Inconsistent updating means that information may be out of date (Gallagher, 1999). Sites disappear, change and move without warning, due to the 'evanescent' nature of the Internet [(Pereira and Bruera, 1998), p. 62].

O'Mahoney's review of Irish health care websites summarizes navigational difficulties (O'Mahoney, 1999). O'Mahoney judged these sites 'disappointing' [(O'Mahoney, 1999), p. 334] due to little dating, unspecified target audiences, poor design, lack of E-mail contact addresses, high readability levels, lack of interactivity, little maintenance and being static or out of date.

#### **Hazardous conditions**

Increasingly, medical professionals and Internet users voice concerns about the *quality* of online health information [e.g. (Maugans, *et al.*, 1998; McLeod, 1998; Boyer *et al.*, 1999)]. Concerns persist although evidence finds more than 90% of Internet users satisfied, having found 'the information they were looking for' (Louis Harris and Associates, 1999) or 'useful' information (Health on the Net Foundation, 1999a; The Associated Press, 2000b). Despite consumer satisfaction, 'incorrect information could...be life-threatening' [(Lunik, 1998), p. 40]. Well-reasoned criticism identifies why the information consumers find may be harmful.



*Lack of peer review or regulation*

'There is no 'arbiter' of truth on the Internet' [(Lunik, 1998), p. 40], no 'quality filter' [(Lacroix *et al.*, 1994), p. 417]. Anyone can develop an Internet site; thus, 'the Web has become the world's largest vanity press allowing anyone with Internet access to act as an author and publisher of material on any subject' [(Richards *et al.*, 1998), p. 281]. The Internet is characterized by uncontrolled and unmonitored publishing with little peer review (Marra *et al.*, 1996; Pereira and Bruera, 1998). Authorship can be misleading as anyone can claim medical expertise; pages may be 'official looking' and mislead consumers into believing they are authoritative [(Pereira and Bruera, 1998), p. 61].

A variety of types of unreviewed sources are available to consumers, including quacks, cranks and charlatans (Gregory-Head, 1999), leading one observer to complain, 'Finding anything means there is a huge pile of rubbish' [(Machles, 1998a), p. 410]. Well-intentioned individuals may provide information based on personal experience; quacks promote unproven remedies, giving false hope and inaccurate information about outcomes; cranks have some scientific background but are disenchanted with traditional science; most alarming are charlatans who 'engage in fraudulent practices with the intent to deceive' [(Pereira and Bruera, 1998), p. 48]. Because the Internet is unregulated, accuracy, currency and bias vary (McGrath, 1997; Lamp and Howard, 1999); inaccurate information is disseminated widely (Richards *et al.*, 1998).

*Inaccurate, misleading and dangerous information*

Typical criticisms find health information on the Internet 'bad, and even dangerous' [(McKinley *et al.*, 1999), p. 265], 'inaccurate, erroneous, misleading, or fraudulent' [(McLeod, 1998), p. 1663], 'incomplete, misleading and inaccurate' [(Silberg *et al.*, 1997), p. 1244] and 'incomplete, contradictory or based on insufficient scientific evidence' [(Abelhard and Obst, 1999), p. 75]. Not only is information incomplete, often it is not evidence based (Pereira and Bruera, 1998; Pandolfini *et al.*, 2000). 'Science and snake oil may not always look

all that different on the Net' [(Silberg *et al.*, 1997), p. 1244]. Dow *et al.* warned that 'fringe, nonscientific therapies may be touted...as valid' [(Dow *et al.*, 1996), p. 152]. Thus, concern exists for both fraudulent and unsubstantiated information on the Internet (Marra *et al.*, 1996).

More experienced users of the Internet for health information seeking are more critical of its quality than less experienced users (Health on the Net Foundation, 1999b). A large and growing majority (69%, up from 53% in a May/June 1998 survey) of Internet users are concerned about quality of online health information (Health on the Net Foundation, 1999a).

Coiera characterizes the potential for harm due to inaccurate online health information as an 'information epidemic' [(Coiera, 1998), p. 1469]. Although limited in quantity, evidence of potential harm due to low-quality online information is emerging [e.g. (Weisbord *et al.*, 1997)]. One study shows that more than half of health information websites offer unreliable information (Abelhard and Obst, 1999). Researchers who assessed the reliability of websites containing information related to home management of children with fevers (Impicciatore *et al.*, 1997) found that the information on only four of 41 websites adhered closely to the primary recommended guidelines. Similarly, a study of online sources regarding childhood diarrhea (McClung *et al.*, 1998) found only 12 of 60 articles from traditional medical sources adhered to treatment recommendations of the American Academy of Pediatrics, even when websites were from major academic medical centers. A study of cancer information on the Internet found 'abundant' materials that were not peer-reviewed and a 6% rate of inaccuracy (Biermann *et al.*, 1999). One study of Internet sites addressing a urology-related topic concluded, 'The number of Web sites providing complete, nonbiased information continues to represent only a small portion of the total' [(Sacchetti *et al.*, 1999), p. 1117]. Finally, an initiative by the Federal Trade Commission identified, in only a few hours, over 400 websites and Usenet newsgroups containing false or decep-

tive claims and products for six diseases (Federal Trade Commission, 1997).

Concerned about 'sensational anecdotes', common to the Internet, Pereira and Bruera searched sites on controversial issues (e.g. euthanasia and medical use of marijuana) and concluded that the majority offered 'unbalanced views with little or poor referencing to scientific data' and noted several commercial sites, particularly those advancing alternative therapies [(Pereira and Bruera, 1998), p. 61].

One culprit in propagating incorrect information is online support groups (LaPerrière *et al.*, 1998). Given countless groups, no means exists for stopping the dissemination of false or misleading information (King and Moreggi, 1998). For example, a study of a bulletin board dedicated to discussing painful arm and hand conditions showed that one-third of the medical information provided was classified as 'unconventional' [(Culver *et al.*, 1997), p. 468], commonly (79%) provided by people lacking professional medical training. Personal experience was the basis of 61% of non-professionals' information; both professionals and non-professionals typically failed to provide an information source.

Not everyone contends that inaccurate information is relatively more abundant on the Internet. McLeod reasons, 'It might be argued that the Internet suffers no more from error and inaccuracy than do many traditional informal sources of health care information, including acquaintances, pamphlets, and popular press articles' [(McLeod, 1998) p. 1663]. Although concern for quality has never been greater, it also has never been easier to crosscheck information and get multiple opinions or sources (Wootton, 1997).

Likewise, not all studies regarding Internet information doubt quality. For example, Maugans *et al.* identified Internet resources for 10 common pediatric neurosurgery topics (Maugans *et al.*, 1998); generally they found that information was highly accurate, with the exception of that found in online support groups and chat rooms. Similarly, a study of four Internet sites providing prescription drug information found 98% or greater accuracy;

but not all sites provided information on all drugs being evaluated (Hatfield *et al.*, 1999).

In summary, Internet searches may yield false and deceptive service, product and treatment claims without providing supporting evidence or sources permitting verification (Dow *et al.*, 1996). Even savvy Internet users 'can have trouble distinguishing the wheat from the chaff' [(Rudin and Littleton, 1997), p. 934]. Sonnenberg claims 'Most people will be unable to determine the qualifications of Web authors and separate truth from opinion' and 'even well-educated users are unlikely to have the background required to critically evaluate medical information' [(Sonnenberg, 1997), p. 152]. As a result, consumers lacking evaluation skills are particularly vulnerable.

#### *Consumers' evaluation skills*

Quality concerns include the public's ability to select valid information (Pereira and Bruera, 1998; Abelhard and Obst, 1999). Sonnenberg questions whether consumers 'can make good selections when more than one site is available to address their concerns' [(Sonnenberg, 1997), p. 151].

'In medicine, the ability to review scientific literature critically, to identify major research flaws, and to interpret correctly the clinical implications of research findings, are skills acquired through training' [(Ayonrinde, 1998), p. 449]. Consumers may misjudge information, become information-overloaded and thereby easily confused, misinformed or misled. Without skills needed to discern validity and familiarity with the scientific review process (Pereira and Bruera, 1998), consumers may: (1) fail to recognize that key information is missing [e.g. (Sacchetti, *et al.*, 1999)], (2) fail to distinguish between biased and unbiased information (Sacchetti *et al.*, 1999), (3) fail to distinguish between evidence-based and non-evidenced-based claims (Ayonrinde, 1998), and (4) misunderstand health information intended for health professionals (Ayonrinde, 1998). These limitations are particularly salient given evidence that people may give greater credibility to information from computers than from other media (Hawkins *et al.*, 1987; Bader and Braude, 1998; Rudin and Littleton, 1997).

*Risk-promoting messages abound*

The Internet is a reservoir of potentially influential risk-promoting as well as health information and messages. For example, the Internet is a source of information about suicide methods (Alao *et al.*, 1999). Some evidence indicates that Internet use may promote sexual risk taking. A recent survey of youth (ages 10–17 years) found that, among those who used the Internet regularly, 19% were the targets of unwanted sexual solicitation on the previous year, resulting in high levels of distress among 25% of those solicited (Mitchell *et al.*, 2001). Further, people who choose to use the Internet to find real-life sex partners are more likely to contract sexually transmitted diseases or to engage in risky behavior (e.g. have anal sex, more partners or partners known to be HIV-positive) than those who become acquainted offline (McFarlane *et al.*, 2000). Toomey and Rothenberg criticized the public health establishment for failing to anticipate this Internet consequence, a foreseeable result of the anonymity of sex facilitated by the Internet [(Toomey and Rothenberg, 2000), p. 486]: ‘For populations with levels of education and income sufficient to support computer use, the Internet has become an efficient facilitator of behaviors and practices that have been taking place for many years among certain high-risk individuals’. Thus, the Internet represents new challenges to public health professionals.

*Potential for online pathologies and maladaptive behaviors*

Among hazards of interactive health communication are the potentials for Internet addiction, validation of serious psychiatric disorders as ‘normal’, disinhibition and the replacement of face-to-face interaction with computer-based interaction. Grohol forecasts pathologies or maladaptive behaviors related to online participation including over-use and related relational and social problems (Grohol, 1998).

Estimates of Internet addiction run as high as 2–3%; however, research is sparse (Griffiths, 1998). Young reports that the concept of Internet addiction, first introduced in 1996, sparked controversy

for two reasons (Young, 1999). Some believed only physical substances could be addictive; others resisted because of the many positive consequences of the Internet. No accepted diagnostic criteria exist. Young defines Internet addiction as pathological Internet use, an impulse-control disorder (Young, 1999). Negative consequences include disrupted sleep patterns, fatigue, lack of exercise, familial and occupational impairment, and relational, academic and occupational problems (Young, 1999). Griffiths raises questions for future research, including addressing to what, and why, people are addicted (Griffiths, 1998).

The Internet may offer reinforcement and validation of normalcy to people with psychiatric disorders, with the potential to facilitate, promote and further disseminate such disorders. For example, Elliott reports the case of ‘apoteomophilia’, a psychosexual disorder involving the desire to be an amputee (Elliott, 2000). Although little research has been published in medical journals, and few psychiatrists and psychologists have ever heard of the term, numerous websites are devoted to the problem, such that Elliott characterizes interest on the Internet as ‘enough...to support a minor industry’ [(Elliott, 2000), p. 72]. The author found one listserv with 1400 subscribers. Participants on the Internet who have a sexual attraction to amputees are known as ‘devotees’, while those with the actual desire are termed ‘wannabes.’ Websites sell photographs and videos of amputees and offer interpersonal access via chat rooms and bulletin boards, where discussions topics include black-market amputations and methods of performing amputations (e.g. gunshot wounds, chainsaw slips) (Elliott, 2000). Elliott observed that many participants seemed to have other psychiatric disorders.

Schnarch expresses concern that the Internet encourages simplistic approaches to relationship development and intimacy (Schnarch, 1997). These include dependence on the validation of others based on self-presentation rather than core self-disclosure, dependence on other-validation rather than self-validation and substituting self-presentation for self-confrontation. Schnarch warns that the Internet affords no opportunity to confront

partners with contradictions between self-presentation and observed behavior (Schnarch, 1997). Online relationships often are attributed high levels of intimacy, likely based on the disinhibiting effects of interacting via media and the lack of non-verbal cues. Disinhibition is characterized by the apparent reduced concern for self-presentation and the judgments of others (Joinson, 1998). Whether online interaction promotes greater relational honesty or deception remains unanswered. Grohol concludes that going online may simply make existing pathologies more evident (e.g. antisocial and manipulative behaviors) (Grohol, 1998).

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### Evaluating health information on the Internet

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#### The problem

The uneven and often indeterminate quality of online health information raises concerns (McLeod, 1998). The Internet is composed of over 30 million pages lacking consistent peer review, editorial systems or safeguards, placing consumers and professionals in need of quality assessment standards (McGrath, 1997; Rudin and Littleton, 1997; McKinley *et al.*, 1999). Silberg *et al.*'s warning captures the problem: '*caveant lector et viewer*—let the reader and viewer beware' [(Silberg *et al.*, 1997), p. 1244]. A 'pressing need' exists for tools to evaluate health information found on the Internet [(Lamp and Howard, 1999), p. 34]. Little scholarship addresses Internet health information quality in depth [e.g. (Ambre *et al.*, 1997; Garrison, 1998; Robinson *et al.*, 1998; Adelhard and Obst, 1999; Rippen, 1999); many authors address quality briefly in the contexts of particular health professions (e.g. dentists, ophthalmologists, pharmacists) or topics (e.g. aging, women's health, health of newborns) [e.g. (Post, 1996; Rudin and Littleton, 1997; Wootton, 1997; Lunik, 1998; McLeod, 1998; Lamp and Howard, 1999)].

#### Criteria for evaluating health information websites

Numerous authors bemoan the difficulty and limitations of establishing quality standards [e.g.

(McLeod, 1998)], yet a review of literature yields substantial consensus regarding such criteria. Health-related websites should be judged by the quality of health information found on them *and* by design features that may facilitate or impede use. Quality should be based on a comprehensive assessment rather than any single criterion. A readily navigable or updated site may contain inaccurate information (Ambre *et al.*, 1997; McLeod, 1998; Rippen, 1999).

#### Quality of health information

Quality of health information found on the Internet should be subjected to the same standards as traditional information, including source and message characteristics, as well as adaptability to targeted audiences.

Internet *sources* include both site sponsors and sources of specific information. Credible Internet sources mirror tradition, including journals, universities and recognized research centers, libraries, government agencies, and professional organizations (Silberg *et al.*, 1997; Lamp and Howard, 1999). However, health information may be found on sites sponsored by little known but credible organizations (e.g. organizations of providers, consumer advocacy groups, voluntary health-related organizations), as well as organizations whose names only *sound* credible, commercial sponsors, and individuals (both professionals and members of the public). Credibility constitutes the 'premier criterion' for evaluating online health information [(Rippen, 1999), p. 4]. *Credibility* is defined as in terms of judgments regarding believability of sources of messages, reflected in two dimensions: *authoritativeness* and *trustworthiness* (O'Keefe, 1990).

*Authoritativeness* (also termed competence or expertise) involves judgments of whether the source is in a position to know what is truthful or correct (O'Keefe, 1990). Consumers should seek evidenced-based information and advice from expert sources (Wyatt, 1997; Appleby, 1999). Typically, physicians and health care organizations are perceived as authoritative (Ambre *et al.*, 1997); however, those associated with medical schools

are deemed more credible by their research involvement. Evidence of authoritativeness includes:

- Clearly identified authorship and/or source. Websites should identify the qualifications and credentials (e.g. educational backgrounds, board certifications, and affiliations with organizations) of their own and cited authors (Kibbe *et al.*, 1997; Silberg *et al.*, 1997; Adelhard and Obst, 1999; Lamp and Howard, 1999).
- Attribution. References to other publications, particularly clinical studies, permit users to verify information independently (Adelhard and Obst, 1999; Rippen, 1999; Silberg *et al.*, 1997).
- Clearly identified editorial practices and/or seals of approval. Sites should specify editorial review processes and identify reviewers (Rudin and Littleton, 1997; Rippen, 1999). The HON seal of approval signifies ostensible compliance with HON quality standards (described below) (Boyer, *et al.*, 1998).
- Opportunities for feedback and interactivity. The potential for E-mail with a site and associated health professionals, permits consumers to clarify technical information and misunderstandings (Silberg *et al.*, 1997; Adelhard and Obst, 1999; Essex, 1999).
- Evidence of monitoring links to other sites (Silberg *et al.*, 1997). A site's own authoritativeness is limited by the credibility of the sites to which it is linked.

*Trustworthiness* refers to judgments regarding the character or integrity of a source in terms of motivation to be truthful (O'Keefe, 1990). Even authoritative sources may be biased (Ambre *et al.*, 1997; Wyatt, 1997). Evidence to assess trustworthiness includes:

- Disclosure of mission, purpose, and processes and standards for posting information (Wootton, 1997; Rippen, 1999).
- Disclosure of potential conflicts of interest by the site's sponsors. Conflicts of interest may be based on financial dependence, theoretical preference, or intellectual investment (Rippen, 1999), and may indicate bias (Kibbe *et al.*, 1997;

Silberg *et al.*, 1997; Wyatt, 1997; Adelhard and Obst, 1999). Information embedded in advertisements needs to be labeled as such (Ambre *et al.*, 1997).

- Disclosure of the collection process, use and final destination of information gathered (either explicitly or via tracking mechanisms) about users (Rippen, 1999).
- Warning signs. Often untrustworthy sites include 'sounds too good to be true' claims [(Federal Trade Commission, 1997), p. 1], products advertised as cure-alls, and phrases like 'scientific breakthrough', 'exclusive product', 'miraculous cure' or 'secret ingredient' [(Ambre *et al.*, 1997), pp. 2–7; (Federal Trade Commission, 1999), p. 1]. Plagiarizing or failing to identify sources may tarnish trustworthiness (Ambre *et al.*, 1997).
- Disclaimers. Disclaimers address a site's limitations, scope, purpose, reporting errors and information currency (Ambre *et al.*, 1997). A disclaimer may disclose a site's viewpoint (e.g. advancing surgical interventions). A common disclaimer warns users not to use a site to replace traditional health care, representing itself as an information rather than a medical-advice source, thus facilitating rather than replacing provider–client interaction (Silberg *et al.*, 1997; Rippen, 1999).

#### *Message characteristics*

Internet content or information may be judged as 'messages', subject to the same evaluation standards as traditional print sources (Garrison, 1998). Evidence of valid messages includes:

- Currency of information. Evidence includes: the date of the last site updating, policies and methods regarding updating, and site development date (Silberg *et al.*, 1997; Adelhard and Obst, 1999; Rippen, 1999).
- Accuracy of information. Judging accuracy independent of other criteria is difficult (Ambre *et al.*, 1997). Users should be wary of information conflicting with commonly agreed upon medical or scientific positions (Ambre *et al.*, 1997).

Substance and depth of content may enhance accuracy (Post, 1996).

- Organization. Information should be presented in a logically organized fashion (Adelhard and Obst, 1999).
- Readability and intelligibility (Appleby, 1999). Health information may be presented in varied formats, including text, graphics and animation; regardless of format, content needs to be understandable to users (Ambre *et al.*, 1997; Wyatt, 1997). However, text on many health websites exceeds the reading level of the typical consumer (O'Mahoney, 1999). Design features may enhance or detract from intelligibility. For example, large and bold print may enhance readability (Essex, 1999); graphics may clarify by illustrating or confuse if too complex.

#### *Audience characteristics*

A site's audience and context should be identified clearly and the site adapted accordingly. Audience refers to targeted users (e.g. consumers or health professionals), while context refers to a site's topic and intended uses (e.g. informational, advisory, commercial) (Adelhard and Obst, 1999). A site's appropriateness, relevance and usefulness should be readily discernable; content and design should match targeted audiences (e.g. reading and language levels) and contexts (Adelhard and Obst, 1999).

#### **Design features**

Format characteristics may enhance delivery of information, but do not affect the quality of message content (Ambre *et al.*, 1997). Design features vary widely, making sites more or less facilitative when seeking particular information or locating specific sites. Facilitative design features include:

- Accessibility. Websites should facilitate navigation through large quantities of information while maintaining simplicity of technology, operation, and format. Complex sites with high-end technology may enhance aesthetic value but reduce access (Lamp and Howard, 1999; Rippen, 1999). Access is enhanced by relatively simple browser technology, providing options when

multimedia browsers are unavailable, and offering options for the hearing- and sight-impaired (Ambre *et al.*, 1997; Rippen, 1999; W3C, 1999). Such options include text equivalents for visual and auditory images; avoiding reliance on color alone to clarify images or messages; and the capacity for activating site elements from a variety of devices (W3C, 1999).

- Ease of use. Logical organization, essential to locating information quickly, underlies a site's usability or ease of use (Post, 1996; Adelhard and Obst, 1999; McKinley *et al.*, 1999). Put simply, the number of steps needed to locate a site or specific information constitutes one operational definition of navigability (Wyatt, 1997). The basic premise behind ease of use is designing a website that builds on the *user's perspective*; formative research can facilitate the creation of a consumer-oriented organizational architecture [e.g. (W3C, 1999; Nielsen and Norman, 2000; Peterson, 2000; Farrell, 2001)]. Navigability is facilitated by organizing and grouping ideas and information by categories that make sense from the consumer's perspective; clarifying that organization by grouping links on a navigation bar or menu while avoiding irrelevant links; labeling links in comprehensible and accurate terms; using consistent page layouts with recognizable graphics; and providing a help or search tool.
- Links between sites. Links between sites help in locating specific information. Useful links match the original site's audience or context, reflect an architecture that permits free movement forward and backward, and contain content meeting the criteria described here (Rippen, 1999). Sites should seek to avoid 'dead-end' links (Post, 1996) and overloading users with links (McGrath, 1997; Wootton, 1997).
- Aesthetic and format characteristics. Websites combining text, audio and visual formats afford adaptability to consumer preferences and learning styles. Aesthetic qualities should contribute to comfort and use. Color coordination, lack of clutter, unobtrusive backgrounds and legibility of text contribute to quality (Post, 1996).

Technical materials may be simplified by translation into pictorial format (Essex, 1999). However, too many graphics may slow access (McGrath, 1997).

### **Mechanisms for evaluating websites**

Access to peer-reviewed resources, user surveys and codes of conduct may facilitate consumers' task of evaluating online health information.

#### *Peer review*

Unlike medical literature, much online health information lacks peer review (Ambre *et al.*, 1997; Rippen, 1999). However, informed consumers increasingly can access peer-reviewed health information (via sites that provide abstracts and full-text journal articles, often with extensive archives), e.g. consumers' access to Medline equals that of professionals. Beyond scientific research articles, consumers can access websites developed specifically to assure high quality evidenced-based information (e.g. Healthfinder, MedlinePlus) to search for information or verify that found elsewhere (Wootton, 1997).

#### *Rating systems*

Few websites feature user-rating systems (Ambre *et al.*, 1997). Some post unofficial reviews, ratings and standards for evaluating sites (Essex, 1999). For example, Quackwatch.com was designed to combat health-related fraud both on- and offline (Barrett, 2001). A review of 'best' attempts to develop systematic rating systems questioned both their validity and benefits, and concluded they may do more harm than good. (Jadad and Gagliari, 1998). As Berland *et al.* point out, when sites or systems rely on voluntary self-assessments, reliability and validity are unknown (Berland *et al.*, 2001). Numerous organizations offer criteria for assessing websites [e.g. (Eng and Gustafson, 1999)], but such assessments are for personal use rather than formal site evaluation.

#### *HON code of conduct*

At present, the most widespread attempt to apply a code of conduct to online health information was developed by HON. HON is a self-governing body

promoting eight ethical standards for online health information online: (1) advice provided by qualified professionals, unless otherwise indicated, (2) support versus replace existing provider-client relationships, (3) confidentiality of user data, (4) clear referencing with links to sources where possible, and dates of modification noted, (5) balanced evidence for claims, (6) information clear, with contact addresses to facilitate clarification, (7) sources of funding indicated clearly, and (8) any advertising (as funding) acknowledged and clearly differentiated from the site's content (Boyer *et al.*, 1998). Websites that comply with the HON code contain the HON logo (Health on the Net Foundation, 1997; Boyer, *et al.*, 1998). As of January 2000, HON registered connections to its code from more than 5000 external servers and more than 20 000 external web pages (Health on the Net Foundation, 2000). However, HON encourages use of their verification system to determine if sites are *bona fide* HON subscribers (versus simply displaying the logo) (Health on the Net Foundation, 2000).

In summary, increasing quality concerns mandate evaluation standards. Despite relative consensus on evaluation criteria, they have not been widely disseminated to the public nor are they a fail-safe method for assuring quality.

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### **Research and the Internet as a source of health information: the vast wasteland or the new frontier?**

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Extant Internet health-information literature is characterized by basic 'how to' presentations, speculative and anecdotal accounts, and reporting little empirical research. Articles educate readers about Internet use, speculate on the impact of online health information and report or project innovations. Little literature reports research regarding Internet use or its effects.

Just 5 years ago, journal articles commonly explained what the Internet *is* to health professionals [e.g. (Guay, 1994; Dow *et al.*, 1996; Huang and Alessi, 1996)]. Much early writing (1993–1996) simply defined key terms, explained use and

projected impact on a profession [e.g. (McKinney and Bunton, 1993; Frisse *et al.*, 1994; Tomaiuolo, 1995; Steiner *et al.*, 1996; Weiler, 1996)]. Even more recently, numerous articles explain the Internet and summarize basic use [e.g. (Gagel, 1998; Littleton, 1998; Lunik, 1998; Machles, 1998a,b)]. Many articles address best sites, in general [e.g. (Judkins, 1996)], or based on profession, specialization or disease or disorder [e.g. (Korn, 1998; Bell, 1999; Mann, 1999)], including articles for consumers [e.g. (Stemmer-Frumento, 1998; Tomlin, 1998)].

Second-generation health-related Internet uses go beyond disseminating information. Numerous authors project what the Internet will offer consumers in the future; often reality is not far behind. Only a few years ago, authors 'predicted innovations' now in practice, such as hospital telephone directories online, patients searching for information about upcoming surgical procedures, newly diagnosed patients using the web for patient education (Doyle *et al.*, 1996), E-mailing physicians (Bazzoli, 1999) and cyberspace visits replacing live visits (e.g. for prison populations, in rural areas) (Keen, 1997). The rate of Internet development quickly renders projections out of date, blurring a sense of present and future. Some 'projections' include: hospital online nurseries to allow friends and family to see newborns (Bazzoli, 1999), physicians using the Internet for patients to review diagnostic information on depression in order to convince the patient of the diagnosis and printing this information as a fact sheet (Stevens, 1998), providers creating customized pages to meet patients' specific needs (Flory, 1998; Stevens, 1998), and patients storing electrocardiogram records on secret web pages for emergency access (Doyle *et al.*, 1996).

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### **Directions for future research: challenges and opportunities**

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This review of literature regarding consumer online health-information seeking mirrors health information on the Internet; the literature often has little evidence base for its claims. Challenges to con-

sumers, public health professionals and researchers alike include the rapidity of change of content, structure and technology embedded in the Internet. Sometimes analysts are challenged to research and publish findings before they are obsolete! The challenge of future research is to devise methods and conceptual frameworks appropriate for investigating the richness of the Internet's dynamics relative to health issues.

Abelhard and Obst, in grappling with research challenges, indicate that new methods may be required with regard to sampling (as users may vary with amount of use, expertise, nature of use) (Abelhard and Obst, 1999). Researchers will be challenged to discriminate effects due to the Internet versus other highly accessible health-information sources (e.g. television, direct-to-consumer prescription drug advertising). Controlled studies may include longitudinal investigations (as use and influence may vary over time), retrospective cohort studies and case control studies, as alternatives to traditional studies using control groups (Abelhard and Obst, 1999).

In response to now-common criticisms and concerns regarding health-information seeking on the Internet, future research needs to assess the 'net gap' as well as the quality of information (message content). Research needs to address the demographic characteristics of participants, to more precisely identify the underserved, as well as the kinds of information consumers are seeking, what they locate, how they judge the quality of information found, what they learn (Wyatt, 1997) and how they are influenced behaviorally. Researchers need to compare the processes, outcomes and cost-effectiveness of traditional versus online health-information seeking (e.g. direct searching compared to interactions with support groups or professionals). Future research, practice and public policy need to focus on reducing the 'net gap' both in terms of accessibility and evaluation skills.

Despite abundant speculation regarding the consequences of consumer participation in interactive health communication, little research has investigated these issues; a lack of compelling evidence



exists regarding relative *effectiveness*; perhaps more importantly, little evidence exists regarding *effects*. Critics bemoan absence of research regarding the Internet's *effectiveness* [e.g. (Eng and Gustafson, 1999)]. However, assessing *effectiveness* presumes a consensus regarding websites' goals and objectives. Public health professionals' goals involve enhancing health knowledge, beliefs and behavior. However, taken collectively, health websites do not reflect a monolithic objective; some are created for profit, others for personal benefit and still others to 'validate' views that lack an evidence base. Thus, from the perspective of their creators, some websites may be deemed effective if they are commercially successful, personally confirming, or succeed in disseminating information and gathering support for risk-promoting or unhealthy functions. Moreover, given the potential for health websites to 'promote disease' as well as health and to disseminate fiction as well as fact (including those designed for health-promotion goals), researchers may do well to think in terms of assessing 'effects' rather than 'effectiveness.'

Ultimately interest and research on *effects* should focus on quality of health and health care. Despite observers' contentions, little research has assessed the impact of interactive health communication on the health care system (Wyatt, 1997; Abelhard and Obst, 1999), although health care (Sonnenberg, 1997), health care interaction, and health and medical outcomes (Adelhard and Obst, 1999) likely are affected.

This article begins by defining health information seeking on the Internet in terms of 'interactive health communication' and focuses on the information seeking function. That terminology, and this review, suggest a conceptual framework for future research and practice: *we may improve our understanding, investigation, and ability to influence processes of health information seeking on the Internet by framing them as communication processes rather than information dissemination or educational processes*. Much of the literature reviewed here focuses on the Internet as a high-tech conveyor in the rapid diffusion of information

or health lessons. However, to do so is to ignore the very nature of the Internet. Compared to traditional planned information dissemination phenomena, the Internet reflects a paradigm shift by offering interactivity and reciprocal influence, pointing toward transactional rather than one-way processes, and blending interpersonal and mass communication processes. Framing Internet use as health communication invites social systems and social influence theoretical frameworks. These frameworks suggest additional avenues for research.

The present review clarifies the interdependence of the Internet with other components of health communication systems, including health care, health promotion, risk-inducing communication, and the roles of everyday interpersonal communication and mass media in health. Understanding the opportunities and influences posed by the Internet as *one component of the larger health communication system* offers directions for research as well as practice. For example, research needs to address (1) the impact of interactive health communication on the physician-patient relationship, as well as how health care providers might influence consumers' use of the Internet, (2) the implications of the Internet for the larger health care system, including medical outcomes and health care costs, and (3) how the Internet influences and is influenced by a managed care environment.

To view Internet use as a communication process activating social influence suggests shifting focus from information to messages and meanings. Although the issue of quality of health information is significant, understanding the Internet's impact (both positively and negatively) defies simply considering information and its accuracy. How and why Internet use validates and promotes functional as well as dysfunctional outcomes (e.g. desire to be an amputee) may be understood in terms of types of messages shared and meanings invoked by those messages for participants. Interpersonal communication concepts, such as empathy, confirmation, validation, self-disclosure and immediacy, shift attention from the content of

messages (information) to their meta-communicative functions (Wilmot, 1980), including sustaining identities and relationships (i.e. matters of social influence). [For further discussion, see (Lewis, 1994; Cline, 2002).] Concepts traditionally employed for understanding planned change messages and campaigns may also illuminate the dynamics and effects of interactive health communication (e.g. audience analysis and segmentation, credibility, homophily, message design, language personalness and intensity, affect, metaphor, one-versus two-sided messages, central versus peripheral message cues and processing, message sequencing, evidence, exposure, tailoring, and an array of persuasion strategies). [See, e.g. (Maibach and Parrott, 1995; Rice and Atkin, 2001).]

The challenge to public health practice is to facilitate health-promoting use of the web among consumers in conjunction with their health care providers. Meeting that challenge requires developing discerning and critical usership among consumers, persuading health care professionals of the importance of collaborating in that facilitation and use, and providing both parties with the strategies, skills, programs, and systems to do so. Meeting that public health challenge requires an evidence base that matches the nature of the phenomenon. Thus, we join Deering in calling for research on the 'optimum' use of the web for communicating about health and medicine, particularly research with an emphasis on *communication* [(Deering, 1998), p. 136].

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