CHAPTER 2

Improving Health Literacy: Finding High-Quality, Web-Based Information

LEARNING OBJECTIVES

- Describe the attributes of websites providing "higher quality" information on health topics.
- Identify factors contributing to consumers' finding and using poor quality or inaccurate Web-based health information.
- Design practical strategies to improve the quality of health information that consumers find when searching the Web.

THE CONTROVERSY

Thirty-four Texas high school students participated in a well-designed experiment to see how well they could determine the accuracy of scientific information about vaccine safety and vaccine danger from Internet searches.[1] Results of their Google searches, their subsequent opinions about the accuracy of their search results, and answers to written questions asking about the strength of evidence were all evaluated by study investigators.[1]

Although more than half the sites that students found were inaccurate, nearly 60% of the students thought they were indeed accurate, and in their written assessments of the accuracy of the information, more than half the students had erroneous factual knowledge about vaccine safety and danger.[1] For example, based on their Web search, student participants thought the evidence to support the statement that "vaccines prevent epidemics" was "mixed," but after later viewing an evidence-based video on vaccines, rated the evidence as "strong to very strong," a statistically significant difference.[1] Similarly, after their Internet search, they noted the evidence was "mixed to strong" that "vaccines do not cause autism," but later rated

this significantly higher, as "strong to very strong" after viewing the evidence-based video.[1]

Although the number of high school students in this study was small, and it is not known whether similar results might happen in any high school in the United States, among these 17- and 18-year-old study participants, a Google search of a controversial scientific topic resulted in students gathering much erroneous knowledge, largely because their searches produced many credible-appearing but inaccurate sites.[1]

BACKGROUND AND SCOPE OF THE PUBLIC HEALTH AND HEALTH POLICY ISSUE

Have you ever tried to quickly find accurate and high-quality information about health on the Internet? If you Google a topic, you may find a list of sites that may or may not be what you are really looking for. Health information is everywhere, but much of the information may be misleading, inaccurate, and not of the highest quality, depending how and where you search.

Contributing Factors—Internet Use Climbs

Nearly three-quarters of U.S. adults use the Internet and more than 60% have conducted searches for health or medical information; nearly half of Internet users have searched for websites that provide information about a specific health condition.[2] The National Center for Health Statistics published estimates from the 2009 National Health Interview Survey, a national health survey of the U.S. population conducted with in-person interviews and using data collected from more than 7,000 adults from the first 6 months of the year. From this survey, they found that 51% of adults had searched for health information on the Internet in the past year, with women (58%) searching more frequently than men (43.4%)[2] (see **Figure 2–1**). In another report, it was estimated that 4.5% of Internet searches globally are for health information.[3]

More recently, in a 2012 nationwide telephone survey of more than 3,000 U.S. adults, the Pew Research Center's Internet and American Life Project found that 81% of U.S. adults used the Internet.[4] In their report, they also noted that of people who use the Internet, 72% reported searching for health information on the Internet in the previous year, a percentage that translates to 59% of all U.S. adults.[4] Additionally, nearly one-third of all cell phone users in the United States used their phone to search for health information,

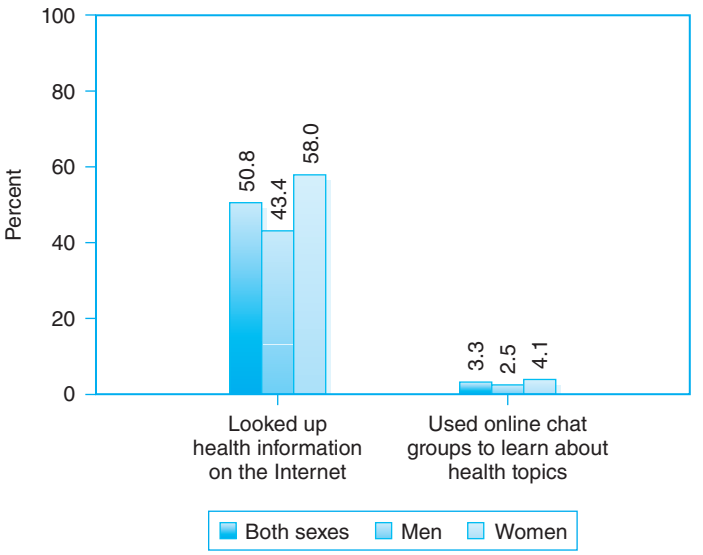

Figure 2–1 Percentages of adults aged 18–64 who in the past 12 months looked up health information on the Internet.

Reproduced from Cohen RA, Ph.D., and Stussman B, B.A., Division of Health Interview Statistics, Health Information Technology Use Among Men and Women Aged 18–64: Early Release of Estimates From the National Health Interview Survey, January-June 2009. National Center for Health Statistics. Available from http://www.cdc.gov/nchs/data/hestat/healthinfo2009/healthinfo2009.htm

with adults under 50, African Americans, Latinos, and those with college education most often conducting phone searches for health information.[4]

How Do People Search for Health Information?

A qualitative study conducted in Germany provides many clues about how consumers find and evaluate the quality of health information.[5] Investigators in this study held focus groups, conducted interviews, and directly observed participants as they searched for health information in response to specific questions. Questions to the study participants included such topics as, for example, the need for malaria prophylaxis for travel to specific geographic locations, or the definition of being overweight.[5] Twenty-one participants in focus groups noted that characteristics of high-quality sites included the organization's expertise, a professional appearance, and referencing scientific materials, as well as being able to easily understand the site's material.[5]

However, when the researchers directly observed how 17 of the study participants actually performed the search, they found some different results. Participants did not begin their searches in government or academic sites, but instead used search engines such as Google and Yahoo, and most used a single search term, even for complicated questions.[5] In addition, when searching, study participants usually chose links appearing on the first search page. By measuring "clicks" the investigators determined that 71.3% used one of the first five links, and 97.2% used a link from the first 10 on the page.[5]

In this study, people were usually able to find the information they were looking for quickly: the average time to find answers to the questions was less than 6 minutes, and ranged from 38 seconds to 20 minutes.[5] However, during their searches, study participants did not use available information to verify the credentials of the authors of the Web-based information they used, and nearly 80% of the time they couldn't remember whether the information was from a government, academic, or commercial source when they had completed their search.[5]

In the Pew Internet and American Life Project report, *Health Online 2013,* the vast majority (77%) of Internet users looking for online health information reported using a search engine, for example, Google, Bing, or Yahoo. More specific health or medical information sites (e.g., WebMD) were only used by an additional small percentage (13%).[4]

What Determines Which Internet Sites Appear First?

Several factors may determine what appears on the first search page, such as consumer-driven searching strategies,[6] website "optimization" at the level of the webmaster,[7] or commercial ads and "pay for placement" strategies.[3] Searching strategies taught in most colleges and universities and also available in public libraries can help people use accurate search terms and improve searching strategies. One example of this, using the word "AND" to narrow a search, is called using Boolean logic and connectors (also called Boolean "operators"), such as AND, OR, or NOT.[8] There are existing guides for businesses and people who develop websites to help them influence how often their site is prominently located during Web searches. Google publishes a *Search Engine Optimization Starter Guide* to instruct users in how to improve website structure, content, and pages, which may "optimize" what is found when people search for topics.[7] Advice is plentiful for business owners about strategies to best use ads on

their websites, sometimes making it more challenging for consumers.[9] Studies suggest that many searchers use just the first page, or frequently, they just use the first few links to find and act on health information.[5] The important perspective for people searching online for health information is to realize that a number of influences determine what links might appear first after searching, at the top of the list and on the first page, and these sites may or may not be the most high-quality or evidence-based websites, unless specific searching strategies are used.

What Health Information Are People Searching For?

People most often search for information on specific health or medical conditions. In the 2012 Pew Internet and American Life Project report, 35% of all U.S. adults have searched online for specific health information related to a specific medical condition.[4] Stated differently, the survey noted that of all the Internet users in the United States who have searched for health information, more than 72% have searched for information related to a specific medical condition.[4] Previous studies found that people may search for information for either themselves, a family member, or a friend.[3,10] Women, adults under 50, and people with some college education and higher incomes were more likely to conduct online searches for specific medical information. Men, older adults, and people with lower incomes also queried health topics online, but not as often.[4]

Another multivariate analysis of the Pew surveys found that women; people employed less than full time; frequent Internet users; or individuals with ongoing medical problems, new medical diagnoses, or those receiving a new medical treatment were all associated with frequent online searching for health information.[11] Frequent health topics of interest (in addition to information about specific diseases or medical conditions) included specific medical treatments, losing or controlling weight, health insurance information, food or drug safety, or information about an advertised pharmaceutical[4] (see **Figure 2–2**). When comparing white, African American, or Latino Internet users, the frequency of searching online for different topics differed only in searches about weight control (higher in African American and Latino individuals), pregnancy and childbirth (highest in Latino individuals), advertised pharmaceuticals (highest in African Americans), and whether the search was done for a specific condition (highest in white Internet users).[4]

Limited published information is available about differences in online health searching by country. For example, about one-quarter of individuals

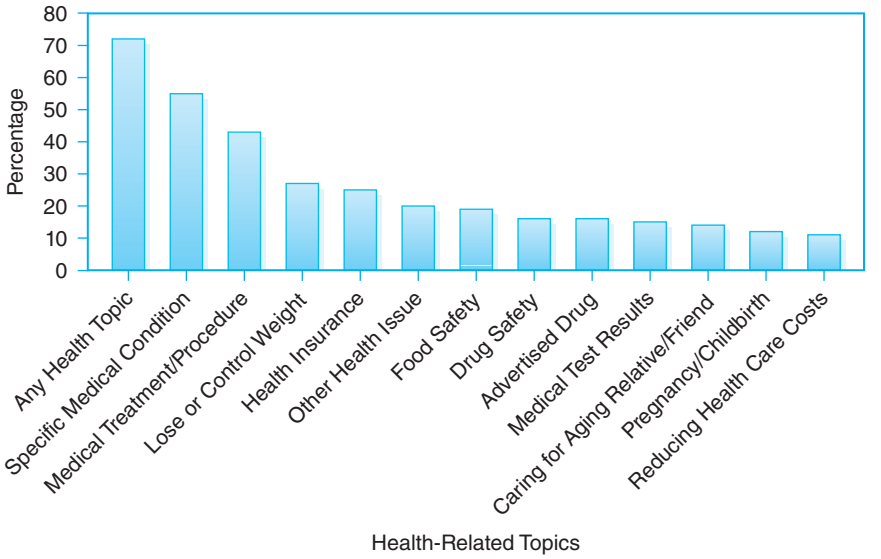

Figure 2–2 Adult Internet users–topics for recent health-related searches 2012.

Data from Fox S, Duggan M. Health Online 2013. *Pew Internet & American Life Project.* Page 10. January 15, 2013. http://www.pewinternet.org/Reports/2013/Health-online.aspx

from the United States and Germany and 19% of individuals from France searched for specific health information frequently, and the percentage was much lower (6%) in people living in Japan. Furthermore, in Japan, more than one-third of those looking for any health information on the Internet do not look for specific medical information.[3,12]

The Pew Internet and American Life Project also looked at social aspects of Internet users who were searching for health information, using the term "e-patient" to describe this group.[13] In this report, more than half of searches (52%) were for someone else. There were many instances where online health searchers were looking for additional healthcare information about a health or medical condition. For example, about one-quarter searched for rankings or reviews of health professionals or hospitals, and 41% read blogs or commentaries about the illness.[13] Use of social networking sites, like Facebook or Twitter, is less common, with only 12% of e-patients using Twitter for information about specific medical conditions, although people aged 18 to 49 are the highest users.[13] About 60% of e-patients report that their health information search affected their own health decisions, or decisions related to someone else, most often for less serious situations.[13] In addition, from 2002 to 2009, several topics have increased in popularity

for online searches, such as information about exercise, weight loss, specific medical conditions and treatments (including medications), mental health conditions, alternative medicine, health professionals and hospitals, and health insurance.[13]

Do People Trust the Health Information They Find on the Internet?

Web surfers looking for health information don't *always* trust what they find. A 2002 Pew study showed reasons why people may reject certain websites, with nearly half of people looking for health information reluctant to use the information because the site was "too commercial."[10] However, in the same report, nearly three-quarters (72%) of people searching for online health information felt they could "believe all or most of the health information online."[10]

Another important perspective is how people actually use the health information they find, especially if the health condition is more complex or serious. In the *Health Online 2013* survey, when people were asked who they consulted for help when they had a "serious health issue," 70% relied on a physician or other health professional and 60% relied on family and friends.[4] In addition, following their Internet searching, more than half the people subsequently talked with a medical professional about the information.[4] But in another study of more than 6,000 U.S. adults from the Health Information National Trends Survey, investigators compared respondents' preferred and actual behavior when looking for health information.[14] What they found was that although nearly two-thirds of respondents trusted physicians, and nearly half wanted to ask his or her physician first for specific health information, in terms of their actual behavior, only 10.9% went to their physician first and nearly 50% went online first.[14]

EVIDENCE BASE FOR PREVENTION AND PRACTICE

Do We Need Quality Measures for Websites?

For well over a decade, health professionals from large national organizations, such as the American Medical Association (AMA) have warned patients about the potential for inaccurate or misleading health information from Internet searches. The AMA has advocated for quality standards that include authors and credentials, references, disclosure of website

ownership, and publication dates to ensure information is current.[15] Other authors agree that health professionals should advocate for quality standards for health information, recommend specific websites to patients, and teach consumers how to search and critically appraise the credibility and quality of what they find.[3]

Berland and colleagues studied the quality of health information in specific health topics, in both English and Spanish.[16] Using ten search engines in English and four in Spanish, they systematically evaluated the quality and reading level of health information in response to hypothetical patient questions about breast cancer, depression, obesity, and childhood asthma. When combining all health information topics, the authors found that for English-language searching, 34% of the links on the first page were relevant, but ultimately only 20% of the links identified on the first page resulted in content directly relevant to the initial search question.[16] In Spanish-language search engines, the percentages were even lower: only 18% of the links found on the first page were relevant, and only 12% of the links identified on the first page ultimately produced relevant content.[16] They also found substantial variation in the extent and accuracy of coverage of these four clinical topics, worse for the Spanish-language sites. They further observed that the general literacy level required to navigate health information on these topics was high, requiring the equivalent of some college-level education to navigate the English-language sites, and high-school level education to understand the Spanish-language sites.[16]

In a review of 1,512 abstracts and 186 published papers, Crocco and colleagues specifically looked for evidence of harm from using online health information.[17] They reported cases in which consumer Internet searches resulted in emotional distress from the inability to find relevant health information or that medical decision making was based on entering different keywords; they found one instance in which dogs were poisoned because of inaccurate information found online and one patient who had an adverse reaction to alternative cancer treatment found on the Internet. Whether the reporting of harm from searching for and using Internet health information was rare or if the risk of harm was actually low could not be determined from this study.[17]

Efforts to Promote Quality of Online Health Information

Numerous organizations have attempted to educate health information consumers about ways to find high-quality and accurate information.

"Codes of conduct" contain criteria to help consumers determine the quality of websites.[18] One example of an organization promoting quality of health information is the Health on the Net Foundation (HON), created in 1995 as a nonprofit and nongovernmental organization.[19] The organization publishes (on the Internet) a voluntary certification system, search function for certified websites, a list of tools and special topics available to individuals, health professionals, and Web publishers. HON principles include: authority, complementarity, confidentiality, attribution, justifiability, transparency, financial disclosure, and advertising.[19] Entering the search term "cancer" in the search box results in a first page with lists of large educational organizations, nonprofit organizations, or healthcare institutions.[19]

Another example of efforts to promote quality includes the AMA[20] principles for websites that was designed for their own materials, but may be useful to other organizations. These include principles for content, advertising and sponsorship, privacy and confidentiality, and principles for e-commerce.[20] There are other examples of organizations such as Health Internet for member states of the European Union[18] and the e-Health Code of Ethics of the iHealth Coalition, from an "e-Health Ethics Summit" hosted by the World Health Organization/Pan American Health Organization in 2000.[21] Quality labels, filtering tools, systems to help Internet users, and third-party labels have also been described.[22]

In a large systematic review of all the methods different investigators have used to assess quality of online health information (both published and unpublished reports in any language), 79 studies were included that reviewed nearly 6,000 health websites and more than 1,000 Web pages.[23] These investigators noted a wide variety of criteria used to measure quality, but often included such attributes as accuracy, readability, disclosures, and presence of references. In 70% of the studies included in this review, authors were concerned about the quality of information, but there was much variation in the approaches taken by the different studies included, making comparisons challenging.[23] Gagliardi and Jadad found that of 98 published methods to evaluate the quality of health-related websites, many were no longer being used only 5 years later.[24] In addition, there were over 50 new methods reported in their study, but most of these could not be verified as effective.[24] Other authors are skeptical of efforts to measure the quality of Internet health information.[25] All of these articles emphasize the challenges of finding effective, sustainable, and practical strategies to educate the public about how to find high-quality health information on the Internet.

Strategies to Find Higher-Quality Health Information Online

Despite the proliferation of codes of conduct and other strategies, the literature suggests most consumers searching for health information use available and popular search engines, like Google.[3,5] At the same time, they do often consult with their physician or other healthcare professional to confirm the accuracy of the information they have found and especially seek medical consultation for serious health conditions.[4] Despite the challenges of defining and measuring the quality of health information, there are some especially helpful resources for Internet users, in addition to the HON and AMA principles already discussed.

The Medical Library Association (MLA) has published (online) a user's guide called "Find and Evaluate Health Information on the Web."[26] In their approach, they both help people using search engines, by suggesting ways to improve search quality, and also direct people to respected health information sites such as MedlinePlus,[27] or Healthfinder,[28] or their "Top 10" list.[26] In addition, the MLA has guidelines to evaluate the quality of the website and information found, including identifying sponsorship of the site, how frequently it is updated, clarity and referencing of the information, and the target audience.[26] The "MedlinePlus Guide to Healthy Web Surfing" emphasizes teaching consumers the principles and strategies for finding high-quality online health information.[29] This site emphasizes the need to find the primary source of the information, and encourage searchers to be a "cyber skeptic." In addition to recommending that consumers look at health information with a critical eye, they advise consumers to consult with their own healthcare professional. In addition, there is a user-friendly tutorial available on their site[29] (see **Figure 2–3**).

What Are the Public Health Benefits of Finding High-Quality Health Information Online?

For 2 months in 2003, during the SARS global outbreak, SARS was the most searched-for topic at Yahoo.[3] More recently, in addition to searching for information about specific health or medical conditions, many adults have also looked for health information about public health topics: 27% of adults who had searched for health information online during the past year looked for information about losing or controlling weight, and 19%

Who or what is the source of the information?

Is the information current?

Are there links and references to the actual research (primary sources)?

Is the information clear and easy to read?

Who are the intended audiences for the information?

What is the source of funding for the site?

Is there bias in how information is presented?

Have you considered discussing the information with your health professional?

Figure 2–3 Searching for health information online–questions to ask.

Data from Medical Library Association. Find and Evaluate Heatlh Information on the Web. 2014 http://www.mlanet.org/resources/userguide.html NS MedlinePlus Guide to Healthy Web Surfing. 2013; http://www.nlm.nih.gov/medlineplus/healthywebsurfing.html

looked for information about food safety, both important and relevant public health topics.[4] These examples highlight the potential benefits of having the general public skilled in health-related Internet searching for the prevention of chronic conditions, or in times of epidemics, natural disasters, or public health emergencies, to help with preparedness. In addition, benefits of becoming more health literate might have implications for health care, facilitating patients' active participation in maintaining their own health. With our changing population demographics, increasingly complex health conditions and treatments, and the availability of new public health information on a daily basis, the challenges of reaching people of different ages, genders, cultures, and education and literacy levels are daunting, but potential benefits are huge.

DISCUSSION QUESTIONS: TEMPLATE FOR DISCUSSION

1. Significance of this public health issue:
   a. Why is this health issue important?
   b. How many people does it impact?
   c. How serious is it?
   d. Is it preventable?

2. What is the evidence base for prevention?
3. What specific strategies should be used to achieve progress on this health issue?
   a. What evidence-based approach would you use?
   b. Where would you start if you are an individual citizen; public health professional; healthcare professional; community, state, or federal policymaker?
4. Specific questions for this topic:
   a. What are the characteristics of "higher quality" websites containing health information?
   b. What are the characteristics of websites containing health information that are *not* as "high quality"?
   c. Can you find specific examples of websites containing health information that are "higher quality" and not as "high quality"?
   d. Can you compare and contrast the sites that you found?
5. What is the controversy?
   a. Define the controversy.
   b. Is controversy a good or bad thing? (Does it help or hinder progress?)
6. *Why* is this health issue controversial?
   a. What specific factors are involved?
   b. Do economics, government, scientific uncertainty, or politics play a role?
   c. What is the role of the media?
7. How would you respond to the controversy?

PERSPECTIVES TO CONSIDER

The ability to quickly find "higher-quality" Web-based information about health is a great skill, but the increased use of the Internet can also potentially result in finding and using misleading or inaccurate information. Conversely, finding high-quality information on reputable sites may improve health literacy, enhance shared decision making between patients and health professionals, and contribute to improvements in public health. The challenge is: how can we best teach the public to find high-quality, Web-based resources about health in a way that improves both individual and population health? Do we give patients a list of example websites or teach them how to be critical of what they find? Probably both are needed. Teaching adolescents how to search for and critically appraise

health-related information could, if systematically taught in educational settings, increase the health literacy of young adults. Giving patients lists of credible and reputable sites and encouraging conversations might contribute to improved healthcare communication and decision making. Additional educational efforts by public health professionals could reinforce the importance of Internet health literacy in areas of clinical medicine and public health issues.

What was notable from currently published studies was how few studies, with the exception of the extensive Pew Internet and American Life Project,[4] have been conducted recently. The most frequent online searchers tend to be more highly educated, and some studies raise questions about literacy levels required to best use available higher-quality health information.[16] Gaps are prevalent in our detailed knowledge of how Internet searching influences health decisions in different geographic locations, different racial and ethnic populations, and especially in those with less income and education. But from the available literature, despite a lack of extensive documentation of harm, it seems obvious that there is the potential for risk. People acting on health-related information from websites that are not evidence-based or from reputable sources, and who don't discuss the findings with healthcare professionals, may not be using the best possible information for these important decisions.

Based on growing Internet use, how people actually search for health information, and Web optimization strategies that place certain sites strategically on the first page, it is possible that many people find and use health-related information from sites of lower quality. Conversely, what was intriguing, were potential possibilities to improve the health of individuals and entire populations, if patient searches could more frequently be connected to credible health information, including public health sources and integrated into actual conversations in healthcare settings. Both public health and healthcare professionals have critical roles in educating individual patients and the general public about how to find high-quality health information online.

For Additional Study

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