Optimizing Online Medical Information

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Abstract

Background: Historically, medical information was available almost exclusively to clinicians. Now, patients and the general public have access to the same information via the Internet through PubMed and medical websites that routinely pull information from peer-reviewed publications. By producing high-quality publications, authors and editorial teams play a role in providing the public with accurate, timely medical data.

Objective: To assess the use and impact of public access of online medical information and the quality of information available at medical information websites.

Methods: Searches were conducted to assess public utilization of online medical information and its impact on clinician-patient interactions.

Results: Estimates of use of medical information websites vary (29%–37% in the US; 49% in Paris, France). Use by patients seeking information about specific disorders or general symptoms is estimated at 16%–99% in the US, 27%–74% in the EU. In the US, ≥20% of patients report that they discuss information obtained online with their physicians. Most patients trust online information, but professional evaluations of online information in the US and EU give quality ratings averaging only 58%–59% of optimal scores.

Conclusions: Online medical information has significant limitations. For their role, authors, working with scientific leaders and editorial teams, may have an indirect positive influence on the quality of information reaching the general public.

Background

- An estimated 5% of all Internet searches globally are performed with the purpose of accessing medical information,[1] and the number of patients obtaining healthcare information online is expected to continue to increase.
- Much of the medical information available online is ultimately derived from the peer-reviewed literature; however, although patients may obtain information directly from abstracts or full-text articles from reputable online sources such as PubMed, patients accessing information from many medical websites are forced to rely on the website content writer's interpretations of the literature.
- The lack of regulation of medical information on the Internet exposes patients to potentially false, incomplete, or misinterpreted information; biased or unsupported claims for medical products; or conflicting claims from legitimate sources, all of which may be difficult for unsophisticated readers to comprehend. Misinformation and poor understanding can have serious implications for patient health.[1]
- Authors, working with editorial teams, may be able to help improve the public's understanding of medical information by ensuring that information presented in the peer-reviewed literature is accurate and clear.

Objective

- To assess the use and impact of public access to online medical information and to evaluate the quality of information available on medical websites.

Methods

- A literature search was conducted using PubMed for recent articles (2008 and later) evaluating public use of online medical information and the quality of information available at medical websites.
- Supplementary searches were performed as needed to follow up on information obtained in the primary search.

Results

Search Results

- A total of 30 articles were identified that dealt with topics related to patient utilization of online medical information or the quality of the medical websites **(Table 1)**.
  - 19 articles described the use of online medical information among patients with a variety of demographic backgrounds and medical conditions.
  - 6 articles assessed the quality of online sources used by patients with different demographic and clinical characteristics.
  - 5 articles were reviews that discussed the merits and limitations of publicly available online sources of medical information.

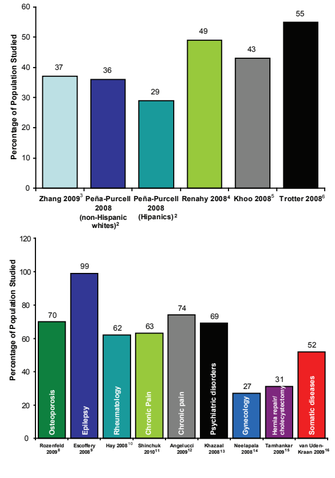
Table 1. Summary of Search Results

Paper Title	Count
Patient use of online medical sources	19
In demographic subpopulations	8
• Use of the Internet for health information among primary care patients in rural west Texas[3]	
• Hispanics' use of Internet health information: an exploratory study[2]	
• Antecedent characteristics of online cancer information seeking among rural breast cancer patients: an application of the Cognitive-Social Health Information Processing (C-SHIP) model[24]	
• Use of and satisfaction with sources of health information among older Internet users and nonusers[25]	
• Do gynaecology outpatients use the Internet to seek health information? A questionnaire survey[14]	
• Health information seeking on the Internet: a double divide? Results from a representative survey in the Paris metropolitan area, France, 2005-2006	
• [The Internet as an information source for family caregivers of dementia patients] (German)[17]	
• Health information seeking by parents in the Internet age[5]	
In clinical subpopulations	11
• Assessing interest in an osteoporosis website: a survey among women eligible for osteoporosis screening[9]	
• Use of computers and the Internet for health information by patients with epilepsy[8]	
• Demographics and attitudes of chronic-pain patients who seek online pain-related medical information: implications for healthcare providers[11]	
• Prepared patients: Internet information seeking by new rheumatology patients[10]	
• Use of the Internet by patients undergoing elective hernia repair or cholecystectomy[15]	
• Health-related Internet use by patients with somatic diseases: frequency of use and characteristics of users[16]	
• Internet use among inflammatory bowel disease patients: an Italian multicenter survey[12]	
• Internet use by patients with psychiatric disorders in search for general and medical information[13]	
• [FAQs on the effects of e-health on the doctor-patient relationship] (Spanish)[26]	
• Patients' use of the Internet for health related matters: a study of Internet usage in 2000 and 2006[6]	
• Use of the Internet by burns patients, their families and friends[27]	
Website quality	6
In demographic subpopulations	1
• The digital divide: a comparison of online consumer health information for African-American and general audiences[22]	
In clinical subpopulations	5
• Quality of chronic pain websites[19]	
• A health literacy assessment of the epilepsy.com website[21]	
• Evaluation of the quality and accuracy of information regarding aromatase inhibitors available on the Internet[18]	
• Role of information available over the Internet: what are the parents of children undergoing tonsillectomy likely to find?[20]	
• An investigation of the quality of breast cancer information provided on the Internet by voluntary organisations in Great Britain[23]	
Review articles	5
• The authority and utility of Internet information[1]	
• The role of quality tools in assessing reliability of the Internet for health information[28]	
• Internet health resources and the cancer patient[7]	
• Internet access produces misinformed patients: managing the confusion[29]	
• The Internet: friend or foe when providing patient education?[30]	

Patient Use of Online Medical Sources

- Estimates of medical website use varied greatly and may have been influenced by demographic or clinical characteristics.
  - Reports of the percentage of the general population that uses online healthcare information ranged from 29%–37% among Americans,[2,3] whereas a reported 49% of Parisian adults[4] and 43%–55% of Australian adults[5,6] access medical websites **(Figure 1A)**.
  - Among patients with specific conditions, a review reported that 16%–64% of cancer patients accessed online health information.[7] Among patients with nonmalignant conditions, our survey revealed Internet usage rates of 62%–99% in the United States[8–11] and 27%–74% in Europe[12–16] **(Figure 1B)**.
  - In general, younger age,[8,12,16,17] higher education level,[11,12,16,17] and higher income[12,16] were associated with greater Internet use; other factors that may be associated with greater Internet use include female sex[10] and greater disease severity.[12]
- Patients who obtain medical information online may or may not discuss it with their doctor, and reports are conflicting as to how discussing this information with a doctor affects office visits.
  - Among patients with chronic pain[11] or rheumatologic conditions[10] who used medical websites, 50% and 20%, respectively, shared the information with their physicians.
  - In the study of rheumatology patients,[10] patients who discussed online medical information with their doctor were more satisfied with their visit; in contrast, a study of medical website use within a Hispanic population reported that patients felt that discussing health-related information obtained online resulted in a worsened physician-patient relationship.[2]

Figure 1. Estimates of Patient Use of Online Medical Information. (A) General Population; (B) Patients Seeking Condition-Specific Information



Quality of Online Medical Sources

- In general, a large proportion of patients who use medical websites believe the information is reliable.[2,3,9,11]
  - In a survey of patients with epilepsy,[9] 77% of the online participants and 54% of the clinic-based participants reported that they would use online sources to help manage their disease.
  - In a survey of patients with chronic pain,[11] 55% reported that they considered pain-related information found online to be useful.
- However, professional evaluations of the quality of online medical information using various rating tools found that medical websites only achieved 58%–59% of optimal scores **(Table 2; Figure 2)**. (These percentages were obtained by conversion of the average scores indicated on the 2 scales cited below; however, these ordinal scales are not calibrated, and the percentages of optimal scores are offered only to provide a general perspective, not a precise assessment.)
  - A study that rated the overall quality of 180 websites on aromatase inhibitors on a 12-point scale (0 = lowest quality, 11 = highest quality) reported an average rating of 6.13; furthermore, only 28% achieved a score ≥9.[18]
  - Another study found the average Quality Website Index score (33-point scale; –16 = lowest quality, 16 = highest quality) of 240 websites used by patients with chronic pain was 2.17.[19]

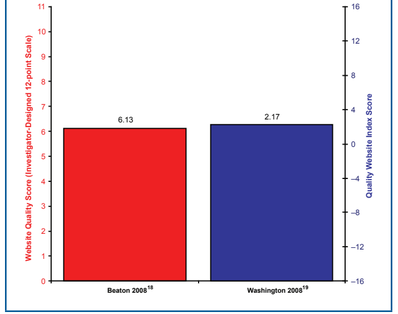
Table 2. Summary of Findings on Website Quality

Reference	Study Description	Endpoints	Key Findings
Beaton C, et al[18]	• Evaluation of the quality and accuracy of information on aromatase inhibitors contained in websites found using the Internet search engines Google, Yahoo, and MSN	• Overall score on a 12-point scale (0=worst; 11=best) that evaluated website quality based on inclusion of the following information: drug name, MOA, drug indications, cancer stage, correct timing, drug benefits, adverse events/risks, source citations, date of information, and clarity of writing	• Of 180 websites evaluated, the mean score was 6.13. • Only 28% of websites identified received a score of ≥9.
Elliott JO and Shneker BF[21]	• Assessment of the reading level of web pages available through the epilepsy.com website	• Flesch Reading Ease assessment	• Only 3% of epilepsy.com websites were written at the 6th-grade reading level or below, and 15% were written at the 8th-grade level or below.
Kind T, et al[22]	• Evaluation of the quality and usability of health websites targeted at the general public and at the African-American population	• Websites were evaluated by 2 independent reviewers for the following criteria: presence of disease-specific information, authority, date of information, justifiability/balance, statement of evidence level	• The overall quality of African-American–targeted websites was lower than that of general health sites. • Disease-specific information was available on 64.7% and 86.2% of general and African-American websites, respectively; of these: ○ Author qualifications were stated in 73% and 96% of African-American and general health sites, respectively. ○ The date of the most recent update was included in 64% and 100% of African-American and general health sites, respectively. ○ Almost all of the African-American (91%) and general (96%) health sites contained justifiable and balanced information; however, only 60% of African-American sites and 80% of general sites reported the evidence level of the information.
Ream E, et al[23]	• Evaluation of breast cancer information provided by 10 websites sponsored by voluntary organizations in Great Britain	• Completeness and transparency of information and website usability were assessed using an investigator-designed tool based on European Commission–quality criteria for health-related websites	• Information found on websites sponsored by breast cancer–specific organizations was generally of high quality with regard to completeness. Transparency, particularly author disclosure and currency of information, was found to be lacking.
Roshan A, et al[20]	• Evaluation of the quality of information available on tonsillectomy contained in websites found using the Internet search engines Google, Yahoo, MSN, AOL, and AskJeeves	• Accessibility, usability, and reliability using the LIDA instrument • Readability was assessed using the Flesch Reading Ease assessment	• Average scores for accessibility, usability, and reliability were 67%, 54%, and 33%, respectively. The average Flesch score was 43.8.
Washington TA, et al[19]	• Evaluation of the quality of websites commonly accessed by patients with chronic pain	• QWI score, which is based on 16 items in 5 domains: etiology, diagnosis, treatment goals, treatment options, and substance abuse • Each item is given a score of –1 (misinformation), 0 (no information) or 1 (correct information), and all items were combined to give the total QWI score (–16=worst; 16=best)	• The mean (SD) QWI score for the 240 sites evaluated was 2.17 (2.2), indicating that the quality of information offered is questionable. • A score ≥10 was achieved by 3.8% of websites, indicating that some high-quality websites are available.

MOA=mechanism of action; QWI=Quality Website Index.

- Some of the specific reasons cited for poor quality ratings among professionals included poor accessibility/usability,[20] lack of reliability,[19] the reading level of the website exceeded the presumed reading level of the user,[20,21] and a lack of transparency (including disclosures related to author credentials, currency of information, and evidence level of the information).[20,23]

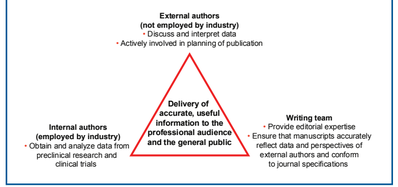
Figure 2. Assessments of the Quality of Website Information



Discussion

- Increasingly, the general population and patients with specific illnesses use the Internet to obtain medical information.
- While much of this information is rooted in the peer-reviewed literature, patients are dependent on the website content writer's interpretation of the medical literature, which may be erroneous or misleading; this fact underscores the importance of presenting accurate and clear information in the literature.
- Improving the quality of online medical information ultimately depends on optimizing the quality of publications in the professional literature, which may be facilitated by positive working relationships between authors and a writing team **(Figure 3)**. This model offers the following advantages:
  - High-quality writing
  - Increased likelihood of manuscript acceptance with fewer requested revisions
  - Optimization of external authors' time, thereby increasing the time they spend conducting research and treating patients
- It is to be hoped that individual researchers who submit papers to the peer-reviewed literature will be cognizant of the growing extent of Internet access of medical information by patients and the general public.

Figure 3. Model for the Development of Timely, Accurate Peer-Reviewed Publications



Conclusions

- A large and growing number of people globally use the Internet to find medical information.
- However, professional evaluations of medical websites have found much of the information provided to be of questionable quality.
- By producing timely, accurate, and clearly written manuscripts, authors, working with editorial teams, may help to improve the quality of medical information reaching the general public.
- Website content writers can also play an important role in enhancing the public's understanding of the peer-reviewed literature through careful interpretation and presentation of existing literature.

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