HEALTH INFORMATION ON THE INTERNET: PATIENT EMPOWERMENT OR PATIENT DECEIT?
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ABSTRACT

Internet is the biggest medical library in the world. It has transformed the way many health seekers find health information. Seekers on net have exponentially increased from 54 million in 1998 to 110 million in 2002 (U.S. figures) and are ever increasing. Act of looking for health or medical information is the third most popular activities online. Search engines are used by almost 81% of the e-patients to look for the information they want. Internet is fast becoming an influential force as more than 70% consumers say that the information on the net has influenced their treatment decisions. However, the reliability of all the health information available on the Internet is questionable. Numerous studies have indicated deficiencies in the quality of information on the Internet. Due to technical and commercial reasons, the results provided by various search engines can be potentially biased. Only about a quarter of health seekers thoroughly check the source, timeliness of information every time they search for health information. In fact, most adults from USA, Japan, France and Germany who participated in a recent survey thought online health care information to be trustworthy, of good quality, easy to understand and easy to find. Efforts are now being taken to ensure the quality of health information on the Internet. Patients need to be educated about the worthiness of a site and also be prescribed the right sites to be consulted for information.

KEY WORDS: Internet, health seeker on net, search engine, health information on internet

INTERNET: THE BIGGEST LIBRARY FOR A LAYPEOPLE

Internet is the biggest medical library in the world. It has transformed the way many health seekers find health information. Seekers on net have exponentially increased from 54 million in 1998 to 110 million in 2002 (in the US alone) and are ever increasing. 80% of adult Internet users, or about 93 million Americans, have searched for at least one of 16 major health topics online. This makes the act of looking for health or medical information one of the most popular activities online, after email (93%) and researching a product or service before buying it (83%). Studies in UK have shown that in November 1999, about 27% of adults were using the Internet on a regular basis and a further survey found that 84% of all users felt the Internet was indispensable. Apart from the community-based studies, even clinic-based studies have shown that one in four patients are accessing health information from the Internet and that half the patients who have computer access already search for medical information.

WHAT DO PATIENTS DO ON THE NET

The surfers are quite focused in their health related searches with a majority (63%) looking for specific disease/condition and almost 47% looking for specific treatment or procedure.

INFORMATION ON THE NET: A RADICAL CHANGE –

Before the advent of the net, information was mainly controlled by the large publishing houses. The Internet has changed the scenario in two ways; at one end it has made publishing of information very easy. The traditional method of publishing involves a lot of reviews and revisions. The traditional process is rigorous, and usually ensures that only high-quality articles are published. It is rare to see obvious errors surviving the extensive reviews that take place before an article appears in print. However on the Internet any individual can publish the information himself at a minimal cost, without any restrictions and reach a global population easily. At the other end, access to this information is also very easy. This unrestricted publishing has led to the debate as to whether this free information can actually be harmful. A number of sites carry a variety of logos suggesting that an award has been donated to denote above-average quality. In fact many of the awards seem to be an effort by the award sites to increase their link popularity.

SEARCH ENGINES- INFORMATION LOCATORS ON THE INTERNET

More than half of the 100 million health seekers on the net use search engine for getting the information. Last time they searched for health advice, 81% of e-patients started at a search engine or used the search function of a general portal such as the Yahoo home page, MSN, or AOL. Search engines are tools designed to help surfer find information on the net. They have two major methods to index and locate relevant content on various sites. This is a combination of computer generated (site crawlers) index and a directory component (generally a manual indexing). The algorithms that decide the ranking of a site for particular information...
HOW RELIABLE IS THE INFORMATION?

The main drawback of the Internet lies in the fact that the Web is unregulated and the quality of the medical information is variable.10 Recently, using the term ‘RA’, Suarez-Almazor et al.11 analyzed 537 hits. Only 51% were considered to be relevant, 51% were the site of a profit industry and 44% promoted alternative therapies. They concluded that many easily accessible sites are run by profit-based companies advertising an alternative medicine product with claims of benefit in Rheumatoid Arthritis. Another group examined the availability of rheumatology resources on the Internet and found that 67% originated from medical organizations and over half contained an advertisement.12 Studies of single medical conditions have also indicated deficiencies in the quality of web based health information.13 Other groups have confirmed that the information is often difficult to find, of poor quality and littered with irrelevant sites, often promotional in nature.11,14

Only about a quarter of health seekers thoroughly check the source, timeliness of information and verify a site's information every time they search for health information. Half of all health seekers search for medical advice and "only sometimes," "hardly ever," or "never" check the source or date of the information they read online.15 Studies have pointed out the difficulty faced by Internet surfers in distinguishing credible health information from that which is not trustworthy.5

Most adults in four countries who participated in a recent Harris Interactive survey16 find online health care information to be trustworthy, of good quality, easy to understand and easy to find. In some cases, these majorities are very large.

EFFORTS AT QUALITY CONTROL ON THE INTERNET

Novel means have been suggested to ensure that the user is guaranteed a certain quality of content when seeking information on the internet.17 Numerous Organizations like HonCode, American Medical Association, Internet Health Care Coalition, Hi-Ethics, MedCertain have come up with ethical guidelines for the information on the net. URAC (www.urac.org.), an independent, nonprofit organization has developed a Health Web Site Accreditation program and subjects sites to 53 rigorous standards of consumer protection. Recently due to these irregularities in the medical information on the Internet Federal Trade Commission launched an initiative, Operation Cure All, to crack down on those making fraudulent health claims. Four companies already have been charged with making unsubstantiated claims about products that they said would "cure" or "effectively treat" illnesses like cancer, AIDS and liver disease. One company claimed a fatty acid would cure most forms of arthritis by "permanently modifying the immune system." Another claimed its shark cartilage capsules and cat's claw capsules were effective in treating cancer, HIV/AIDS and arthritis.

AMOUNT OF INFORMATION

The other problem faced by the medical surfer is the volume of information which is ever increasing. Edworthy18 repeated the search carried out by Suarez-Almazor et al.11 and found that there had been a 10-fold increase in the number of hits in the 2-yr period after the original search. The direct result of this overwhelming information is the amount of time spent in finding the exact information.

DOES INFORMATION ON THE NET INFLUENCE THE VISITORS?

Information given in the form of leaflets and computerized instruction has already been shown to increase knowledge.19,20 A randomized trial of information leaflets for patients with arthritis has also showed significant improvements in knowledge, pain and depression21 thus indicating health benefits of the information. Internet has been a major influential force with more than 70% consumers saying that the information on the net has influenced their treatment decisions.22 Three-quarters (73%) of health seekers say the Internet has improved the health information and services they received.6 Patients have reported that they found it relatively easy to obtain the medical information using the net and more than half discovered information not previously known.12 Other groups have confirmed that 67% originated from medical organizations and over half contained an advertisement.12 Studies of single medical conditions have also indicated deficiencies in the quality of web based health information.13 Other groups have confirmed that the information is often difficult to find, of poor quality and littered with irrelevant sites, often promotional in nature.11,14

Medical search engines: Special search engines have been designed for specific medical searches. These include medhunt (http://www.hon.ch/MedHunt/), Medical World Search (http://www.mwsearch.com/), CiteLine.com (http://www.citeline.com/G1SE/search). However no data is available as to their popularity and usage.

Thus, the net has enormous amount of
information, a large portion of which is unregulated and potentially misleading. The search engines play an important role presenting the information to the surfers and this introduces a commercial aspect in the information that is being presented (sponsored results). Given the fact that the majority of the surfers consider information on the net to be reliable, of good quality and also the fact that it potentially affects their health decisions; hence the need to look for solutions to the problem.

ANY SOLUTION? –

- Prescription of reliable sites — Apart from prescribing drugs, medical professional probably should also start prescribing the right sites to be seen for further information about the patient’s condition. This would not only provide authentic material to the patient but also save the time of the patient in these searches. However, this approach is hampered by the net unfriendliness of the medical community and the time constraints involved in keeping updated with the best patient education site.

- Providing reliable information ourselves - Another solution could be having our own website or subscribing to services that provide patient teaching handouts.

- Patient education - Education of the patients and the community as a whole about the various Internet health accreditation facilities should also be aimed at.

- Quality tips on the net - http://www.ihealthcoalition.org/content/tips.html—provides tips to surfers to assess quality of content of these medical sites.

- Online quality assessment tools - The net also provides various online instruments to assess the health information. One such; DISCERN (www.discern.org.uk/) is funded by UK National Health Service Executive Research and Development Programme. It provides a questionnaire that can help consumers to judge the quality of written information on treatment choices. However it is a bit complicated with the consumers having to rate the site as per the questions. HSWG - IQ Tool (http://hitweb.mitretek.org/iq/default.asp) is a more Consumer friendly tool with questions requiring only a yes or no answers to judge the credibility of the site. Users can deploy the tool when visiting a Web site they wish to evaluate and have to go through the process of completing the questionnaire in order to arrive at a quality score.

Thus, we health care professional should now assume the role of a complete consultant helping our patients sort the information available on the internet and arrive at informed and intelligent decisions.

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