Creating informed consumers and achieving shared decision making

Empowering consumers with health information on the internet

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BACKGROUND The internet has become a powerful tool to disseminate health information and there are millions of people accessing this free information for a second medical opinion. Consumers seeking information from this resource are more responsible for their own health. However, the quality of health information on the internet varies and there is no simple instrument that can effectively evaluate its quality.

OBJECTIVE This paper reviews recent studies on the validity of instruments or guidelines developed for evaluating health information. It describes government initiatives around the world in establishing quality health information and proposes an alternative way of empowering consumers with reliable health information. It emphasises the importance of the role of primary family physicians in this consumer education process.

DISCUSSION The debate over the quality of health information on the internet and the attempt to use instruments to evaluate the quality of web information are discussed. The relationship between family physicians and consumer informatics in this information age is also addressed.

Currently, increasing numbers of consumers are obtaining health care information from the internet and are using this information to assume more responsibility for their health care. This dynamic growth is a result of health consumer demand and the expansion of quality health care websites. The internet has become the most effective way for consumers to access a range of free health information and online support.[1] For health providers, the internet is a very effective tool for disseminating health information, health education and providers' services. It is estimated there are more than 1 million websites dedicated to every conceivable health subject and in excess of 50 million people seeking health information on the internet.[2] This number will continue to grow.

Why do consumers seek heath information on the internet?

Consumers can:
- obtain a wide range of opinions regarding a particular disease, for themselves and relatives
- search directly for health information, health organisations or providers
- identify specialists and seek information about provider services
- participate in support groups, and
- consult with health professionals.[2]

The majority of consumers seeking health information for themselves wish to obtain disease information for discussion with their physicians.[3] A recent study evaluated the usefulness of different health information sources, health providers' opinions, medical journals, newspapers, friends, radio, the internet, etc.[4] The study found that consumers who sought health information on the internet rated it as the second most useful source after medical or nursing professionals.[4]

Online support, such as face to-face discussion, offers an alternative to profes-

sional care, providing social support, shared experience and behavioural models.[5] Online support groups can be more helpful than physicians in many respects such as convenience, emotional support, cost effectiveness and in-depth information, selectivity, anonymity and 24 hour availability.[2] In the case of some consumers who feel anxious about asking about sensitive health issues, this medium can provide effective solutions to approaching a medical practitioner with frequently asked questions.[6]

Benefits of using internet health information

The internet can serve as a supplementary approach to existing health care services and systems. Studies have shown that consumers empowered with health information obtained from the internet can make better informed decisions and therefore have a sense of control over their health, develop stronger provider-client relationships, and are more compliant and satisfied with advice and treatment.[7–9] The internet also provides an opportunity for patient associations and professional bodies to collaborate in creating useful databases. As consumers increasingly use the internet in order to manage their health actively and independently, they are more likely to take this active role into encounters with providers. All this can result in improved disease prevention, improved treatment outcomes and more efficient services.[8,10] To achieve such benefits, it is important that the information that consumers acquire in this way is accurate.

The risks

There have been concerns over the health information published in this free, rapidly changing and uncontrolled medium. Accuracy, reliability, completeness and currency of the information have been the central points of the concerns.[11–13] As there is no peer review process or regulation on publication of information on the internet, information could be potentially hazardous. Anyone can claim medical expertise. As such, criticisms are that such free information is bad, even dangerous, inaccurate, erroneous, misleading and fraudulent.[14,15] A recent systematic review of the studies examining health information on the internet found 70% of the studies concluded that quality was a problem in accuracy, completeness, readability, design, disclosures and references provided.[16]

A recent study attempted to analyse cases of harms associated with use of health information from the internet by reviewing all articles in Medline, Cinahl Health Star, PsycInfo, and Embase.[17] Of 1512 abstracts, 186 full articles were reviewed and there was only one case of actual medical harm (hepatorenal failure) that occurred in an oncology patient who had obtained wrong information from the internet. The study concluded that the internet's capacity for harm was likely to be equal to, or exceeded by, its capacity for providing good and useful health information to users in a relatively inexpensive and timely manner. This was made advisedly, the authors acknowledging there could be many reasons why published incidence of harm associated with the improper use of health information is so low in academic journals. For instance, many cases were probably never reported, as cases may be regarded as not newsworthy enough to be published.

Establishing quality online health information for consumers

'Gold standards'

To assist internet users in avoiding inaccurate information, a number of academics and organisations have attempted to set up 'gold standards': instruments and guidelines for evaluating the quality of health information on the internet. These instruments and guidelines typically include a list of indicators intended to assist internet users in determining the authoritiveness and trustworthiness of websites. However, these guidelines can only assist internet users in avoiding inaccurate information if the indicators really do correlate with accuracy (or inaccuracy).

Are they really 'gold'?

There has been intense debate in the past few years on the usefulness of 'gold standards'. A literature search found the most frequently cited criteria were those dealing with the content, design, and aesthetics of the site; disclosure of authors, sponsors or developer; currency of information; authority of source and ease of use.[16] However, there have been difficulties in developing simple criteria.[18] One study indicated that some proposed indicators from published guidelines for evaluating the quality of health information on the internet were not correlated with accuracy (or inaccuracy).[19] The study found that neither an author having medical credentials, nor the citing of peer reviewed medical literature were necessarily indicators of accuracy. Up-to-dateness of information may only be an indicator for information that is rapidly changing, eg. AIDS research. This study also found the presence of advertising on a website had no correlation with inaccuracy. In fact, it is common practice for companies that produce a new therapy to sponsor advertising on the new treatment. It is also normal practice that many randomised clinical trials are sponsored by pharmaceutical companies and the results from these trials are well accepted as evidence.

One research group performed a series of studies monitoring internet rating instruments for health information and found that of 98 instruments used to assess the quality of web information, many were no longer available and there were also many incompletely developed rating instruments continuing to appear.[1,20] The study questioned whether these instruments should exist in the first place and whether they lead to good or harm.[20]

Such studies alert researchers to

rethink the necessity of developing gold standards.[21] Defining quality standards for such a disparate collection of resources is also challenging. As information on the internet is very different from that found in medical journals and can be created and presented in different formats and updated rapidly, it is unlikely that it can be evaluated simply by any instruments. Interestingly, the World Health Organisation's attempt to establish a domain name, '.health', for all health sites to guide internet users to reliable sites was rejected by the US based Internet Corporation for Assigned Names and Numbers (ICANN) based on the doubt of the usefulness of a single body having a policing role.[22]

Current initiatives

Since the quality of online health information from different sources varies, and it is difficult to assess the quality of web information using current instruments, there should be an alternative way to ensure that consumers are guided to only credible and accurate health information. Realising the importance of this, health authorities in a number of countries have launched initiatives to check and collate accurate information and stream it into a single source.

Government and health organisation initiatives

As early as 1997, the US Department of Health and Human Services, together with other federal agencies, launched the project 'Healthfinder' aimed at providing online quality health information. Since then, Healthfinder has been recognised as a key resource for finding the best government and nonprofit health and human services information that links to a wide range of carefully selected information.

Other US government health organisations have developed a number of websites with different focusses, such as cancer care and women's health. Also, the National Library of Medicine has established a consumer version of Medline, Medlineplus.

Health authorities in the UK have launched similar projects, eg. Electronic Quality Information for Patients (EQUIP) and OMNI. The latter is a gateway to quality health and biomedical information. The Cochrane Collaboration's Consumer Network has established a separate website with review synopses written for an audience of consumers. In Germany, the Agency for Quality in Medicine has developed a Clearinghouse for Patient Information project, which is an extension of an existing project of Clearinghouse for Clinical Guidelines.

In 2001, the Australian Commonwealth Department of Health and Aging, launched HealthInsite, to provide consumers with access to up-to-date health information resources on different diseases. All information available through HealthInsite has been assessed by the editorial board using HealthInsite quality standards. Consumers can locate their search in an A–Z disease map or by entering key words. These sites are listed in Table 1 and contain comprehensive lists of diseases and links. A search of one or two websites should provide sufficient information for most consumers.

Guidelines and codes of ethics

There are also other organisations such as the Health on the Net Foundation (www.HON.ch), the Internet Healthcare Coalition (www.ihealthcoalition.org) and Health Internet Ethics (www.hiethics.org) that are dedicated to health information online and evaluating online sources of health information from product sites developed by manufacturers to peer reviewed electronic publications. They also publish health codes of ethics, develop well informed health care information for consumers, health professionals, educators, marketers and media, and offer patient support and discussion groups. Although these are American sites, many of the guidelines and codes of ethics are relevant to Australian health care.

Educating and empowering consumers

The aims of government initiatives in developing these health information resources are to provide consumers with well researched studies and evidence based choices. These initiatives encourage consumers to seek quality health information on the internet and thereby adhere to proper guidelines on treatment, thus ensuring good adherence. Unfortunately, this rich resource of health information appears to be under utilised by consumers.[23] The success of government initiatives in empowering consumers with good health information is very much dependent on health providers' involvement. Health providers, especially general practitioners, should play a role in educating consumers to take full of advantage of this valuable health information resource and assist in their information needs.[24]

Many consumers would like their physicians to guide their online searches for medical information. A poll by Cyberdialogue found that 70% of all patients would like their physicians to recommend a health care website for their condition, but only 4% of patients receive such a recommendation.[25] Most physicians do not feel comfortable enough with the internet to provide this service, as they are unsure about the quality of the website, quality of the content, and especially the ethics of the site. Patients usually do not have enough knowledge to distinguish between unbiased information and the information designed to push a product or service. As such, there is a clear need for health providers to be aware of trusted and quality health information sites in order to educate patients to fully utilise the rich resources of health information on the internet (Table 1).

Consumers wishing to extend their searches beyond the information resources set up by government health organisations should always proceed with caution. Table 2 lists tips to help

Table 1. Government initiatives in developing credible health information* (English language only) on the internet for health care professionals and consumers

Health information product	Website	Organisation
HealthInsite	www.healthinsite.gov.au	Department of Health and Aging, Australia
Healthfinder	www.healthfinder.com	Department of Health and Human Services, US
Health Information	www.health.nih.gov	National Institute for Health, US
Mental Health Infosource	www.mhsource.com	Continuing Medical Education Inc (CME Inc), US
MedlinePlus Health Information	www.nlm.nih.gov/medlineplus/	National Library of Medicine, US
HealthWeb	healthweb.orv/	National Network of Libraries of Medicine and Committee for Institute Cooperation, US
The National Women's Information Centre	www.4woman.gov	Department of Health and Human Services, US
Cancernet	www.cancer.gov/cancer_information/	National Cancer Institute, US
Electronic Quality Information for Patients (EQUIP)	www.equip.nhs.uk	Health Authorities and Primary Care Trusts, UK
Cochrane Consumer Network	www.cochraneconsumer.com	Cochrane Collaboration International
The Help for Health Trust	www.hfht.org	Centre for Health Information Quality (CHIQ), UK
OMNI (Organising Medical Networked Information)	omni.nc.uk	CHIO, UK
Clearinghouse for Patient Information project	www.patienten-information.de10.06.02	Agency for Quality in Medicine, Germany

* The PDF version of this information can be downloaded from: http://www2.fhs.usyd.edu.au/him//pdf_docs/government_initiatives.pdf

Table 2. Guidelines for finding quality health information on the internet*

- Choosing an online health information resource is like choosing your doctor. A good rule of thumb is to find a website that has a person, institution or organisation in which you already have confidence. If possible, you should seek information from several sources and not rely on a single source of information.
- Authors' credentials should always be identified, along with their affiliations and financial interests, if any, in the content. Phone numbers, email addresses or other contact information should also be provided.
- Don't be fooled by a comprehensive list of links. Any website can link to another and this in no way implies endorsement from either site. Also check if the linked sites are current.
- Find out if the site is professionally managed and reviewed by an editorial board of experts to ensure that the material is both credible and reliable.
- Sources used to create the content should be clearly referenced and acknowledged.
- Medical knowledge is continually evolving. Make sure that all information is up-to-date and there is a date of last update or proposed update.
- Any and all sponsorship, advertising, underwriting, commercial funding arrangements, or potential conflicts should be clearly stated and separated from the editorial content. A good question to ask is: Is there anything for the author(s) to gain from proposing one particular point of view over another?
- Avoid any online physician who proposes to diagnose or treat you without a proper physical examination and consultation regarding your medical history.
- Read the website's privacy statement and make certain that any personal health or other information you supply will be kept absolutely confidential.
- Most importantly, use your common sense! Be suspicious of miracle cures.

* Modified from The Internet Healthcare Coalition's website: http://www.ihealthcoalition.org/content/tips.html.
** The PDF version of this information can be downloaded from: http://www2.fhs.usyd.edu.au/him//pdf_docs/Guidelines_forquality.pdf

determine the quality of internet information. These tips are not intended to be used as indicators for quality of health information, but they can be quite useful as guides. Such guidance may be handed to consumers during consultations if physicians think the extra information could help consumers in their decision making and improve outcomes of medical services.

Patient education from sources other than face-to-face contact with a physician should be seen as supplementary to the medical advice of physicians, rather than as competition. Information is a form of therapy, and should lead to improved referrals, improved treatment adherence, and more realistic outcome expectations. If consumers are guided to information based on quality evidence, their decision making should be enhanced, bringing them into the decision making loop. This allows consumers to be more involved with their own care. As the medical profession changes from a 'gatekeeper' model to a patient choice model, consumer education will take on a much greater role.[25] Once informed, consumers will be able to bring new strategies into their acquisition of health information and participate in their care. Medical and health care communities should establish approaches that empower consumers to use the internet as part of a total health care strategy rather than simply warn them about internet hazards.[26]

Conclusion

It is quite clear there is not much point in debating how good health information is on the internet. Evidence has clearly shown the benefits that health information on the internet can offer to consumers. As there are many credible and well examined health information sites now freely available, developed by government and nongovernment health organisations, the question remains as to what role health providers should play in empowering consumers with decision

making tools to access these rich resources effectively and correctly. Health providers should recognise that many consumers are using the internet as a source of health information and inevitably most consumers will become users of online health information in this internet age. Instead of fearing that consumers could access wrong information without proper guidance, it would be wise to educate them about quality information sites and the correct way to locate sound health information.[27] It is as important to provide consumers with correct information resources as it is to provide advice during face-to-face consultations. It is one step further in the health providers' role of serving consumers and helping their self education.

SUMMARY OF IMPORTANT POINTS

- The quality of health information on the internet varies as widely as it does in other media and instruments developed to evaluate it have not been proven to be useful.

- Consumers empowered with health information obtained from the internet take a more active role in their health, have more informed decision making and improved adherence.

- Health organisations around the world, including the Department of Health and Aging, have launched initiatives to establish reliable and quality resources of online health information for consumers.

- General practitioners should realise that most consumers will inevitably become users of online information in this internet age. They have an important role to play in empowering consumers by guiding them to reliable health information resources. In this way, shared decision making and better outcomes of health services can be achieved.

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