

Shortcomings of health information on the Internet

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SUMMARY

Disseminating health and medical information on the Internet can improve knowledge transfer from health professionals to the population, and help individuals to maintain and improve their health. There are currently several medical information websites that directly target the general population with the aim of providing information about health problems, self-care and prevention. However, this new technology also hides several shortcomings, such

as: (i) uneven quality of medical information available on the Internet; (ii) difficulties in finding, understanding and using this information; (iii) lack of access for the unconnected population; and (iv) the potential for harm and risks of over-consumption. To be able to overcome these dangers, it is important that public health practitioners and health professionals be involved in the design, dissemination and evaluation of Web-based health and medical information.

Key words: health information; internet

PROMISES OF HEALTH INFORMATION ON THE INTERNET

Information technologies herald a major change in the dissemination of health and medical information, with the promise of transferring knowledge from health professionals to the general public. This transfer will help individuals to maintain and improve their health, and will reduce the gap between health professionals and the population in terms of power and communication.

Recent studies show that in Canada and the United States, more than half of the population has access to the Internet, and the majority of Internet users seek health information (Dickinson and Ellison, 2000; Pew Internet and American Life Project, 2001). The three main ways of accessing online health information are: (i) searching for health information; (ii) participating in support groups; and (iii) interacting with health professionals (Cline and Haynes, 2001).

Health information is more and more available on Internet, with the continuous growing of

medical information websites. While many of them are intended for health professionals, more and more websites directly address the population with a view to providing information about health problems, self-care and prevention. Moreover, online health support groups, which provide social support and information, offer participants 24-h availability, anonymity and exposure to an increased number of opinions and expertise (Cline and Haynes, 2001).

One also finds interactive applications on the Internet, such as programs for physical activities or smoking cessation (American Heart Association, 2002). With these programs, it is possible to support participants by e-mail, track their progress with online personal activity calendars, and create virtual support groups where participants can interact. There are also experimental interactive modules for managing chronic diseases; patients, along with professionals, will be able to track and treat their disease, and prevent complications. There will

also be the Internet-based medical record, accessible to the patients via their computers. With this record, health professionals will be able to transmit targeted information to their patients and vice versa. For example, it will be possible to integrate a list of healthy recipes into the record of diabetics to help them change their diet. Also, individuals will be able to record their glucose level, such that it will be available at all times for the physician (Jadad, 1999).

This new era of health information technology thus has the potential for providing users with health information specific to their needs and characteristics (Robinson *et al.*, 1998). These new technologies also have shortcomings, however, which receive less attention and could hinder the above-mentioned potential.

QUALITY OF HEALTH INFORMATION ON THE INTERNET

The rapid development of medical information on the Internet raises the issue of its quality (Impicciatore *et al.*, 1997) and of potential dangers related to its erroneous or unsuitable use (Allain *et al.*, 1998). At present, it is impossible to assess the magnitude of this problem because studies on the subject are not consistent with one another. While some authors consider that the quality of medical information on the Internet is poor (Doupi and Van der Lei, 1999; Lathe *et al.*, 2000), others feel that it is of equal value to information provided by other media (Sandvik, 1999; Hellowell *et al.*, 2000). These contradictory results are not surprising when we consider the large number and variety of sources for medical information on the Internet. Because of this problem, criteria for evaluating Internet health information quality have been developed by several organizations (Eysenbach *et al.*, 2000; Winker *et al.*, 2000). These criteria take into account not only website content (quality, reliability, accuracy, scope, etc.), but also form (design, aesthetics, interactivity, use of media, etc.), accessibility (fee for access, navigability, functionality, etc.), credibility of sources, and confidentiality policy (Kim *et al.*, 1999; Winker *et al.*, 2000). Until now, however, the impact of these criteria on the design and the use of health information websites has been relatively weak because they are subject to the good will of website designers, and also because users are unaware of them.

DISPARITY OF ACCESS

Although the Internet has the potential for greater equity in health knowledge, disparity of access to the Internet is a real threat to this equity (Eng *et al.*, 1998; Mandl *et al.*, 1998). While the proportion of the population using the Internet is growing strongly, and although more than half of all Canadians have access to this medium, access is not the same for all (Dickinson and Ellison, 2000). In Canada, as in the US, Internet use is strongly connected to socio-economic status (Pew Internet and American Life Project, 2001). While 65.1% of households in the upper-income quartile regularly use computer communications, this proportion decreases to 13.2% for the lower-income quartile, i.e. is nearly five times less. One finds the same phenomenon in the US, where even though the majority of the population use the Internet, some subgroups such as black populations with low incomes have almost no access to this new medium (Brodie *et al.*, 2000).

Age is also an important factor for accessibility, with what is labeled a 'gray gap' (Pew Internet and American Life Project, 2000b). In Canada, ~46% of people ≤ 55 years old are regular Internet users, but this percentage falls to 27.5% among 55- to 64-year olds, and to only 7.2% among people aged 65 years or over (Dickinson and Ellison, 1999). Thus, it is the poorest and the elderly, i.e. those who have the greatest number of health problems and the greatest need for information, who are the least connected. The risk here is that even more medical and health knowledge is concentrated in the hands of the richest, thereby increasing social disparities in health (Eng *et al.*, 1998).

However, one could argue that with time, Internet access will spread to the whole of society, as was the case with television. Moreover, there are several private or government initiatives intended to help households to buy computers and to supply Internet access (schools, libraries and subsidies to connect families in Quebec). However, universal access to the Internet will not eliminate disparities in the use of available health and medical information (Morris *et al.*, 1997; Robinson *et al.*, 1999). Access is a necessary condition, but it is not sufficient. By way of comparison, we know that universal health insurance in Canada has not eliminated disparities in access to health care services (Kawachi and Kennedy, 1999; Santé Canada, 1999; Wagstaff and

van Doorslaer, 2000). In fact, the most important barriers to the use of health and medical information on the Internet are the difficulties in finding it and, for a large part of the population, in understanding and using it properly.

DIFFICULTIES IN FINDING, UNDERSTANDING AND USING HEALTH INFORMATION ON THE INTERNET

There are many sources of health and medical information on the Internet, and they are growing very quickly. In 2000, there were >70 000 health-related sites (Grandinetti, 2000). However, there are very few tools to help people find relevant information in this mountain. For example, the scientific quality of information is difficult to evaluate by the public (Shepperd *et al.*, 1999; Pandolfini *et al.*, 2000), for whom the most important thing is to be able to find the information they need, to understand it and to apply it (Pautler *et al.*, 2001). The few studies on the subject show that this is not always the case. For example, Berland's study shows that when using the most popular search engines (AltaVista, Google, Lycos, etc.) to find information on breast cancer, obesity, depression or asthma, only one link out of five leads to a website with relevant information (Berland *et al.*, 2001). Furthermore, while available information is often valid, in many cases it is incomplete. Berland's study (Berland *et al.*, 2001) demonstrates that important information for each of the selected health problems is missing on most of the studied websites. This lack can negatively influence user decisions. For example, lack of information about alternative treatments prevents users from making an enlightened choice. Moreover, locating accurate health information may also be difficult because of lack of user-friendliness and lack of permanence (sites disappear and change without warning) (Cline and Haynes, 2001).

Once the information is found, and assuming that it is valid and complete, users must understand it and put it into practice (D'Alessandro *et al.*, 2001). At present, most medical information websites present technical information to a population unfamiliar with medical literature. In addition, the difficulty with technical terms and the required reading skill level is also a problem. Berland's study (Berland

et al., 2001) shows that English medical websites generally require high school level or greater reading ability. But nearly half of all Canadians have difficulty with written information in their daily activities (Direction générale de la promotion et des programmes de la santé, 1998), and in the US, people with the greatest health care needs have low information access due to lower health literacy level (American Medical Association, 1999). These people, who are also those with little or no access to the Internet (the poor, the elderly, etc.), are excluded from these sources of medical information. But even with Internet users, it is likely that some of them have difficulties reading and understanding medical information displayed on this medium. Unfortunately, there is no information on the magnitude of this problem.

POTENTIAL FOR HARM AND RISKS OF OVER-CONSUMPTION

There is a potential for harm from Internet-based information because of the presence of inaccurate and misleading information. Besides the fact that information can be incomplete or based on insufficient scientific evidence, one can also find false or misleading information, particularly in regard to online support groups, where sensational anecdotes and unbalanced views are common (Pereira and Bruera, 1998). For consumers who interpret information incorrectly or try inappropriate treatments, this could lead to a health hazard.

Another problem with the Internet is that it is now possible for pharmaceutical companies to promote their products directly and at very low cost to consumers. Products can be promoted directly on company websites, in partnership with medical information websites, or by means of advertisement banners on other websites. These new ways of disseminating medical information carry important risks of conflict of interest and over-consumption of medication (Meyers, 2001). Indeed, it is difficult for Internet users to distinguish between material promoting drugs and non-promotional information about health problems and their treatment. Furthermore, although the knowledge of various therapeutic alternatives allows patients to be better informed and to make enlightened choices, it can also lead them to press health professionals to prescribe useless medication.

Finally, it is now possible to make more-or-less legal online purchases of drugs (e.g. Viagra), something that can pose a threat to people's health due to over-consumption, dangerous products, medicinal interaction, etc. (deKieffer, 2000). In light of the above, the danger from a public health perspective is that the Internet could lead to an increase in the use of health services and drugs without engendering a positive impact on care quality, disease prevention or health promotion.

CONCLUSION

For educated people who know how to find useful information on the Internet regarding self-care and disease prevention, and who also know how to deal with the health care system, the Internet holds great promise. Studies show that most Internet users are satisfied with the information they found and half of those seeking health information reported that their findings influenced treatment decisions (Pew Internet and American Life Project, 2000a). But for the rest of the population, including the less educated, the elderly and those with many health problems, Internet promises will come true only if health information is designed according to their needs and capacities.

First, it will be necessary to facilitate Internet use by supporting access in homes and public places (public libraries, schools, etc.). It will also be necessary to develop new support services, such as the Internet on the television (WebTV) or Web-specific terminals that are simpler to use. It would be also interesting to combine the Internet with other media, such as *NHSDirect* from the National Health Service in Great Britain, which provides health information available both on the Internet and by telephone (National Health Service, 2002).

Secondly, much work needs to be done in the area of organizing health and medical information so that it is easier to find, relevant, and ready to be used, even for people with a low level of health literacy. New information technologies can provide more visual and interactive learning opportunities than pamphlets and older forms of health instructions (Kickbusch, 2001). To do so, medical information websites must be developed in partnership with lay people, especially those in need of health information. It is important to learn how people

use the Internet, what information they need, and how this information must be organized and presented so that they can use it adequately to maintain and improve their health.

Thirdly, public health practitioners and health professionals must be integrated into the process of diffusing medical information on the Internet. Not only can they guarantee the quality of information, but they can also create a link between this information and their patients. They could, for example, suggest medical information to their patients by directing them to relevant websites (in particular via the computerized medical file, accessible to patients by the Internet and containing links to targeted medical information). While these new technologies will no doubt decrease the health professionals' power because they will share their knowledge, better informed patients could also improve their relationship with doctors and their compliance with prescribed treatments.

For public health, the challenge will be to facilitate health-promoting use of the Web among consumers in conjunction with their health care providers (Cline and Haynes, 2001). It will be particularly important to find incentives to include under-served individuals in the use of the Internet for medical information, because this population is the one that needs the most health information and that is the least attracted by these new technologies.

Finally, the major challenge in the coming years will be to measure the impact of the Internet, as a source for medical information, on health beliefs and behaviors, health care services, and population health to determine the extent to which the promise held by this new medium is fulfilled.

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REFERENCES

- Allain, P. Y., Schuck, S., Beaufile, C., Zekri, O., Ganilsy, M. and Allain, H. (1998) Drugs on the Internet. Hazards of public health. *La Presse Medicale*, **27**, 117–121.
- American Medical Association (1999) Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs. Health literacy: Report of the Council on Scientific Affairs. *Journal of the American Medical Association*, **281**, 552–557.
- American Heart Association (2002) *MyHeartWatch*. [Http://www.myheartwatch.org](http://www.myheartwatch.org) (last accessed 13 February 2002).
- Berland, G. K., Elliott, M. N., Morales, L. S., Algazy, J. I., Kravitz, R. L., Broder, M. S. *et al.* (2001) Health information on the Internet. Accessibility, quality, and readability in English and Spanish. *Journal of the American Medical Association*, **285**, 2612–2621.
- Brodie, M., Flournoy, R. E., Altman, D. E., Blendon, R. J., Benson, J. M. and Rosenbaum, M. D. (2000) Health information, the Internet, and the digital divide. *Health Affairs*, **19**, 255–265.
- Cline, R. J. and Haynes, K. M. (2001) Consumer health information seeking on the Internet: the state of the art. *Health Education Research*, **16**, 671–692.
- D'Alessandro, D. M., Kingsley, P. and Johnson-West, J. (2001) The readability of pediatric patient education materials on the World Wide Web. *Archives of Pediatrics and Adolescent Medicine*, **155**, 807–812.
- deKieffer, D. E. (2000) Direct sale of sildenafil (Viagra) to consumers over the Internet. *New England Journal of Medicine*, **342**, 742.
- Dickinson, P. and Ellison, J. (1999) *Être Branché ou ne pas l'être: Croissance de l'Utilisation des Services de Communication par Ordinateur*. Indicateurs des services, Statistique Canada, Ottawa.
- Dickinson, P. and Ellison, J. (2000) *Les Canadiens se Branchent: l'Utilisation d'Internet par les Ménages reste à la Hausse en 1999*. Serie sur la connectivité, Statistique Canada, Ottawa.
- Direction Générale de la Promotion et des Programmes de la Santé (ed.) (1998) *Effets du Niveau d'Alphabétisme sur la Santé des Canadiens et des Canadiennes*. Publication Santé Canada, Ottawa.
- Doupi, P. and Van der Lei, J. (1999) R-x medication information for the public and the WWW: quality issues. *Medical Informatics and the Internet in Medicine*, **24**, 171–179.
- Eng, T. R., Maxfield, A., Patrick, K., Deering, M. J., Ratzan, S. C. and Gustafson, D. H. (1998) Access to health information and support: a public highway or a private road? *Journal of the American Medical Association*, **280**, 1371–1375.
- Eysenbach, G., Yihune, G., Lampe, K., Cross, P. and Brickley, D. (2000) Quality management, certification and rating of health information on the Net with MedCERTAIN: using a medPICS/RDF/XML metadata structure for implementing eHealth ethics and creating trust globally. *Journal of Medical Internet Research*, **2**, e1.
- Grandinetti, D. A. (2000) Doctors and the Web: help your patients surf the Net safely. *Medical Economics*, April, 28–34.
- Hellawell, G. O., Turner, K. J., Le Monnier, K. J. and Brewster, S. F. (2000) Urology and the Internet: an evaluation of internet use by urology patients and of information available on urological topics. *BJU International*, **86**, 191–194.
- Impicciatore, P., Pandolfini, C., Casella, N. and Bonati, M. (1997) Reliability of health information for the public on the World Wide Web: systematic survey of advice on managing fever in children at home. *British Medical Journal*, **314**, 1875–1879.
- Jadad, A. R. (1999) Promoting partnerships: challenges for the internet age. *British Medical Journal*, **319**, 761–764.
- Kawachi, I. and Kennedy, B. P. (1999) Income inequality and health: pathways and mechanisms. *Health Services Research*, **34**, 215–227.
- Kickbusch, I. S. (2001) Health literacy: addressing the health and education divide. *Health Promotion International*, **16**, 289–297.
- Kim, P., Eng, T. R., Deering, M. J. and Maxfield, A. (1999) Published criteria for evaluating health related web sites: review. *British Medical Journal*, **318**, 647–649.
- Latthe, M., Latthe, P. M. and Charlton, R. (2000) Quality of information on emergency contraception on the Internet. *British Journal of Family Planning*, **26**, 39–43.
- Mandl, K. D., Katz, S. B. and Kohane, I. S. (1998) Social equity and access to the World Wide Web and E-mail: implications for design and implementation of medical applications. *Proceedings of the AMIA Symposia*, 215–219.
- Meyers, A. D. (2001) Facial plastic surgery Web site ethics. *Archives of Facial Plastic Surgery*, **3**, 58–60.
- Morris, T. A., Guard, J. R., Marine, S. A., Schick, L., Haag, D., Tspis, G. *et al.* (1997) Approaching equity in consumer health information delivery: NetWellness. *Journal of the American Medical Association*, **4**, 6–13.
- National Health Service (2002) *NHS Direct*. [Http://www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk) (last accessed 13 February 2002).
- Pandolfini, C., Impicciatore, P. and Bonati, M. (2000) Parents on the Web: risks for quality management of cough in children. *Pediatrics*, **105**, A1–A8.
- Pautler, S. E., Tan, J. K., Dugas, G. R., Pus, N., Ferri, M., Hardie, W. R. *et al.* (2001) Use of the internet for self-education by patients with prostate cancer. *Urology*, **57**, 230–233.
- Pereira, J. and Bruera, E. (1998) The Internet as a resource for palliative care and hospice: a review and proposals. *Journal of Pain and Symptom Management*, **16**, 59–68.
- Pew Internet and American Life Project (2000a) *The Online Health Care Revolution: How the Web helps Americans take Better Care of Themselves*. [Http://www.pewinternet.org](http://www.pewinternet.org) (last accessed 13 February 2002).
- Pew Internet and American Life Project (2000b) *Who's not Online: 57% of those without Internet Access say they do not Plan to Log on*. [Http://www.pewinternet.org](http://www.pewinternet.org) (last accessed 13 February 2002).
- Pew Internet and American Life Project (2001) *More Online, Doing More: 16 Million Newcomers gain Internet Access in the Last Half of 2000 as Women, Minorities, and Families with Modest Incomes Continue to Surge Online*. [Http://www.pewinternet.org](http://www.pewinternet.org) (last accessed 13 February 2002).
- Robinson, C., Flowers, C. W., Alperson, B. L. and Norris, K. C. (1999) Internet access and use among disadvantaged inner-city patients. *Journal of the American Medical Association*, **281**, 988–989.
- Robinson, T. N., Patrick, K., Eng, T. R. and Gustafson, D. (1998) An evidence-based approach to interactive health communication: a challenge to medicine in the information age. Science Panel on Interactive Communication and Health. *Journal of the American Medical Association*, **280**, 1264–1269.

- Sandvik, H. (1999) Health information and interaction on the internet: a survey of female urinary incontinence. *British Medical Journal*, **319**, 29–32.
- Santé Canada (1999) *Pour un Avenir en Santé : Deuxième Rapport sur la Santé de la Population Canadienne*. Santé Canada, Ottawa.
- Shepperd, S., Charnock, D. and Gann, B. (1999) Helping patients access high quality health information. *British Medical Journal*, **319**, 764–766.
- Wagstaff, A. and van Doorslaer, E. (2000) Income inequality and health: what does the literature tell us? *Annual Review of Public Health*, **21**, 543–567.
- Winker, M. A., Flanagan, A., Chi-Lum, B., White, J., Andrews, K., Kennett, R. L. *et al.* (2000) Guidelines for medical and health information sites on the internet: principles governing AMA web sites. American Medical Association. *Journal of the American Medical Association*, **283**, 1600–1606.