Preventive health information on the Internet

Qualitative study of consumers' perspectives

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ABSTRACT

OBJECTIVE To explore how best to make high-quality preventive health information available to consumers on the Internet.

DESIGN Focus groups.

SETTING Three urban workplaces and one local hospital with patients from a rural family medical practice.

PARTICIPANTS Twenty-two men and 17 women patients.

METHOD Qualitative survey of four focus groups, analysis of transcripts and researchers' notes.

MAIN FINDINGS Five themes characterized participants' perceptions of a consumer website of evidence-based preventive guidelines: content expectations, website design, trustworthiness of content, marketing, and the implications of consumer health information on the Internet.

CONCLUSION Consumers want preventive health information both for taking care of themselves and for participating in a more informed way in their health care when they see a physician. Findings of this study reveal some ways in which consumers' use of Internet health information can affect physicians' and other health professionals' work.

RÉSUMÉ

OBJECTIF Explorer les meilleures façons de présenter aux consommateurs de l'information de grande qualité en prévention médicale sur Internet.

CONCEPTION Des groupes témoins.

CONTEXTE Trois établissements de travail en milieu urbain et un hôpital local comptant des patients d'une pratique familiale rurale.

PARTICIPANTS Au total, 22 hommes et 17 femmes.

METHODOLOGIE Un sondage qualitatif auprès de quatre groupes témoins, l'analyse des transcriptions et des notes des chercheurs.

PRINCIPAUX RÉSULTATS Cinq thèmes caractérisaient les perceptions qu'avaient les participants d'un site Web présentant des lignes directrices en prévention, fondées sur des données probantes: les attentes à l'endroit du contenu, la conception du site Web, la fiabilité du contenu, le marketing et les répercussions de l'information en prévention médicale sur les consommateurs.

CONCLUSION Les consommateurs veulent de l'information en prévention médicale autant pour prendre soin d'eux-mêmes que pour participer de manière plus éclairée à leurs soins lorsqu'ils consultent un médecin. Les conclusions de cette étude ont permis d'identifier des façons dont l'utilisation par les consommateurs de renseignements présentés sur Internet en prévention médicale peut avoir des répercussions sur le travail des médecins et des autres professionnels de la santé.

*T*he Internet is a fast-developing communication tool. The number of Internet users in Canada continues to rise, with more than 11 million Canadians (about 45%) now on-line.[1] this figure is expected to grow more than 17% by 2004, representing 65% of all Canadians.[1] An estimated 43% of Internet users go on-line to gather health care information and obtain answers to health care questions[2] from more than 34 000 health-related websites.[3]

The Internet has moved beyond distributing static text-based facts and become a communication medium that allows users to interact with information. There are numerous advantages to using the Internet: consumers can access information in the privacy of their homes and at convenient times; various websites appeal to consumers with various learning styles[4]; and the broad reach of mass communication is combined with the persuasive characteristics of interpersonal channels through interaction between message source and receiver.[5] Some authors have suggested that the Internet can do more than other mass media to help change health behaviour.[5]

Along with the advantages of the Internet, there are inherent disadvantages. Inaccurate medical information can be distributed from unqualified sources.[4,6,7] An assessment of 60 articles published on the Internet by traditional medical sources found that only 20% followed current American Academy of Pediatrics' guidelines for treatment of childhood diarrhea,[8] and another study found that only four of 41 articles closely followed recommendations from published guidelines for managing children's fever at home.[9] The Scientific Panel on Interactive Communication

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and Health suggested that misleading information could lead to inappropriate treatment or delays in seeking necessary medical care.[7] Thus the quality and accuracy of health information on the Internet must be assessed.[9-12] A recent Internet survey found that 69% of Internet users believe the quality of information needs to improve.[13]

Using as an example the evidence-based recommendations of the Canadian Task Force on Preventive Health Care, formerly the Canadian Task Force on the Periodic Health Examination, this study explores how best to make high-quality health information available to consumers on the Internet in a usable form. Our findings have implications for physicians and other health care professionals in understanding how their patients are using Internet health information. The findings will also help us discover ways to provide consumers with high-quality information.

METHODS

In spring 1999, four focus groups were conducted to investigate consumers' information needs and preferences for a website on preventive clinical practice guidelines.[14] A purposeful sampling strategy was used to find health care consumers with a range of occupational backgrounds. Subjects were chosen from three urban workplaces (two large manufacturing companies and one large financial institution) and one rural family medicine practice. A contact person at each site recruited participants under the guidance of the research team.

Eligibility criteria required participants to be between 35 and 65 years, to be interested in participating in a focus group discussing preventive health care information on the Internet, and to have had experience "surfing" the World Wide Web at least two or three times a month. Each participant received a $40 gift certificate. Ethics approval was received from the University of Western Ontario's Ethics Review Board.

Focus group conduct and analysis

A trained moderator conducted the focus groups. Participants were asked what type of information they wanted on the website and how they wanted that information presented. An interview guide with specific questions was developed, but the moderator was free to word and sequence questions in the most appropriate manner and to pursue areas in greater depth.[15] The moderator summarized information to allow participants to verify interpretations and offer additional comments, a process called member-checking.[16] Focus

groups lasted from an hour to an hour and a half. An assistant moderator audiotaped the focus groups and took detailed field notes. Audiotapes were transcribed verbatim.

Following each focus group, moderator and assistant moderator discussed the group and prepared debriefing notes. After the fourth group, they decided that saturation of participants' thoughts and opinions had been reached. The moderator and two other team members read the transcripts independently, looking for key phrases and themes, then met to discuss their analyses of each transcript. During these meetings, transcripts were coded using a list of key words and themes developed from the researchers' independent analyses.

The moderator completed a secondary analysis of the data, examining similarities and differences across and within the focus groups by each theme area. Team discussion preceded a comprehensive written summary of the secondary analysis, which led to clarification and agreement on main themes. The assistant moderator independently analyzed the debriefing notes and transcripts and prepared a list of key messages to compare with the results of the team analysis. This process ensured that the findings were grounded in participants' perceptions and not in researchers' biases.[16]

FINDINGS

There were 39 participants (22 men, 17 women); each group had eight to 12 participants. Fifteen participants were 35 to 40 years old, 13 were 41 to 50, eight were 51 to 60, and two were 61 to 65 (one participant's age was unknown). One focus group was composed of men only. About two thirds of participants had been using the Internet for 2 or more years: 26 had computers with Internet access at work; 36 had computers with Internet access at home.

Five themes characterized participants' perceptions of a consumer website on evidence-based preventive guidelines: content expectations, website design, trustworthiness of content, marketing, and implications of consumer health information on the Internet.

Content expectations. Participants' searches were often triggered by need for information on illness and treatment for themselves, friends, or family members. When asked about their need for information on prevention, they indicated that they wanted authoritative information on how to prevent disease (specifically exercise, back care, immunization, alternative therapies, precautions for foreign travel, and nutrition).

> … a website that would be an authority on healthy, healthful foods. What would be a healthful food…like disease prevention support. A site that would be an authority rather than having discussions and myths.

When asked directly what screening information they wanted, participants identified screening frequency and the effect of age and family history.

> There has been lung disease and that sort of thing in the family. So I'm interested in looking at [that] from the point of view of how often should I have an x-ray done… I would certainly go to the "net" to see if there's been any studies of about how often I should have it done, and the same with mammograms and that sort of thing… is it once every year, once every 5 years, is it based on age, genetics?

Participants wanted information presented in a balanced format, with various points of view explained and uncertainties elaborated. "I want to see the controversial. I want to see the pros and cons, and I want to read it all, and then I'm going to make my own decision." They frequently recommended including a question-and-answer page with expert responses to users' questions. Some participants indicated that patients' stories made information understandable and left users feeling "less alone." "I'd like to hear some personal stories too. Like get it down to my level, not just the professional level." Participants also wanted links to other health information websites, with country of origin labeled.

Website design. Connected with participants' content expectations were their suggestions on website design, including organization of information and website navigation. Participants wanted the website to follow "the KIS theory—keep it simple" and strongly recommended that the information "be written in laymen's terms so it is readable and understandable." They also wanted information organized in layers with quick access to a brief summary of recommendations and the option for users to "drill down" to get more detailed information. "I think probably some recommendations at the front. I mean that's usually what I'm looking for, especially if it's for preventive, if you can have those on the first page or very close to it."

Participants suggested that a schedule of age-related recommendations would help them find out what to investigate at various ages. Age-related messages might also capture people's interest: "I go and look when I've got something to look for, but the

preventive—I'm dealing with today not [tomorrow] but if I saw that on this site, 'Are you turning 40?' I'd go." Some participants suggested users could enter personal information, such as age and family history, to have the website generate personally relevant information.

Participants wanted a website that was easy to navigate. "A website itself should be as simple as possible so people can go in, and even those who have little computer knowledge can go in and navigate through it easily." Quick access to the home page from anywhere on the site and use of search functions and indexes organized by topic, function, and alphabet were suggested to enhance navigation.

Visual appeal was important. Where "all text gets boring," participants suggested, "… high-profile graphics catch your attention. They make you want to explore further." They believed graphics made the material easier to understand: "Most patients understand what is going on by the picture, not by the words." In two groups, however, participants were concerned about increased downloading time with excessive use of graphics.

Trustworthiness of content. An important concern of participants was trustworthiness of information on the Internet. "The problem with a lot of the health-related information out on the 'net,' is there is just so much garbage that you'd like to have a place where you can go to find stuff that has somehow been legitimized [with] actual backing behind it." The source of Internet information dominated participants' discussions of trustworthiness.

> I think most people trust an organization that they have heard of for a general rule. If it is something on there that I have never heard of or it is not familiar to me, immediately I get the idea in my head, "Well, is this some goofball that has just thrown this on the Web?" and "How good is this information?"

Trusted organizations included consumer advocate groups, such as the Canadian Cancer Society, and well-known medical institutions, such as the Mayo Clinic. Government-sponsored sites were generally viewed as credible, but some participants questioned potential political motives. Participants tended not to trust corporate websites, specifically those of pharmaceutical companies or those clearly intended to advertise products.

Participants wanted health information to be current and websites dated. "There's nothing more

frustrating than a stale Internet site either, so you need to be committed to keeping it up and then putting a date on it." They also wanted evidence to substantiate the information given. It helped "arm" them in discussions with their physicians.

> Yes, you put references where the information came from so it has credibility. Then you go in and talk to your doctor and he asks well where did that come from, and not only did it come from your site which I'm sure is credible, but this is the credible person or group that they got their information from.

There was, however, a dissenting voice. "I'm not sure credibility is such a large issue. You know there are a lot of 'hokey' things on the Internet, but they're not in serious areas like medicine."

Marketing. In all focus groups, participants spontaneously recommended marketing the website, especially in primary care offices and other health care facilities. "I think you would have to publicize the existence of the site in doctors' offices and things like that, and in hospitals. Doctors have to refer you to it, I think." Other suggestions included television, radio, magazines, and links to websites of other credible organizations. While registering the site with Internet search engines was recommended, one participant suggested that directly advertising the universal resource locator (URL) was most important.

Implications of consumer health information on the Internet. Many participants provided insight into consumers' use of Internet health information for decision making. Participants want to be actively involved in decisions about their health, "I think, as a culture, we have evolved to the point where we want to participate more in our own health care, whether it be preventive or postdiagnosis." They thought information would help in decision making: "I think we may have to take the onus for our own health, and having something like this [website], or having something out there that we can actually rely on would be very beneficial."

Participants would use information to understand an area better or to help determine what questions to ask their physicians: "I think that one of the issues there is that the information you gather from it [the Internet] may help you position yourself to ask the right questions when you go to a doctor." They used the Internet as a "second opinion" and brought printouts of Internet health information to their physicians.

Most participants saw the Internet as a resource, similar to a library or reference manual, and not as a replacement for a physician.

> If you use the Web and consider it a reference document, then you are not going to take this reference document and use it as the Bible. You are still going to maintain your physician's trust or his way of doing things. I mean, you might have a little doubt if what you are reading is completely contrary to what he is saying, but then that's up to you. Maybe you want to move on to some other physician. I think it's general information to use as a reference to give you a little more understanding, but not to be used as The Word.

Discussion

This study provides important insights into consumer perspectives on how the Internet can be used to make preventive health information accessible and useful to the general public. The findings summarized in **Table 1** also reveal ways in which consumers' use of Internet health information can affect physicians' and other health professionals' work. The type of information provided by the Canadian Task Force on Preventive Health Care was helpful in orienting participants to issues related to the quality, credibility, and organization of information.

Table 1. Important messages for health care professionals

Physicians and other health professionals should be aware of how their patients are using Internet health information.

Participants in this study used the Internet:

- To find health information for themselves, friends, or family members
- To determine questions to ask their physicians
- To get a second opinion
- To learn more about what their physicians said
- To bring to their physicians
- To help in decision making

Physicians and other health professionals can:

- Reinforce their patients' concerns about the quality of information on the Internet
- Help their patients learn how to judge the quality of information on the Internet
- Direct their patients to trustworthy websites
- Develop strategies to work with the Internet information patients bring to their health care visits

Consumers want information on prevention for caring for themselves and for participating in a more informed way in health discussions with their physicians. A website could provide basic information to answer questions and help patients prepare appropriate questions for physicians, to get more detailed information following a visit to a physician, and to provide a "second opinion." Physicians should try to be familiar with what is available on the Internet and what information sources their patients are using.[17]

Internet use could affect doctor-patient relationships. If patients share the information they find with their physicians, physicians need to develop strategies to deal with this information. Physicians can encourage patients to bring them good information, reinforce the importance of credible sources, give patients handouts printed from websites, and refer patients to high-quality evidence-based sites. Pemberton and Goldblatt[18] suggest that, if physicians accept increasing consumer use of Internet health information, they can develop doctor-patient relationships based on trust and teamwork. Dissuading patients from using Internet health information could damage doctor-patient relationships and leave patients looking elsewhere for medical advice.[19]

The fact that participants wanted high-quality information from sources they could trust underscores the potential for shared decision making[20] and allows physicians and other health professionals an active role in helping patients get the most out of their Internet searches[19-21] and in directing them to trustworthy sites.[22] Further research into the role of health information in shared decision making will be important as medical practice evolves in this era of patient-centred care and electronic information.

Strategies for communicating and disseminating credible information in a form that consumers can understand and use are essential.[23] Organizations that generate evidence-based guidelines must develop such strategies. Continued research is required, however, to further understand what consumers want and what they consider acceptable evidence.

Participants wanted information in understandable language with appealing design and good organization. Layering was important: beyond initial access to brief summaries, they also wanted to be able to access more detailed information if they chose. Constructing information in a hierarchy would help users cope with large amounts of data and complex information.[24,25]

Limitations

Transferability of these findings is limited to populations similar to participants in this study. Conducting all focus groups within 2 weeks limited concurrent data collection and analysis and the opportunity to modify the data collection process.[26] (After each focus group, researchers discussed the findings and determined whether questions needed to be altered.)

Finally, in-depth exploration of some interesting issues was limited. For example, we did not have time to explore in detail what "evidence" meant to participants, and there was some indication that participants' ideas about what "prevention" was differed from ideas of other participants and health professionals. This gap between consumers' needs and evidence-based research has been identified in the literature.[27]

Conclusion

Although many of the findings of this study might seem evident and predictable, this paper makes several important contributions. First, there is no published research on the markers that indicate to users the quality and credibility of on-line health information (or any type of information).[28] Establishing what helps people decide what to believe and not to believe on websites is an important first step. Second, user-based approaches to designing health information products, whether on-line, in print, or for personal delivery, are essential.[27] This paper can help providers of health information decide not only how to design the interface but also how best to organize information and what other features (eg, organization's reputation, examples, evidence) to highlight or avoid (eg, commercial sponsorship).

The findings open some intriguing avenues for future research. For example, what do consumers mean when they say "evidence" and how does this compare with professionals' use of this concept? How do consumers conceptualize "prevention?"

Finally, the Internet could have a profound effect on how patients and health professionals interact. Research is needed to better understand the effects of Internet health information on doctor-patient relationships and on shared decision making. ❧

Contributors

Drs Quintana and **Marshall** *were involved in research design, data analysis, and manuscript preparation and revision.* **Dr Feightner** *was involved in conceptual development of the study, preparing the funding proposal, developing the research design, final decisions on data acquisition and analysis, and manuscript preparation, revision, and final editing.* **Ms Wathen** *participated*

> **Editor's key points**
> - This qualitative study describes patients' preferences regarding health information on the Internet, specifically information on preventive health measures.
> - Patients wanted information that was authoritative, trustworthy, and balanced; they preferred websites that were organized simply, navigated easily, and designed attractively. They thought good sites should be publicized.
> - Many patients saw Internet information as complementary to their physicians' advice. It helped give them background to better participate in decisions about their health.
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> **Points de repère du rédacteur**
> - Cette étude qualitative décrit les préférences des patients en ce qui concerne l'information médicale sur Internet, en particulier sur les mesures préventives.
> - Les patients voulaient des renseignements documentés, fiables et équilibrés; ils préféraient les sites Web organisés avec simplicité, faciles à consulter et de conception attrayante. Ils étaient d'avis qu'il faudrait faire de la publicité sur les sites de bonne qualité.
> - Plusieurs patients considéraient l'information sur Internet comme un complément aux conseils de leur médecin. Elle leur permettait d'avoir en main des renseignements généraux les aidant à mieux participer aux décisions concernant leur santé.

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