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Health Information via the Internet: What Seniors Want

Julia Pennbridge, Ph.D.
Susanna Molnar, M.A.
O'Keeya Singleton, B.A.
Quinnie Le, B.S.
Mary Espinoza
Shubha Kumar, B.S.

The National Health Foundation

Corresponding Author: Julia Pennbridge, Ph.D.
515 South Figueroa Street, Suite 1300
Los Angeles, California 90071
(213)538-0747

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Abstract

Research has shown that while much is known about how to design and build websites for seniors, little is known about what health related information they want. A computer training organization asked the National Health Foundation to provide the content for a health information web-portal it intended to create for seniors. Focus groups with computer-literate seniors showed that although they want several different kinds of information in language that is easy to understand (e.g., the most common medications for different conditions and cost comparisons, drug side-effects and interactions, most recent research findings), what seniors most want is to participate in face-to-face trainings about how to obtain reliable and up-to-date health information via the Internet.

Key words: seniors, health information, Internet

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Introduction

As the health care industry continues to change, stakeholder groups—health plans, hospitals, physician groups, special interest groups, and researchers—are seeking ways to increase access to health related information using the Internet. There is a special interest in helping seniors, who use most health care services, to become comfortable with accessing web-based health information. While this is the goal, many seniors must first learn how to use computers and then to conduct effective searches. This paper reports findings from a focus group study of computer-literate seniors, specifically about their experiences using the Internet to find health information and about what information they want to access. After a brief background review, study methods and findings are presented followed by a short conclusion.

Background

There are many different efforts to increase consumers' Internet access to health information. Some health plans (e.g., Kaiser Permanente, Pacificare) and hospitals (e.g., Cedars-Sinai, Mayo Clinic) provide their patients with on-line health information, physicians are writing e-prescriptions that send patients to particular health information websites, and special interest groups (e.g., American Lung Association, American Diabetes Association) provide extensive health information on their websites. Furthermore, researchers are documenting why and how different groups access Internet based health information (Dickerson, Reinhart, Feeley, Bidani, Rich, Garg, & Hershey, 2004; Meischke, Eisenberg, Rowe, & Cagle, 2005; Metcalf, Tanner, & Coulehan, 2001), and are developing tools for evaluating website quality (Center for Information Therapy).

Along with these efforts, considerable research has been done on what seniors want in a website. The National Institutes of Health has summarized this research into criteria for website design and text writing. These criteria have been developed with sensitivity to the vision, cognitive, hearing, and motor skill limitations seniors may face, including design elements, such as typeface, type size and weight, physical spacing, colors used, and writing criteria around style, phrasing simplicity, organization, etc. Other research argues that web-designers must also be sensitive to cultural issues and describes how to use computers to change attitudes and behaviors. Websites can be analyzed for cultural sensitivity using a normative framework that includes perceptual, behavioral and symbolic components, and web designers are encouraged to be aware of all these elements as they work (Singh, 2005). In addition, Stanford's Persuasive Technology Laboratory has summarized the roles and functions computers play and how they can be used to make a website "persuasive," that is, help consumers change their behaviors.

All this research is going on at the same time that more seniors are using computers and the Internet. In 2003, the Los Angeles Urban League Ron Brown Center of Long Beach (Center) that trained seniors to use computers wanted to improve seniors' access to web-based health information. The Center staff felt strongly that this could be achieved by building a web portal that would simplify seniors' Internet access to health information. The Center approached the National Health Foundation (NHF) for help with the health content that such a portal required. NHF agreed to conduct some preliminary research. This included a review of best practices to follow when building websites for seniors and a series of focus groups with computer-literate seniors to clarify their health information needs.

As has already been discussed, review of current best practices in building websites for seniors showed that while much was known about how seniors want their websites to look and

work, there was little data about the kinds of information seniors want from their Internet health information searches. This became the central topic of the NHF's focus groups, which were conducted at the Atlantic Community Economic Development Corporation (ACED) and funded by a grant from the Michael J. Connell Foundation.

Method

As previously mentioned, research was conducted in two areas. Best practices for designing seniors' websites was researched and summarized by LaVonna Blair Lewis' (Professor, Health Administration Program, USC School of Policy, Planning, and Development) Masters in Health Administration candidates. The National Health Foundation conducted the focus groups with computer literate seniors. Initial recruitment efforts focused on the seniors who had completed computer training classes and then expanded to other kinds of senior serving organizations. The focus groups were designed to help researchers learn both what information seniors want and how they currently conduct Internet searches. Recruitment activities and focus group design are discussed below.

Recruitment

Focus groups were conducted at ACED, which provides computer training, at a nominal cost, to seniors living in a large metropolitan area. Participants were recruited from and through 33 organizations that included Community Centers, Senior Housing complexes, the City Management Association, Neighborhood Services Bureaus, the Senior Citizens' Commission, radio stations, small business and entrepreneurial associations, the local AARP, the Housing Authority, hospital and church programs, and professional clubs. Recruitment was conducted by presentations to staff and boards of directors and through distribution of flyers.

Seniors, aged 56-84 (primarily 65+), were recruited and participated in focus groups between April 28, 2004 and June 15, 2004. Six focus groups were held with 46 computer and Internet literate seniors (24 women and 22 men).

Focus group design

The focus groups were designed a) to obtain information about seniors' experiences with finding health information on the Internet, b) to increase understanding of the kinds of information seniors want, and c) to identify currently available information that meets seniors' needs.

The focus group format was as follows:

1. Welcome & introductions
2. Computer & Internet literacy test (10 minutes)
3. Discussion about participant experiences of and desires for Internet-based health information (20 minutes)
4. Computer lab session that included undirected and directed searches (minimum 1 hour)
5. Lunch

During the literacy test, staff was able to assure all participants were comfortable using computers and accessing the Internet, and was able to assess the different competencies of participants. When participants returned to the computer lab to conduct their searches (#4 above), they were paired based on equivalent competencies. Each pair sat at one computer, one on the keyboard and the other on the mouse. This, as was explained to the participants, was to encourage them to talk to one another as they conducted the searches so that we could hear their issues and concerns. NHF staff observed each pair (in two cases staff worked individually with participants with challenging personalities).

The computer lab sessions began with the pair identifying search topics and conducting their own searches; it ended with them being sent to specific sites (depending on their search topic) by staff. In both these undirected and directed searches, participant-pairs were asked the same series of questions about the credibility, appropriateness and usefulness of site information. Their answers were documented on standardized data collection forms.

Findings

This section reports on 1) seniors' experiences in searching the Internet for health information, 2) researchers' observations of seniors health information search efforts, and 3) what health information seniors say they want.

Seniors' experiences

Participants had mainly used the Internet for recreational (as one male participant commented, "it's pretty good for gambling") or genealogical searches (women seemed more interested in this than men); few had used it to search for health information. Those who had, had primarily used it to get information that would supplement (often by confirming) what their physicians had told them or to make sure they were asking their physicians the "right" questions. Generally women were more interested in finding this information than men. Very few participants were comfortable conducting health information searches for themselves or others, although one had recently conducted Internet-based health information searches for staff of a hospital's senior program.

Those who had searched for health information on the Internet had various attitudes towards their experiences. Most said they were frustrated by not getting the exact information they wanted and overwhelmed by the volume of information they found; they did not know how to narrow their searches; and they did not know which sites to trust or which information was

reliable. One small group (they had all attended the same Community College computer classes) appreciated having access to the broad scope of information the Internet provides.

Very few of the participants used chat rooms (only two reported participating in bulletin boards) and they were not interested in learning how to use them. They agreed they would not sign up for regular email updates about particular issues or health conditions and would certainly not pay for this information, although one man said before his wife died they received email updates on her condition. Several were interested in finding information about interactions between the medications they were taking, although most agreed that they relied on their pharmacists to make sure their physicians were prescribing correctly.

Seniors' Internet searches

In their undirected searches, paired participants agreed upon a topic and began searching without any comment or recommendation from staff. In almost every case, participants began by typing their topics into an Internet search engine, such as Google or Yahoo, which provide a means to search for and access information on the Internet using key words or phrases. Participants then read the first page from the top to the bottom; they did not scan some pages to get a sense of what was available nor did they try to narrow their search topics. When they picked a site, they typically could not tell us why, although their choices seemed to depend on a single word or a recognized sponsor. For example, two male participants looking for information about exercise picked a site that included "home equipment" in the first sentence. They thought that was what they wanted and did not consider the fact that it was a commercial site. Although when they saw that they were being encouraged to buy something, one said, and the other agreed, "I don't want to pay that much; there must be a cheaper way."

Clearly most of these seniors do not know or understand how the Internet is organized. They do not appreciate the differences between commercial, non-profit, government and academic sites (i.e., .com, .org, .gov and .edu) and are not familiar with suffixes to differentiate among sites. They also do not know how to identify site sponsors, nor do they understand what advertising or sponsored links represent. Even the most sophisticated users had not previously visited the sites staff sent them to (typically government sites) but they all “liked these sites a lot.” After the first focus group, and at the seniors’ request, NHF distributed typed lists of these sites so that participants could easily return to them.

This list includes the following sites:

- www.nihseniorhealth.gov which is specifically designed for seniors with a large font, simple layout and content.
- www.seniornet.org which is specifically for seniors and provides some health information but generally provides social opportunities and financial and legal information.
- www.medlineplus.gov which is not specifically for seniors but provides access to health and medicine articles, research reports, etc.
- www.healthfinder.gov which is not specifically for seniors but provides a good starting point for health related searches.
- www.diabetes.org which is not specifically for seniors but includes excellent and easily accessible information.
- www.medicare.gov which provides specifics on Medicare coverage.
- www.niams.nih.gov which is a good source for information about arthritis, musculoskeletal and skin diseases.

- www.clinicaltrials.gov which lists the topics and locations of government funded clinical trials.
- www.kff.org/medicare/rxdrugscalculator.cfm through which seniors can calculate their probable out of pocket costs under the new Medicare drug law.
- www.californiahealthline.org which provides daily summaries of health related media stories from around California and nationwide.

Information seniors want

Seniors would like to access several different kinds of information using the Internet. They include:

- The most common medications for particular conditions and cost comparisons,
- Drug side-effects and interactions, both between western medicines and between western, eastern and “natural” medicines,
- Medicare & Medicare supplemental insurance coverage options and cost information,
- A list of experts on particular diseases or treatments throughout California,
- The most recent research findings summarized in simple language, and
- Recommendations for which websites to use for which issues.

However, while seniors are interested in being able to access this information, they are most interested in being trained about how to find the health information they need. They do not want just another website. As many seniors said, “there are too many of them already.” They want to learn about how to recognize a “good” site, how to conduct efficient research and how to find information for themselves. That is, metaphorically, they want to be taught how to fish and not to be given the fish.

The strength of this desire was made clear as the word spread from the seniors participating in the focus groups. While initially ACED and NHF recruited for focus group participants, after the first two to three focus groups had been completed, seniors began calling to participate in the “classes.” This is due, seniors explained, to their expectation of leaving focus groups feeling that “you’ve given your ideas.” But, as several seniors said as they left our focus groups, “I feel as though I’ve learned a lot.”

Conclusion

The Los Angeles Urban League Ron Brown Center of Long Beach and the National Health Foundation began this project with an expectation of developing a website through which seniors could easily access the health information they want. In preparation for this work, the NHF conducted focus groups with computer literate older Americans (primarily 65+). These groups included structured observations of seniors conducting their own searches and discussions about their experiences using the Internet to find health information. This research revealed that seniors do not want more websites; instead they want to learn how to efficiently find the information they need from websites they can trust. Consequently, the NHF determined that building another website would be less useful than finding ways to provide seniors with the training they want. Additionally, the seniors participating in this study preferred face-to-face trainings in computer labs, not “train yourself” programs.

These seniors very much wanted to know how to use the Internet to find health information. They know that the entire health care system is moving towards consumers taking more personal responsibility for their care, and they are ready to do so. They also know that to do this they must have, and use, good health information and that the Internet provides one of the most cost effective ways of getting that information to them.

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