# Consumer Informatics: Elderly Persons and the Internet



*by Robert J. Campbell, EdD*

This paper reports the findings from a study designed to determine whether, when appropriately trained, older adults would use the Internet to gather healthcare information and actively seek information that could directly affect their own treatment and care.

Results show that older adults are willing to use the Internet to locate health information. However, familiarity with Internet-based healthcare resources did not lead participants to adopt significant levels of Internet use or change the way they participated in their own healthcare.

These results suggest that the Internet may not have as great an influence on how individuals manage their healthcare, and point out the fact that seniors 65 and over may still cling to a paternalistic model when working with their own healthcare provider.

## Introduction

The Internet is changing how individuals gather healthcare information and has helped to foster the consumer healthcare movement.[1] The Pew Internet & American Life Project[2] estimates that more than 93 million adults currently use the Internet to locate information about general health topics, specific chronic diseases, treatments and procedures, diet, fitness, physicians' credentials, and the efficacy and safety of taking a specific medication. However, as Internet use continues to grow, pronounced differences are beginning to develop among different age groups and ethnic populations, especially when people use this resource to locate health information.

Research shows that older Americans are in danger of being cut off from one of the most provocative communication media of the 21st century.[3] In the United States, adults 65 and older make up 12.4 percent of the population, with only 4 percent of this group using the Internet.[4] When viewed alongside other age groups, older adults' use of the Internet pales in comparison. For example, the 2000 Census reports that approximately 80 million adults between the ages of 30 and 49 live in the United States.[5] Of those 80 million, 75 percent, or 60 million, have used the Internet[6] (Table 1).

**Table 1: Use of the Internet Based on Age**[7,8]

| Age Group | Total Population | Number Using the Internet | Percentage |
|---|---|---|---|
| 18-29 | 34,964,001 | 26,922,280 | 77 |
| 30-49 | 80,148,577 | 60,111,395 | 75 |
| 50-64 | 54,274,684 | 31,479,316 | 58 |
| 65 and older | 34,991,753 | 8,000,000 | 4 |

Several differences exist among elderly people who are using the Internet as an informational resource. For example, many connected seniors are white females who have a college education, own a computer, and live in a high-income household. Older men, for one reason or another, are not as fervent as females in their desire to use the Internet.[9] Racial differences also exist among elderly persons, with only 11 percent of African-American and 21 percent of Hispanic seniors using the Internet to access information.[10]

Because of their health problems, it seems logical to assume that adults 65 and older would have the most to gain by learning how to use the Internet to locate, retrieve, and disseminate healthcare information. This article reports on the results generated from part of a study designed to train older adults living in an urban area with a high concentration of senior citizens how to use

the Internet to locate health information. In the past, older adults relied primarily on their physicians for healthcare information. The main focus of this study was to determine whether older adults, when appropriately trained, would begin to use the Internet to gather healthcare information and actively participate in their own healthcare.

## Methods

To facilitate the training of elderly persons, a large suburban Pittsburgh public library and two senior community centers agreed to sponsor a series of Internet training seminars and make their resources available to the research team. The library and senior community centers were used as the settings for the training because the elderly participants who did not have a computer at home could use the computers in these facilities to search the Internet.

The choice of training centers also allowed the research team to reach a wide range of individuals with varying socioeconomic backgrounds. The training sessions were advertised in two local newspapers, a local suburban magazine, and a local senior citizen newsletter. Flyers were also placed in the library and senior community centers where the training was to take place. The sessions occurred over five weeks, with meetings once a week for two hours. Participants were asked to commit to attending all five sessions. Each session began with an overview of the day's topic, followed by intensive hands-on instruction and practice. The sessions used constructivist teaching techniques and self-directed learning.

Constructivism emphasizes placing learners in situations where they learn to solve specific problems, in this case locating information related to their healthcare. This approach allows learners to construct knowledge that is more meaningful and useful to them for recall in future problem-solving scenarios. Each lesson used a different method for engaging the participants to find medical information relevant to their individual needs. Small groups of approximately 10 to 12 made individual attention possible for the hands-on portion of each session. A course packet was provided to the participants to serve as a reference for future use.

## Data Collection

Questionnaires were distributed at the beginning and end of the five-week training session. The surveys were designed to capture baseline information about the participants' experience using computers and searching the Internet. The surveys also measured participants' levels of anxiety toward computers, levels of self-efficacy, and health locus of control. The results of these measures are reported elsewhere.[11]

To measure participants' heath information–seeking behaviors, a 17-question Internet survey was developed. This survey was designed to elicit participants' feelings in three areas: level of participation in their healthcare, use of the Internet to locate health information, and use of the Internet to locate health information before and after a visit to their healthcare provider.

## Participants

A total of 79 people, ages 60 to 83 (mean age 69.76 years), self-volunteered for the Internet training, with 70 completing the five-week program. Of those 70, 58 (83 percent) were female, and 12 (17 percent) were male. Pearson chi-square and Cramer's V were used to test the strength of the relationship between gender, education, and computer use. Significance was found with Pearson chi-square (p=.017) and Cramer's V (.443, p=.017) between gender and education. This result showed a marked difference between the education levels of females and males taking part in this study. For more participant demographic information, please refer to Table 2.

**Table 2: Participant Demographics**

| **Participants** | | **58 (83%) female** | **12 (17%) male** |
|---|---|---|---|
| **Education level** | **Total** | **Female** | **Male** |
| Postgraduate training | 25 (36.0%) | 24 (96.0%) | 1 (0.04%) |
| College degree | 18 (26.0%) | 10 (56.0%) | 8 (44.0%) |
| Some college or technical training | 12 (17.0%) | 10 (83.0%) | 2 (17.0%) |
| High school degree | 12 (17.0%) | 11 (92.0%) | 1 (0.08%) |

| | | | |
|---|---|---|---|
| Less than high school degree | 1 (.014%) | 1 (100)% | 0 |
| Other | 2 (0.03%) | 2 (100)%) | 0 |
| **Employment status** | | | |
| Retired | 54 (77.1%) | 45 (83.0%) | 9 (17.0%) |
| Work full time | 4 (5.7%) | 3 (75.0%) | 1 (25.0%) |
| Work part time | 6 (8.6%) | 5 (83.0%) | 1 (17.0%) |
| Not employed | 1 (1.4%) | 0 | 1 (1.4%) |
| Homemaker | 5 (7.1%) | 5 (7.1%) | 0 |
| **Computer use** | | | |
| Used a computer on average greater than ten times | 63 (90%) | 52 (83%) | 11 (17%) |
| Never used a computer | 7 (10%) | 6 (86%) | 1 (14%) |
| **Computer at home?** | **Yes** | **No** | **No Response** |
| | 53 (76%) used 4 to 6 times per week | 17 (24%) | |
| Used computer to search Internet | 38 (54.3%) | 25 (35.7%) | 7 (10.0%) |
| Used a public computer | 39 (56.0%) | 31 (44.3%) | |
| Used public computer to search Internet | 25 (36.0%) | 29 (41.0%) | 16 (23.0%) |
| Used Internet to locate health information | 30 (42.9%) 4-6 times total | 40 (57.0%) | |
| Used e-mail | 46 (66.0%) | 24 (34.3%) | |
| Joined online support group or chatted | 5 (7.1%) | 65 (93.0%) | |
| **Health status** | | | |
| Has a health problem | 59 (84.3%) | 11 (16.0%) | |
| Has a chronic health problem | 45 (64.3%) | 11 (15.7%) | 14 (20.0%) |
| **The Internet and healthcare** | | | |
| Can the Internet help you manage your healthcare? | 56 (80%) | 14 (20%) | |

## Results

*Descriptive Statistics*

Internet surveys were mailed to 70 participants. From that number, 52 (70 percent) completed surveys were returned. In terms of Internet use, 45 (86.5 percent) had looked up health information on the Internet. However, the majority used the Internet either monthly (26.9 percent) or with some other frequency (46.0 percent), for example, when needed, to locate health information.

To develop a picture of how Internet use influenced their healthcare behaviors, participants were asked if their levels of participation had changed since being introduced to the Internet. Thirty-three (63.5 percent) said yes, whereas 19 (36.5 percent) said no. Over a six-month period, 46 participants (88.5 percent) had seen a healthcare provider, with 39 (75.0 percent) stating that they played a collaborative role with their doctor and worked together to make important decisions. However, when asked if they used the Internet before or after their last visit or to develop a list of questions to ask their doctors, the majority of participants responded no. When asked if they had a set of medical Web sites (see Appendix A) they used to retrieve healthcare-related information, 25 (48.1 percent) said yes, and 18 (34.6 percent) said no. See Table 3 for a complete listing of results.

| | | | |
|---|---|---|---|
| **Did your levels of participation in your healthcare change since you began using the Internet?** | **Yes** 33 (63.5%) | | **No** 19 (36.5%) |
| **Did you use the Internet to locate health information?** | **Yes** 45 (86.5%) | | **No** 7 (13.5%) |
| **Internet use** | | | |
| Daily | 1 (1.9%) | | |
| Weekly | 5 (9.6%) | | |
| Monthly | 14 (26.9%) | | |
| Other (when needed) | 24 (46.0%) | | |
| Did not respond to question | 8 (15.0%) | | |
| **Internet and healthcare** | | | |
| Visited a healthcare provider in the last six months | **Yes** 46 (88.5%) | | **No** 6 (11.5%) |
| **Role played in last visit with a healthcare provider** | | | |
| Doctor made all the decisions | 6 (12.0%) | | |
| Made the decisions and asked doctor for opinions | 3 (5.8%) | | |
| Played a collaborative role with doctor | 39 (75.0%) | | |
| Other | 2 (3.5%) | | |
| Did not respond to question | 2 (3.5%) | | |
| Used Internet prior to office visit | **Yes** 23 (44.2%) | **No** 25 (48.1%) | **No Response** 4 (7.7%) |
| Used Internet to prepare a list of questions for doctor | **Yes** 18 (34.6%) | **No** 30 (57.7%) | **No Response** 4 (7.7%) |
| **Number of questions asked at last office visit** | | | |
| One | 3 (5.8%) | | |
| Two or three | 23 (44.2%) | | |
| Four or five | 12 (23.1%) | | |
| Six or more | 10 (19.2%) | | |
| Did not respond to question | 4 (7.7%) | | |
| **Did you use the Internet to locate health information after a visiting with a healthcare provider?** | **Yes** 19 (36.5%) | **No** 33 (63.5%) | |
| **Do you have a set of medical Web sites you use to retrieve healthcare-related information?** | **Yes** 25 (48.1%) | **No** 18 (34.6%) | **No Response** 9 (17%) |

*Textual Comments*

To gain more insight into how participants used the Internet to locate health information and determine how that information influenced their relationships with their healthcare providers, participants were asked about:

1. the type of health information retrieved
2. the influence the Internet had on their relationship with their healthcare provider
3. whom they shared the health information with
4. the purpose for locating health information after a visit with a healthcare provider
5. anecdotes regarding their experiences using the Internet to locate health information

Participant responses for each question are summarized below and cogent comments are provided. For a more detailed presentation of participants' comments, see Tables 4 to 8.

*Question 1: Type of health information retrieved*

The majority of participants (50 percent) used the Internet to retrieve information on "general topics" (such as throat swallowing, back surgery, cochlear implants, and blood pressure).

**Table 4: Type of Health Information Retrieved**

| Category | Distribution | Examples |
|---|---|---|
| General | 26 (50%) | Throat swallowing, back surgery, cochlear implants |
| Medication information | 16 (31%) | Contraindications, side-effects of specific drugs |
| Specific information | 3 (6%) | How do you treat liver disease? |
| Did not respond to question | 7 (13%) | |

*Question 2: Influence of Internet on relationship with healthcare provider*

A large portion of participant responses were grouped under the category of "personal empowerment." Nineteen (37 percent) gave responses that illustrated a more confident, self-actualized individual who was not intimidated by their healthcare provider. The Internet, based on participants' comments, gave them the power they needed to play a more active role in their healthcare. Responses from this category included: "I feel that I am more comfortable asking questions when a medication is prescribed. I'm not as intimidated, since I feel that I possess the tools to check when in doubt," and "I am not as hesitant in asking questions about my own health and making suggestions for possible treatment."

**Table 5: Influence of Internet on Relationship with Healthcare Provider**

| Category | Distribution | Examples |
|---|---|---|
| No change | 12 (23%) | |
| Improved communication | 11 (21%) | I gathered information about my condition and discussed it with my physician. |
| Personal empowerment | 19 (37%) | I feel that I am more comfortable asking questions when a medication is prescribed. |
| Conflict | 3 (6%) | The specialist/oncologist didn.t have the facts and information that I had. When I asked questions he was very vague. I was not willing to take the medication (and told him so) and he wrote out the prescription anyway and then tried to end the appointment as soon as he could. He didn.t seem to like my questions and my ability to think about my decisions. |
| Did not respond to question | 7 (13%) | |

*Question 3: Whom health information was shared with*

Participant responses fell into three groupings: "did not share information," "did share information and received a positive response," or "did share information and received a negative response." In the first grouping, 18 (35 percent) participants did not share health information with their provider. In the second grouping, 16 (31 percent) participants shared information and received a positive response.

In the third grouping, 11 (21 percent) participants shared information with their provider but received a negative reaction. Within this grouping, participants' comments showed healthcare provider reactions ranging from initial defensiveness to total

disregard for the information found on the Internet. One of the more cogent comments was: “Most doctors have been defensive. My mother’s primary care doctor, although a bit defensive, realized that I knew all about her disease and that I knew more about the newer treatments that he did. He was willing to compromise with me on the treatments.”

**Table 6: With Whom Was the Health Information Shared?**

| Category | Distribution | Examples |
|---|---|---|
| Did not share information | 18 (35%) | |
| Did share information and received a positive response | 16 (31%) | [The physician was] pleased and encouraged me to learn and be involved with my care in whatever method that opened up to me. |
| Did share information and received a negative response | 11 (21%) | [The physician] wasn't familiar with it and said something disparagingly: "I don't know where you got your information." |
| Did not respond to question | 7 (13%) | |

*Question 4: Purpose for locating health information after visit with healthcare provider*

Nineteen participants identified themselves as having used the Internet to retrieve health information after seeing a healthcare professional; from their comments, three distinct categories appeared. Participants used the Internet to “check on medications (15 percent), “find updates to information concerning a specific health problem” (6 percent), or “verify” (15 percent) information they were told during their most recent visit to their healthcare provider. The remaining 63 percent did not use the Internet after a visit with their healthcare provider.

**Table 7: Purpose for Locating Health Information After a Visit with a Healthcare Provider**

| Category | Distribution | Examples |
|---|---|---|
| Check on medications | 8 (15%) | To determine the side effects of medications prescribed. |
| Updates to information concerning a specific health problem | 3 (6%) | I again compared the different sites to see if any updates had occurred, as you know health information always been updated by new research. |
| Verify information | 8 (15%) | To verify validity of health provider's information. |
| Did not use Internet after a visit with a healthcare provider | 33 (63%) | |

*Question 5: Anecdotes regarding experiences using the Internet to locate health information*

Participants’ responses were grouped into the following categories: “no unique experiences” (31 percent), “general comments” (5.8 percent), “constraints” (12 percent), “enjoyed introduction to the Internet” (19 percent), and “positive health outcomes” (15 percent).

One of the more memorable comments made by a participant fell under the category of positive health outcomes. “I think the use of the Internet helped save my mother’s life. She had Clostridium difficile and a bacterial infection that was not responding to antibiotics. I was able to discuss the mechanics of the disease with my mother’s doctor. He was willing to try a different drug along with probiotics. I knew that the probiotics he suggested and the dosage was too low and ineffective. I then told him that I used a more powerful probiotic in a much stronger dosage. But it worked!”

**Table 8: Anecdotes Regarding Experience Using the Internet to Locate Health Information**

| Category | Distribution | Examples |
|---|---|---|

| | | |
|---|---|---|
| No unique experience | 16 (31%) | |
| General comments | 3 (6%) | Sometime I have to read a lot of material to find satisfying information. Many times I learn information that my doctor is not aware of. Sometimes the side effects of medicines are frightening. |
| Constraints | 6 (12%) | Illness has prevented my access to the Internet. I am improving now ... and plan to use the Internet for medical and health information. |
| Enjoyed introduction to the Internet | 10 (19%) | Excellent course and materials. I plan to use them for reference when needed. |
| Positive health outcomes | 8 (15%) | I think the use of the Internet helped save my mother's life. |
| Did not respond to question | 9 (17%) | |

## Discussion

The results of this study suggest that older adults are willing to use the Internet to retrieve health information; however, Internet use did not translate to greater levels of participation, especially when interacting with a healthcare professional. Although a majority of the participants (63.5 percent) felt that Internet use changed their healthcare participatory levels, this was not substantiated in reported usage patterns. For example, when participants were asked if they used the Internet prior to an office visit, after an office visit, or to develop a list of questions for their physicians, the majority had not. Furthermore, when participants were asked the frequency with which they used the Internet to locate health information, the majority (72.9 percent) used the Internet on a monthly basis or as needed (other). This suggests that Internet use has not greatly affected participants' levels of participation in their own healthcare.

Although usage levels among participants were rather low, the textual comments provide evidence that the Internet can be a beneficial resource to the elderly healthcare consumer. For instance, a majority of the participants (50 percent) used the Internet to locate health information at a general level (for example, throat swallowing), at a medication level (31 percent; for example, side-effects or contraindications), or at a more specific level (6 percent; for example, how to treat a specific disease). Textual comments indicated that the Internet increased participants' perceptions of greater participation in their own care. Nineteen (42 percent) participants believed that the Internet empowered them to have a more direct relationship with their physician. The findings of this study suggest that as more older adults became comfortable using the Internet to locate health information, chances are greater that they will use this resource to locate information that has a direct impact on the type and quality of care they receive. More opportunities need to be provided to older adults so they can take advantage of the Internet as a resource for healthcare information.

## Future Directions

Future studies should look at more quantitative methods of validating how older adults using the Internet to locate health information participate in their own healthcare. For example, during a visit with their healthcare provider, do these older adults ask more questions of their provider and ask for more detailed explanations in regard to a specific health problem? Another important consideration is how to get more men, and older adults from lower income and diverse ethnic backgrounds, involved in using the Internet to find healthcare information. In this study and others,[12] a majority of the participants were well-educated women who enjoyed a moderate to high level of economic status. Studies have shown that patients who ask questions, elicit treatment options, express opinions, and state their preferences regarding treatment during office visits with their physicians have measurably better health outcomes than those who do not communicate.[13] Therefore, engaging these individuals could affect their health outcomes.

Another area ripe for future research is how Internet use by elderly persons affects costs, utilization, and overall health. For example, does use of the Internet lead to quicker diagnosis, treatment, and recovery, thereby reducing present and future burdens on an already stressed healthcare system? Or does Internet use lead to higher utilization of services because patients request that more tests and procedures be performed to diagnose a particular health problem, even when those tests are not warranted? Finally, does Internet use to locate health information truly influence the decisions elderly adults make in the terms of their own health care?

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## Notes

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## Appendix A

Set of Web Sites Identified by Participants as Sites They Used to Locate Medical Information

| Web Site | Full Title |
|---|---|
| http://www.oncolink.org | Abramson Cancer Center of the University of Pennsylvania |
| http://www.aarp.org | American Association of Retired Persons |
| http://www.abms.org | American Board of Medical Specialties |
| http://www.ama-assn.org | American Medical Association (Physician Locator) |
| http://www.sleepapnea.org | American Sleep Apnea Association |
| http://www.imaginis.com | Imaginis: The Breast Health Resource |
| http://www.cdc.gov | U.S. Centers for Disease Control and Prevention |
| http://www.drugdigest.org/DD/Home | Drug Digest |
| http://www.guideline.gov | National Guideline Clearinghouse |
| http://www.intelihealth.com/ | Harvard Medical School.s Consumer Health Information |
| http://www.healthanswers.com | Health Answers |
| http://www.healthfinder.gov | Health Finder |
| http://www.healthytalkradio.com | The Deborah Ray Show Health Talk Radio! |

| | |
|---|---|
| http://www.iherb.com | Health Information and More |
| http://www.ivanhoe.com | Ivanhoe Broadcast News |
| http://www.mayoclinic.com | Mayo Clinic |
| http://www.nlm.nih.gov/medlineplus/ | MEDLINE Plus |
| http://www.michaeljfox.org/ | Michael J. Fox Foundation for Parkinson.s Research |
| http://www.nci.nih.gov | U.S. National Cancer Institute |
| http://www.nih.gov | U.S. National Institutes of Health |
| http://www.licensepa.state.pa.us | Pennsylvania Department of State Bureau of Professional and Occupational Affairs |
| http://www.ncbi.nlm.nih.gov/entrez/query.fcgi | PubMed |
| http://www.quackwatch.com | Quack Watch: Guide to Quackery, Health Fraud, and Intelligent Decisions |
| http://www.upmc.com | University of Pittsburgh Medical Center |
| http://www.webmd | WebMD |
| http://www.fda.gov | U.S. Food and Drug Administration |

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