THE IMPACT OF INTERNET INFORMATION ON THE DOCTOR-PATIENT RELATIONSHIP

by
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A Master's paper submitted to the faculty of the School of Information and Library Science of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Master of Science in Library Science.

Chapel Hill, North Carolina
August 2002

Approved by:

_______________________________________
Advisor
The behaviors and attitudes of primary care doctors and their patients were investigated regarding the use of Internet information in their communications. Twelve providers and 113 patients were interviewed regarding their use of the Internet and their views of how its use affects their day-to-day relationships. Relationships between the amount of computer use and medical searching, as well as between information brought by the patient and changes in the plan of treatment, or education that took place were examined. None of the patients brought in information on paper to their doctors, possibly suggesting a reluctance to threaten the relationship. Patients with chronic illnesses were more likely to be satisfied with their search for Internet information. Patients who felt that their doctors were more “inclusive” of them in their decisions were more likely to bring in information and be pleased with the response of the doctor.

Headings:

Physician-patient relations

Attitudes toward computers

Medical information

Patient education

Internet searching
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Introduction

In the traditional doctor-patient relationship, the doctor has been the “information broker” for the patient, who, generally speaking, has had little access to quality medical information. Information transfer has been limited to what the doctor could explain in the course of an office visit, what he or she gave in the form of handouts, what the nurse could explain, or what the patient could find in the public library, material which has often been limited, dated, or at an inappropriate level. In recent years, several sources of increased patient information have developed. First, patients themselves have been demanding more information from the doctor, and therefore have received more. Second, we have seen the growth of support groups, usually sponsored by a medical or patient group concerned about a single disease, and which are sources of extensive information for the patients involved. The mass media are providing more information to consumers than ever before. Last, and perhaps most importantly, the widespread use of the Internet has made previously unobtainable information available to anyone with access to a computer and a modem.

The question to be addressed in this paper is whether the change in the patient’s information base has altered the relationship between the patient and the doctor, and, more specifically, whether the doctor may feel somewhat threatened since the patient who brings in the result of Internet, or even Medline, searches, may appear to know more than he or she does. “This exposure of an apparent gap in the doctor’s knowledge may
alarm both parties and, in view of the potential disruption to doctor-patient relationships, a new approach of trust and teamwork is required.” (Pemberton & Goldblatt, 1998, 594).

There is some evidence that the degree of comfort that a doctor has with the results of an Internet search by a patient may be related to the degree of comfort he or she has with using the computer at all, as well as using it for medical information (Deloitte & Touche, 2000). I hypothesize that it also has to do with the degree of collaboration that exists between a patient and his or her doctor. A shared approach to decision-making is considered the ideal (Gerber & Eiser, 2001).
LITERATURE REVIEW

Gerber (2001) believes the research agenda on online information and the patient–physician relationship for the future will fall into three areas: an assessment of the effects of Internet medical information usage by patients on patient outcomes, satisfaction, and willingness to share decision-making responsibility; determination of changes in physician efficiency, satisfaction, and willingness to share decision-making responsibility; and studies of methods to increase access to computer-based information for patients with low computer and print literacy, which assess process and outcomes measures. This literature review will discuss use of the Internet by doctors and patients, doctor-patient communication, and methods used to study these issues.

Doctors’ Familiarity with the Internet

Doctors in the past have been latecomers to the incorporation of computers and the Internet into their practices and lives. According to an AMA survey (2000), 37% of physicians are using the Internet, up from 20% in 1997. Dixon (2000), using a new survey instrument, evaluated Canadian doctors in primary care on their information technology usage and devised specific adoption strategies for each cohort. The underlying theoretical model was an adaptation of Davis’ (1989) Technology Acceptance Model, and was named ITAM (Information Technology Adoption Model). It
incorporated physicians’ finesse (defined as the ability and willingness to transfer knowledge and skills from one task to another), knowledge (a proxy for the breadth and depth of knowledge), perceived usefulness (the perceptions of the individual about the innovation), and perceived ease of use (the individual’s perception about how easy the innovation is to learn and use.) There was a return rate of the surveys of 54% and there was no significant difference between the demographics of the responders and the non-responders. All of the attitudes and behaviors identified were successful in identifying low, intermediate and high users of IT, including usage of IT, intent to use IT, interest in using IT, perceptions regarding the usefulness and ease of use of IT, and finesse and knowledge. The conclusion of the paper is that physicians with low finesse and low perceptions of ease of use might benefit from implementation techniques designed to change finesse and attitudes, whereas training and hardware might benefit those at the more advanced stage. The relevance of this to the current proposal is that one could stratify MDs into groups more or less comfortable with the Internet, and determine whether the groups are more or less receptive to patients’ use of Internet materials.

There is mostly anecdotal evidence that MDs are uncomfortable with patients’ use of Internet material. One study, quoted by Noel Schactman (Apr. 2000) from the Forrester Report, shows that 72% of doctors stated that they would not respond to patients’ emails, and another 19% said that they would do so only if compensated. As for informational websites, one doctor is quoted, “Doctors are negatively impacted by these sites because they waste doctors’ time. Patients come in armed with printouts and say, ‘Take a look at this.’ Often it’s snake oil. Or the correct diagnosis of something they don’t have.” Another said, “It’s another thing to worry about at a time when we don’t
need one more thing.” This study is difficult to evaluate, primarily because it cannot be easily accessed. But it is suspect for another reason as well. The quotes from it are exaggerated in their tone, as if the site has a vested interest. Without access to information on their study design, these quotes must be interpreted with caution.

Deloitte & Touche (2000) did a larger study, in which a representative sample of 1200 physicians was drawn from the American Medical Association physician database, the most comprehensive database of physicians in the US today. This sample was surveyed using in-depth telephone interviews. The respondents were stratified by their level of interest in using the Internet. The groups consisted of “All”, “Online MDs” (i.e., those who had accessed the Internet at least once during the past year, 90% of total), “Daily User MDs” (i.e., those who accessed at least once a day for any reason, 55% of total), and “Professional User MDs” (i.e., 75% of online time was for professional reasons, 24% of total). A minimum of 60% of all of these users searched medical databases. 54% of “all” users agreed that, “It’s a good thing when patients bring the results of net searches with them.” The doctors in this study appear to use the Internet much more than doctors in other studies, and they appear to be more positive toward the use of the Internet by patients. The study appears well designed and to offer valuable data. However, there is no discussion of the characteristics of the group who refused study, so the study may be flawed on the basis of an incomplete or skewed sample.

**Patients’ Use of the Internet**

55% of the American public with Internet access (52 million people) have used the Web to get health or medical information, (Pew Research Center, 2001). Of those,
92% said the information was useful, and 81% learned something new. According to this study, most people who search the Web for medical information are searching to find out about a specific diagnosis (rather than for exercise or wellness sites), and more search after a doctor’s visit than before, though a user is more likely to search afterward on behalf of a relative, and more likely to search before the visit for him- or herself. This suggests that the user may not be satisfied with the quantity of information given by the doctor, or perhaps with the three-way communication between the family member, the doctor and the Internet user.

Potts (2002) surveyed doctors with respect to their patients’ use of the Internet, and the effects of their searching on their health care and health. In this study, the overwhelming fact is that most doctors didn’t know how many of their patients were accessing web material (the general estimate was 1-2%), and many (nearly half) did not have an opinion on whether the web was harmful or helpful. Of those who had an opinion, 40% saw benefit from the information, and 8% saw actual harm. Examples of harm were late diagnoses of cancer, and drug interactions or overdoses from web purchases (the prime example was misuse of Viagra.)

**Doctor-Patient Communications**

Communication between doctor and patient is the essence of a successful visit. It is thought that the “best” doctor-patient relationship is one in which the patient and the doctor are both seen as contributing to a good outcome (Canavan 2001). In communications parlance, this is a “negotiated relationship” although there are a number of ways to think about the doctor-patient relationship.
Stewart & Roter re-classified the three models of the doctor-patient relationship to four: paternalistic (equivalent to active-passive), mutuality (corresponding to mutual participation), default (corresponding more loosely to something between the active-passive and cooperation-guidance) and consumerist. The consumerist perspective acknowledges the fact that patients increasingly have a choice and means to object or complain if dissatisfied - this may be professionally or, increasingly, through litigation (suing the doctor)… The most recent models reflect the growing consumer orientation of health care, with patients being viewed as having rights to fair and considerate treatment, to information and to consideration of their needs. The principle motive for these models has come in the form of clinical audit and the use of patient satisfaction measures. To evaluate outcomes by looking beyond the limited endpoints of cure and morbidity rates has been the major shift in perspective of the last decade of the 20th Century. (University of Hong Kong, 1999).

We have been party to an evolution that has seen the archetypal ‘doctor’ shifted from being a figure of absolute authority to becoming a trusted and valuable advisor and ‘scientific director’ as we, the patients, manage a multi-faceted illness ourselves. To my mind this evolution is productive, sometimes even inspiring. To conclude, my experience has been that the ideal Doctor patient relationship is a collaborative one. As in any relationship, the first step for a patient is to find the right Doctor to meet their needs. For the relationship to be fruitful both patient and Doctor have a role to play. The particular nature of each relationship will be negotiated between the individuals concerned, probably with subtle negotiations around ‘power’ and ‘authority’ (Canavan, 2001.)

How doctors communicate regarding patients’ Internet information is not yet known. The authors of several articles saw opportunities in these interactions. Curley (2001) states that there are opportunities lost when a doctor is defensive about Internet information. First is the opportunity to develop a dialogue with the patient. Second is the opportunity to direct the patient’s information-seeking. Third, and perhaps most important, is the chance to assess the quality of the information. But, according to Pemberton (1978), it is also important to have a strategy for dealing with the Internet, e.g., to get the patient to email a summary before visiting: “Try to react in a positive manner to information from the Internet. Accept patient and family contributions as part
of the management team. Accept that they may have valid information that you have not
come across. Don't be dismissive or paternalistic, or derogatory of comments made by
others on the Internet, or refuse to accept Internet material, or try to one-up your patients
and their families regarding the information” (594).

Some doctors have taken the opportunity to provide patients with good
information by setting up a website or providing a list of links for the patients to visit.
One doctor describes patients as falling along an information continuum. On one end is
someone who has no medical understanding at all. At the other is a person who is an
expert searcher (and that may be someone with a chronic illness who has done a lot of
work with it.) “People in the lower range, the passive medical consumer you treat as you
treated patients before; people in the middle range, you educate; people in the upper
range, you treat as a colleague” (Stephens, 1999, 42, 38).

Kaplan et al. (1996) surveyed 7730 outpatients in 300 internal medicine and
family medicine practices. Patients were asked questions at the end of each visit to find
out to what degree the practitioner had a “participatory decision-making style.” Patients
whose physicians were in the last quartile of the survey (least participatory) lost patients
at double the rate of those in the first quartile, and it is known from other studies that the
patients of non-participatory physicians do not do as well (in maintaining their blood
sugar levels (Greenfield, 1988), (Rost KM et al., 1991), controlling their arthritis (Kaplan
et al., 1993), controlling their blood pressure (Kaplan et al., 1989), or curing their peptic
ulcers (Greenfield et al., 1985)) as those patients who feel part of the decision making
process. It is the thesis of this paper that doctors who have a participatory decision-
making style and who have more familiarity with the uses of the computer will find it
easier to integrate Internet information brought in by the patient.

**Methods Used in Previous Studies**

The methodologies to evaluate this question have been those used to evaluate
other aspects of the doctor-patient relationship. It is sometimes difficult to get good
information, because this relationship, like many other human relationships, is carried out
in privacy and in confidentiality. In an attempt to survey dentists’ attitudes, Hazelkorn
(1996) used actors to simulate patients. This study used actors with actual dental
pathology to evaluate the behavior of dentists without the dentists’ knowledge. The topic
being studied was whether a dentist would treat a patient differently if he thought the
person was homosexual vs. heterosexual vs. a drug user. After the actor had left the
office, the investigator interviewed the dentist, and revealed the study. “Of the
approximately 400 [dentists], only six became upset when they learned that they were
uninformed subjects.” This study received approval from the IRB of the university, as
well as from the Director of the Office for Protection from Research Risks of the US
Dept. of Health and Human Services because “it was considered a survey, no treatments
were provided, the patients were not harmed, the subjects were debriefed, they were paid
for their services, and their anonymity was assured.” (p. 128)

Hazelkorn states that it is difficult to get accurate information about providers’
behaviors from a survey or an interview, especially if the information sought was of an
emotional or difficult nature. Survey data also may be biased due to failure of study
participants to remember, to the desire to say what the interviewer wishes, or to the desire
to appear more competent than they are. The idea of trained observers might be an ideal way to gather information in cases in which the subjects might act differently if they knew they were being evaluated, but it seems offensive to use subterfuge to collect information on people who might feel they “ought” to act a certain way. In spite of approval by two IRBs, the procedure still seems ethically questionable.

**Summary**

There seems to be little information in the literature relating a doctor’s participatory style to the transmission of information to the patient, and little relating his or her style to computer use. There are a small number of descriptive essays – what might be called “anecdotal evidence” in this area, as well as a number of flawed, or limited studies, but few right on target, which means that this should be a fertile field for future investigation. Survey information is difficult to evaluate because of recall inefficiency. Ideally, an observational interview would provide the most information, but such a process is fraught with logistical and ethical issues.
METHODS

The question to be examined in this paper is whether doctors and patients have a different relationship if the patient brings in information to the office visit. Does the communication style of the doctor alter the information gathering of the patient? Does information gathering by the patient alter the doctor’s communication style? Is there a difference between doctors who do and do not include the patients in the decision-making process or between patients who are and are not computer-literate in information transfer?

The doctors in this survey were chosen primarily for their willingness to participate in the project. There were seven doctors in Richmond, VA, all primary care providers, enrolled via personal contact. There were also five primary care providers, including one nurse practitioner, located at the University of North Carolina Student Health. All but one of the doctors were general internists or family practitioners; the other one was a pediatrician. The providers all filled out a questionnaire regarding their use of computers and the Internet, as well as their feelings about patients’ use of the Internet for medical purposes. The consent forms and questionnaires are attached (see Appendix A). Each practitioner also agreed to allow his or her patients to be interviewed.

Approximately a day was spent in each office, although very often patients of multiple doctors in each office were interviewed on the same day. The patient consent form and interview schedule are attached (see Appendix B.) Most patients were seen
prior to the doctor’s visit (in the examining room); some were seen by the doctor first, and those too sick, or unwilling to be seen, were not interviewed. The patients of the pediatrician were interviewed in the waiting room, which worked well because his practice was relatively new, and few patients were in the waiting room at one time. The nurse for each doctor acted as triage, and would direct the interviewer to the next patient. An attempt was made to see all the possible patients in the office at a given time, without selection, but this was not always feasible if patients of multiple doctors were being seen. Each patient was identified by a code number and by the doctor he or she saw. In the case of the pediatrician, the parent(s) of the patient were interviewed.

The difficulties with this method are that even if the doctor was enlisted, the nurse might not be, and one nurse in particular perceived the study to be disruptive; she tried to terminate it prematurely. It also may be a great imposition on the doctor’s time, and a hindrance in the smooth running of the office. Some patients felt that it was an imposition, and if a person were ill, or his or her child were ill, no attempt was made to perform an interview. Altogether 113 patients were interviewed, 80 from the community practices, and 33 from Student Health.

SPSS 11 was used to evaluate the data.* When it became clear that there were essentially two different study populations (the Community practices and the Student Health practices), evaluation of each was done separately when appropriate.

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* Assistance from Catherine Zimmer, PhD, of the Odum Institute, is gratefully acknowledged.
RESULTS

The results are organized into three sections. Section 1 will present doctor responses to the questionnaire (see Appendix A for a basic tally of responses), Section 2 will present patient responses to the interview (see Appendix B for a basic tally of responses), and Section 3 will present the effects noted on the doctor-patient relationship.

Section 1: Doctor Responses

Demographics – Doctors

There were no African-American or Asian doctors in this group; there were proportionately more women among the Student Health doctors, but not significantly so.

*Table 1. Breakdown by Gender of Doctors in the Two Practices*

<table>
<thead>
<tr>
<th></th>
<th>Community Doctors</th>
<th>Student Health</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>6</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Female</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>7</strong></td>
<td><strong>5</strong></td>
<td><strong>12</strong></td>
</tr>
</tbody>
</table>

The doctors varied widely in their use of computers (see Table 2). Six of the 12 used a computer more than 10 times per day, whereas 2 “never” used it.

*Table 2. Computer Use by Doctors*

<table>
<thead>
<tr>
<th>Computer Use</th>
<th>Number of “yes” responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>I use it more than 10 times a day.</td>
<td>6</td>
</tr>
<tr>
<td>I use it every day, but less than 10 times.</td>
<td>2</td>
</tr>
</tbody>
</table>
I use it more than once a week, but less than once a day. 1
I use it less than once a week. 1
I never use it. 2

The two most common uses were for personal email (9 of the 12) and for contacting the lab for patient information (8 of the 12.) None played games or had mounted a web page, and only one used it for finances.

Table 3. Uses Made of Computers by Doctors

<table>
<thead>
<tr>
<th>Activity</th>
<th>Number of “yes” responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Check personal email.</td>
<td>9</td>
</tr>
<tr>
<td>Read the news.</td>
<td>7</td>
</tr>
<tr>
<td>Play games.</td>
<td>0</td>
</tr>
<tr>
<td>Surf the web.</td>
<td>5</td>
</tr>
<tr>
<td>Shop.</td>
<td>6</td>
</tr>
<tr>
<td>Use the stock market (finances).</td>
<td>1</td>
</tr>
<tr>
<td>Contact the hospital or lab for patient information.</td>
<td>8</td>
</tr>
<tr>
<td>Get discharge summaries.</td>
<td>7</td>
</tr>
<tr>
<td>Send or receive consults.</td>
<td>3</td>
</tr>
<tr>
<td>Check email from patients.</td>
<td>6</td>
</tr>
<tr>
<td>Perform medical searches for diagnostic problems.</td>
<td>7</td>
</tr>
<tr>
<td>Search for patient handouts for specific conditions.</td>
<td>7</td>
</tr>
<tr>
<td>My office has a web page for communication with patients.</td>
<td>5</td>
</tr>
<tr>
<td>I myself have mounted a web page.</td>
<td>0</td>
</tr>
</tbody>
</table>

The use of the computer by doctors, both at home and at work, varied by the practice type, that is, Student Health vs. Community doctors. Each doctor was asked whether he or she ever did a number of tasks on the computer, e.g. check personal or patient email, read the news, play games, surf the web, get patient discharge summaries and so on. Each of these answers was a yes-or-no, and the sum of the answers was tabulated. There were 14 possible positive answers; the actual number of positive responses ranged from 0 to 11. Comparison between that figure and whether or not a
doctor was in the Community group or in the Student Health group revealed no
significant difference.

**Doctors’ Use of Computers in their Medical Practice**

Seven of the 12 doctors searched for medical information for diagnostic problems
on the Internet, and the same 7 also searched for patient handouts on the web. Only the
Student Health doctors had a web page for patient use.

Only the use of personal email by the doctor ($\chi^2 = 5.600 \text{ with } 1 \text{ df and } p < 0.05$)
and the use of the computer for news/weather/sports ($\chi^2 = 5.182 \text{ with } 1 \text{ df and } p< 0.05$)
were significantly related to whether the doctor searched for medical literature or gave
handouts to patients. However, there was no significant difference between the sexes or
in the year of graduation from medical school in the use of handouts or medical searching.

Two doctors used their computers in other ways than were choices on the
questionnaire, one for generating “information prescriptions” to instruct the patient what
to look up on their website, the other to do multi-office scheduling. One doctor was very
positive about the use of computers in doctor-patient communications. He said, “It is an
increasingly important mode of information gathering and communication. MDs need to
embrace it -- help provide sites, information of legitimate use to themselves and their
patients.” Others were more cautious. “It mainly depends on the source -- there are
many unreliable or even dangerous web sites out there – for example, those promoting
anorexia and bulimia.” Others felt, like the patients, that, “The more patients know,
the better in general. However, the validity and usefulness of information is variable.”

A doctor’s feelings about the patients’ use of the Internet were estimated by his or
her choice of answers to the question, “How do you feel about Internet information brought in by patients?” The doctor could choose multiple possibilities. Nine of 12 doctors chose, “It’s helpful to know what the patients are thinking about,” and, “Sometimes I learn things from it,” and 7 chose, “It is a good teaching tool.” It is noteworthy that no doctor in this group chose either of the first two options, “In my opinion, it is a waste of everybody’s time”, or, “It can be very time consuming with little to be gained.”

**Section 2: Patient Responses**

**Demographics -- Patients**

The study sample consisted of 113 patients, 80 from the community practices, and 33 from Student Health. In the aggregate there were 99 whites, 10 African-Americans, and 4 Asians and others (see Table 4). The racial breakdown by practice type shows that 85% of the community doctors’ patients were white, whereas 95% of the Student Health patients were white. Breakdown by gender reveals 61% female, 39% male, in both groups, which is very close to the national average for doctor’s visits (59% of office visits nationally are by females, according to the U.S. Department of Health and Human Services, 1999). The age breakdown between the two groups, however, is markedly different, as one would expect, with a near normal distribution of ages in the Community group (median age = 51.6 years, s.d. = 18.7), but nearly all the Student Health group in their teens and twenties. When the single outlier is removed from the Student Health group (age = 52), the median age of Student Health patients is 22 years, s.d. = 2.8.
Table 4. Gender and Racial Breakdown of the Two Practices

<table>
<thead>
<tr>
<th>Gender</th>
<th>Race</th>
<th>Community Practice</th>
<th>Student Health</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>White</td>
<td>41</td>
<td>17</td>
<td>58</td>
</tr>
<tr>
<td></td>
<td>African-American</td>
<td>6</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>3</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>50</td>
<td>19</td>
<td>69</td>
</tr>
<tr>
<td>Male</td>
<td>White</td>
<td>27</td>
<td>14</td>
<td>41</td>
</tr>
<tr>
<td></td>
<td>African-American</td>
<td>2</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>1</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>30</td>
<td>14</td>
<td>44</td>
</tr>
</tbody>
</table>

A slightly larger percentage of Student Health patients brought information to the doctor than did the Community patients, but this difference was not statistically significant. Thirty-three of the Community patients (41%) brought information in; 47 (59%) did not. Seventeen (51%) of the Student Health patients brought information in; 16 (49%) did not.

The breakdown by type of work is shown in Figure 1. All the Student Health patients were students except one, who was a spouse. In the Community group, the two largest occupational groups were executives and white collar workers, with those who did not work, stayed home (with children), or were retired adding up to a larger group than any other. These patients were drawn from a fairly affluent section of Richmond, VA; many wives with advanced degrees stayed home with their children.
Figure 1. Breakdown of patients by type of work and type of practice

Educational level was as expected, given how the practices were selected (see Table 5). Only one of those whose educational level was known had less than a high school education, and there was a remarkable number with advanced degrees in the Community group. One-third of the Student Health group were graduate students, and one was a post-doc. This is similar to the mix found in the general UNC population.
Table 5. Education Level of Patients

<table>
<thead>
<tr>
<th></th>
<th>Community Practice</th>
<th>Student Health</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unknown</td>
<td>20</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>&lt;HS</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>HS</td>
<td>12</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Some college</td>
<td>19</td>
<td>21</td>
<td>40</td>
</tr>
<tr>
<td>College grad</td>
<td>15</td>
<td>11</td>
<td>26</td>
</tr>
<tr>
<td>Postgrad</td>
<td>13</td>
<td>1</td>
<td>14</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>80</strong></td>
<td><strong>33</strong></td>
<td><strong>113</strong></td>
</tr>
</tbody>
</table>

A new variable, “inclusion”, was derived for the purposes of analysis by combining the values of the patient answers to the following questions: “If there were a choice between treatments, would this doctor ask you to help make the decision?” and “How often does this doctor make an effort to give you some control over your treatment?” This combination was felt to represent the patient’s feeling of the “inclusiveness” or the “patient-centeredness” of the doctor.

The values of the patients’ answers to each of the “inclusion” questions could range from 0 to 5. Thus the numeric value of “inclusion” could range from 0 to 10. Patients in the community practice group averaged 7.0 (s.d. = 3.29), and patients in the Student Health group averaged 8.4 (s.d. = 1.39), a statistically significant difference (F = 5.216, with 1 df, p = .024). If the patients were “included,” their doctors were more likely to search for information (F = 2.097, with 9 df and p = .036) or to give medical handouts F = 2.097, with 9 df and p = .036.) “Inclusion” is not at all related to the patient’s type of employment, except that it is related to the various categories of non-employment (i.e. retired, stay-at-home, student, unemployed) (F = 4.913, with 3 df, and p = 0.004).
There was no significant relationship between the gender of the patient and whether their doctors searched for medical information ($\chi^2 = 2.109$ with 1 df, $p = 0.146$).

There were no statistically significant relationships between the doctor’s choice of statement about his or her feelings about the patient’s use of the Internet and his or her “inclusion” of the patient in decision-making.

**Patients’ Use of Computers**

Most (84%) of the patients had access to the computer at home. Patients were questioned on the hours they spent per month using the computer, and these data were also grouped into categories. The overall median was 45 hours per month, with the intraquartile range being 16 to 120 hours per month. More than half (58%) of the Community patients used the computer 30 hours per month or less, with the largest single category being those who “never” used the computer (24%). Only 5% used the computer more than 180 hours per month. The median number of hours for the Community patients was 30 hours per month, with the intraquartile range being 1.5 to 93.75 hours per month. The Student Health patients spent significantly more time on the computer, with 12% using it more than 180 hours per month. The median number of hours for the Student Health patients was 75, with an intraquartile range of 45 to 155 hours per month. The statistical significance of the difference between groups cannot be specified, but it is notable that the median number of hours of use of the Student Health patients was 250% of the hours of use by the Community patients.

**Medical Computer Use by Patients**
The majority of the study sample had done Internet searches for health information, either for themselves or someone else (see Table 6). There are statistically significant differences between the groups in Table 6 as well, in the amount of searching done for medical information for oneself and others ($\chi^2 = 16.595$, with 2 df, $p< 0.01$).

**Table 6. Medical searching for self or others by type of practice**

<table>
<thead>
<tr>
<th></th>
<th>Community Practice</th>
<th>Student Health</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neither</td>
<td>39</td>
<td>3</td>
<td>42</td>
</tr>
<tr>
<td>Either self or others</td>
<td>26</td>
<td>16</td>
<td>42</td>
</tr>
<tr>
<td>Both</td>
<td>15</td>
<td>14</td>
<td>29</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>80</strong></td>
<td><strong>33</strong></td>
<td><strong>113</strong></td>
</tr>
</tbody>
</table>

Thirty-nine people (49%) among the Community group did not search at all, as one might expect from their relatively low usage of computers. Only 15 (19%) searched for both themselves and others. In the Student Health group, only 3 (9%) did not search for medical information, whereas 14 (42%) searched for information both for themselves and others.

Medical searching by the patient is highly associated with shopping online ($\chi^2 = 28.020$ with 2 df, $p < 0.001$), getting news, weather, or sports online ($\chi^2 = 28.770$, with 2 df, $p < 0.001$), making financial transactions online ($\chi^2 = 16.874$ with 2 df, $p < 0.001$), surfing ($\chi^2 = 0.808$ with 1 df and $p = 0.369$) and using email ($\chi^2 = 36.393$ with 2 df, $p < 0.001$). Putting up a personal web page is also related, but not quite as strongly ($\chi^2 = 10.022$ with 2 df, $p < 0.01$). Age is negatively associated with hours of time on the computer ($\chi^2 = 81.393$ with 49 df, $p < 0.01$). The action of searching for medical
information by the patient is highly associated with the amount of time the patient spends on the computer each month (F = 3.000, with 19 df, p < 0.001).

According to the Pew Research Center (2000), 55% of the American public with Internet access (52 million people) have used the Web to get health or medical information. In this study, 61% of the Community patients who had access to a home computer (a group who are probably more similar to the American public than the university students are) sought medical information online, whereas 90% of the Student Health group searched for medical information online. Conducting Internet searches for health information was associated with the presence of a computer in the patient’s home ($\chi^2 = 19.561$, with 2 df, p < 0.001).

What kinds of patients brought in information to their doctors? Fifty patients of the total 113 brought information to their doctors. There is no significant difference between those who did bring in information and those who did not in age (p = 0.906), educational level (p = 0.160), amount of time they spent on the computer (p = 0.660), whether they have ever done medical searching (p = 0.701), or other activities on the computer such as following news, weather or sports (p = 0.293); finances (p = 0.606), shopping (p = 0.835), surfing (p = 0.369) or music online (p = 0.628). No demographic data predicts whether patients bring in information or not. But bringing in information is associated with the degree of “inclusion” that the patient experiences ($\chi^2 = 19.178$, with 9 df and p< 0.05). “Inclusion”, as described earlier, is a derived value comprised of the patient’s assessment of how and whether the doctor and the patient make decisions together about the patient’s medical care.
Section 3: Effects on the Doctor-Patient Relationship

What effect did the information brought in have on the encounter with the doctor? The answers to the question of whether the patient’s treatment changed with the addition of his or her information were assigned by the researcher into one of four categories: “No answer,” “No,” “Yes,” or “No, but I felt better.” Most patients fell into the category of feeling reassured or understanding more about the treatment that the doctor gave, and those who felt included in the medical process were also significantly more likely to be satisfied with the doctor’s response to their bringing information ($\chi^2 = 53.967$ with 27 df and $p< 0.01$). Those who had no answer were those who did not bring information to the encounter.
Figure 2. Patients who felt their treatment was changed by bringing in information to the doctor

Regarding information found on the Internet or in other sources, most people agreed with this 19-year-old student: “It was helpful, but not as helpful as talking to the doctor. It helps better to get information from the person who knows you – you can ask questions.” Many people expressed some suspicion of the information they found, like this 22-year-old student: “I was researching pneumonia that I had -- it was helpful. But anyone can put things on the net.” A 28-year-old male systems analyst concurred: “I’m leery of websites. Have to take them with a grain of salt.” Another 21-year-old UVA student expressed dissatisfaction: “Dissatisfied, confused. WebMD does not have satisfactory answers.”

A 52-year-old student noted the lack of context. “It varies --sometimes I can't find the information I want. The quality varies. You can come up with massive numbers of articles with no discussion of what they are.” Others expressed a lack of satisfaction
with its convenience like this 32-year-old operations manager: “I haven’t really been satisfied – it takes too long to find the information.” A 45-year-old auto mechanic made an interesting remark about the adversarial posture of some of the sites: “I was 50% satisfied. You have to take it with a grain of salt. Some sites you can’t trust. Often it is the alternative view vs. the AMA.”

Several patients had found the information to be very positive. One 53-year-old man with Crohn’s disease who found disease specific sites and support groups felt that it was a lifesaver. He frequently brought in information he found to his gastroenterologist rather than to his primary doctor. Other positive comments included those of a 33-year-old website builder: “I was extremely pleased. It answered a lot of questions; I researched drugs.” He added a caveat, though. “You must keep the sources in mind.” It is also notable that he did not bring any information to his doctor.

Of the sixty-five patients who commented on their search for medical information, 30 were positive or very positive, and 45 were hesitant, equivocal or downright negative. In general the positive comments were much less detailed (often just one word answers) than the negative ones.

All 50 of the patients who brought in information brought it “in their heads” rather than by a printout or a magazine article. They brought it in via questions which presumably could be couched more tentatively than hard copy might have been. It was a surprise to find how many people felt that it was presumptuous or insulting to bring questions to the doctor. Some did not want to take part in the decision-making process, like this 74-year-old retired secretary who felt that “she wants the doctor to make decisions for her.” She also said that “she doesn’t see why people should need to ask, if
they trust their doctor.” Another 70-year-old retired clerk said, “I like to talk face to face with the doctor; I don't read books, I let the doctor tell me.” A 21 year old firefighter said, regarding bringing information to the doctor: “Interesting thought, but I don't know how it would be acted on, since you come to them (MDs) for advice, they don't come to you for advice.” One 23-year-old student said, “I'm a little hesitant to talk about information from the web -- it may be disrespectful or annoy the doctor -- it undermines his authority.” This somewhat traditional attitude appears to be still very common, and not only among the older generation.

However, some of the patients had less positive feelings about their communications with doctors. For example, a 45-year-old auto mechanic said, “I'm dissatisfied with communication with doctors in general. I wait for hours, then have 5 minutes of time to marshal my thoughts and ask all my questions.” A 43-year-old childcare teacher said, “I would bring information to the doctor frequently. I am skeptical -- if what you're saying doesn't make sense, I won't do it.” A 25-year-old UNC student reflects what many doctors think, that “for most people, [Internet information is] probably helpful; for a segment, it will cause hypochondria.” Another patient concurred with the possibly confusing and upsetting effect of finding dubious Internet information: “It’s a mixed blessing -- it depends on how used you are to the Internet. You must approach it with a critical eye. I would hate to think of my grandmother looking for information.”
DISCUSSION AND CONCLUSIONS

The question to be examined in this paper is whether doctors and patients have a different relationship if the patient brings in information to the office visit. Does the communication style of the doctor alter the information gathering of the patient? Does information gathering by the patient alter the doctor’s communication style? Is there a difference in information transfer between doctors who are and are not “patient-centered”, or between patients who are and are not computer-literate?

Some of these questions turn out not to be answerable given the numbers and selection of the research subjects. The question of whether information searching changed relationships with doctors or the other way around cannot be answered. My feeling is that the receptive mode of the doctor is the more important factor, both because I think, in general, that patients reflect what their doctors allow, and also because the surprising finding of protectiveness for doctors among some patients suggests that patients may be reluctant to bring in information if they feel the doctor won’t be receptive. Protectiveness on the part of patients may simply be a remnant of the uncommunicative old days in medicine, when a doctor had to request that the name of a drug be put on the prescription bottle, but it also may represent one element of a relationship in flux.

In this study it was shown that searching for medical information by patients is highly related to their computer use. Thus it seems probable, as the American population continues to use computers for more and more purposes, that medical searching will become more frequent as well. However, neither patients nor doctors are particularly
comfortable with this impending change. Patients are often as suspicious of searching for web information as the doctors are. Many don’t have faith in their ability to choose sites properly and efficiently. The doctors are gradually embracing this new mode of information delivery; the doctor who hands out “information prescriptions” is in the vanguard, because to do that implies that she has a reliable place to send her patients for further information, whether it be a web page, or a community health librarian. It is also to be commended that many doctors used information brought in by their patients as a teaching tool, to explain more about the condition or the treatment. This seems to me to be the ideal use of information brought in by the patient. A few doctors used that information to learn more themselves, which is also commendable.

The positive benefits of the Internet in finding medical information for patients was marked in a few cases, particularly for one who found support groups for his condition to be “lifesaving”. It may be that searching for information is more frequent for patients who have chronic disease, because typically those people can’t get the desired depth of information on their conditions from a series of office visits. The people who seemed most happy with their Internet information were those who had diseases such as diabetes, Crohn’s disease, a child with Praeder-Willi syndrome (a genetic condition associated with severe obesity and mental retardation), and a brother with schizophrenia.

A problem with this study is that the doctors selected may have been from a biased group. These doctors, perhaps more than many, were willing to undergo questioning about their use of computers and their relationships with their patients. These doctors may also be more likely to be computer literate and more concerned with
patient communication than others. The providers were all primary care specialists, and these groups may place more emphasis on patient teaching than do other specialists. Perhaps it is a result of the possibly biased group of doctors that no one expressed any feeling of being threatened by the information coming into their offices. Or it may be that many, or even most, patients present the information in such a way that the doctor is protected from a feeling of intimidation.

Several assumptions were made in this study. For example, it is assumed that choosing to search the web and choosing to give handouts to patients marks better patient relations than not. It is of note that all doctors who searched the web gave out handouts and vice versa. Also, it was assumed that shared decision-making and some control over the choice of treatment, aggregated herein as the variable “inclusion”, by the patient were qualities suggestive of a more positive communication style on the part of the doctor. And it has been shown above that those doctors whose patients felt included were significantly more likely to get information and questions from the patients.

In summary, this study has illuminated several aspects of the doctor-patient relationship in the new Information Age. Some patients are reluctant to bring in information because of a perceived threat to the doctor’s authority and self-esteem. Even though this study did not confirm that perception, other studies have suggested that it may be a problem in some instances. Some people are suspicious of both the doctor’s information and information from other sources, and it appears to me that these people might benefit more than others if the doctor used the Internet information as a teaching tool. It seems clear that in the future the use of Internet information will become a larger part of the practice of medicine, and that both doctors and patients are in need of safe,
authoritative, and user-friendly sites on which to find accurate information. The “information prescription” to a known source used by one of the doctors in this study might solve the needs of both of these groups.
References


Appendix A

Cover Letter for Doctor-Participants

What this is:
This is a survey of practicing physicians about their comfort and familiarity with the Internet and how much they use it in their work life.

Who I am:
I am a Master’s student at the UNC School of Information and Library Science, and I am a retired MD. I’m interested in exploring if and how a patient’s use of Internet information alters the doctor-patient interaction. Dr. Barbara Wildemuth will supervise this project.

Why you should do this:
It’s an interesting topic, not very time-consuming, and it is to be hoped that the project will further our state of knowledge about this subject.

Other facets:
I’m interested not only in people who use the Internet all the time, but also those who are a little nervous about it (the Luddites among us.)
I’m also interested in your patients. With your permission, I want to administer a very brief questionnaire to them, about their use (or their family’s use) of medical information on the Net, and also about the decision-making style that they, and you, have developed.
My plan is that I would spend half a day at the office interviewing patients either as they finish up, or while they are waiting to be seen. I plan to question five patients from each doctor who are Internet users, and five who are not.
The UNC Institutional Review Board has approved these questionnaires.

References:
If you want personal references about me, or if you are interested in the journal articles that support this research, let me know.
Thank you for your time.

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Barbara Wildemuth, PhD
wildemuth@ils.unc.edu
919-962-8072

Questions for Physicians (Total 12 Doctors)
(Please circle the appropriate answer, and make any additional comments at the end.)
I consent to participate in this survey on the subject of “Internet Information in the Doctor-Patient Relationship”, and to allow my patients to take part in the interviews as well. I understand that this study is entirely voluntary, and the information will be kept completely confidential.

(Signature and date)

How comfortable are you using the computer?  

I use it more than 10 times a day. 6
I use it every day, but less than 10 times. 2
I use it more than once a week, but less than once a day. 1
I use it less than once a week. 1
I never use it. 2

What do you use the computer for?  Circle all that apply.

Check personal email. 9
Read the news. 7
Play games. 0
Surf the web. 5
Shop. 6
Use the stock market (finances) 1
Contact the hospital or lab for patient information. 8
Get discharge summaries. 7
Send or receive consults. 3
Check email from patients. 6
Perform medical searches for diagnostic problems. 7
Search for patient handouts for specific conditions. 7
My office has a web page for communication with patients. 5
I myself have mounted a web page. 0
Other. 2

Have patients ever approached you with information that they got from the Internet?

No, it’s never happened. (Skip to the end.) 0
Yes, but only once or twice. 0
Yes, it has happened as often as once a month. 7
Yes, it happens nearly every week. 5

How do you feel about Internet information brought in by patients? (Choose as many as seem appropriate.)

In my opinion, it’s a waste of everybody’s time. 0
It can be very time-consuming with little to be gained. 0
It’s so easy for them to get the wrong information, and it’s hard to reverse the misconceptions. 4
It’s helpful to know what the patients are thinking about. 9
It is a good teaching tool. 7
Sometimes I learn things from it. 9
It all depends on which patients are bringing the information in. 5

Any comments on your experience with patients and the Internet? (Please use the back if necessary.)

Demographics
Year of graduation from medical school. (Range 1971-1997)
Do you have a home computer (for yourself)? 9
Gender M or F (9M, 3F; Table 1, p. 12)
Appendix B
Consent Form for Patients

Introduction to the Study:
• We are inviting you to be in a research study of how people use the Internet to find information about their health, and whether finding this information changes their relationship with their doctors.
• Dr. Cynthia Merrill of the University of North Carolina at Chapel Hill is doing this study. Dr. Barbara Wildemuth will be supervising the project.
• We hope to find out from the study how the Internet has changed the use of medical care.

What Will Happen During the Study:
What will happen is that you will be asked a few questions about your use of computers and how you and your doctor make decisions.

Your Privacy is Important:
• We will make every effort to protect your privacy.
• We will not use your name in any of the information we get from this study or in any of the research reports.

Risks and Discomforts:
• We do not know of any personal risk or discomfort you will have from being in this study.

Your Rights:
• You decide on your own whether or not you want to be in this study.

Institutional Review Board Approval:
• The Academic Affairs Institutional Review Board (AA-IRB) of the University of North Carolina at Chapel Hill has approved this study.
• If you have any concerns about your rights in this study you may contact the Chair of the AA-IRB, Barbara Davis Goldman, Ph.D., at CB# 4100, 201 Bynum Hall, UNC-CH, Chapel Hill, NC 27599-4100, (919) 962-7761 email: aa-irb@unc.edu.

Summary:
• I understand this is a research study to see what difference the use of the Internet might make in the relationship between my doctor and me.
• I will be asked some questions about this.
• I can refuse to be in the study for any reason.

I have had the chance to ask any questions I have about this study, and they have been answered for me.
I have read the information in this consent form, and I agree to be in the study. There are two copies of this form. I will keep one copy and return the other to the investigator.
Patient Interview

First, I’m going to ask you some questions about your use of computers.  

Do you have access to a computer?  
At home          95  
At work          46  

How much do you use computers?  
Never.          19  
1-19 hrs/mo.          9  
20-30 hrs/mo.         23  
31-60 hrs/mo.         24  
61-120 hrs/mo.        14  
121-180 hrs/mo.        16  
181-240 hrs/mo.         5  
>240 hrs/mo.          3  

3. What do you use the computer for?  
Check personal email.                                        85  
Read the news, weather or sports      51  
Play games.         38  
Surf the web.         74  
Shop.          60  
Financial information/stock market.      40  
Music.            5  
My office has a web page.       64  
I myself have mounted a web page.      16  
I have searched the Internet for medical information for myself.  58  
I have searched the Internet for information for another person.  42  
I have been pleased with the information I have gotten from the Internet.  
38 patients made comments about their degree of satisfaction.
How comfortable are you using the Internet?

- I use it more than 10 times a day. 22
- I use it every day, but less than 10 times per day. 46
- I use it more than once a week, but less than once a day. 6
- I use it less than once a week. 14
- I never use it. 20

(5 no answer)

Now, I’m going to ask you some questions about making decisions about your medical care.

How do you and your doctor make decisions about your medical care?

If there were a choice between treatments, would this doctor ask you to help make the decision?

- No answer  7
- Definitely no  5
- Probably no  3
- Not sure  12
- Probably yes  27
- Definitely yes  59

How often does this doctor make an effort to give you some control over your treatment?

- No answer  15
- Never  5
- Not very often  5
- Not sure  23
- Usually  19
- Always  46

Have you ever brought in information that you found, either on the Internet or elsewhere, to your doctor?

- Yes = 50
- No = 63

Or, has someone in your family found information for you on the Internet about your health? Who was this? 3 -- parents
How did bringing the information change your treatment, or your feelings about your treatment?

N/A = 46
Yes = 10
No = 17
No but felt better = 40

Any other thoughts or comments?

Now, I’m going to ask you a few questions about yourself.

Approximate age, ethnicity, and gender (observation). (Median 42.0 years, intraquartile range 48.0 years)
Type of employment. (Figure 1, p. 18)
Level of education. (Table 5, p. 18)