Patients Looking for Information on the Internet and Seeking Teleadvice

Motivation, Expectations, and Misconceptions as Expressed in E-mails Sent to Physicians

Gunther Eysenbach, MD; Thomas L. Diepgen, MD, PhD

Objectives: To analyze the motivation, expectations, and misconceptions of patients seeking teleadvice or medical information on the Internet. To explore the possible economics and problems of direct physician-to-patient teleadvice via electronic mails (e-mail).

Design: Exploratory survey of 209 unsolicited e-mails mostly sent to physicians by individuals seeking teleadvice.


Patients: Two hundred nine patients and information-seeking individuals, mainly with dermatologic problems.

Main Outcome Measures: Previous contacts with live physicians, disease duration, level of frustration expressed in the e-mails, and type of information sought.

Results: Many dermatologic patients who request teleadvice have a chronic disease (81%) and seek a second opinion. Seventeen percent express frustration about previous encounters with live physicians. Forty percent of all e-mails could have been answered by a librarian, 28% of all e-mails were suitable to be answered by a physician via e-mail alone, and in 27% of the cases any kind of consultation would not have been possible without seeing the patient. In at least 5 instances patients attempt self-diagnosis.

Conclusions: We found examples for the beneficial effects of the provision of medical information on the World Wide Web but also evidence suggesting that patients are trying to use information on the Internet as a supplement for physicians and that teleadvice might be over-used by chronically ill and frustrated patients looking desperately for additional information. Telemedicine via e-mail could substitute a physician visit or telephone call in some cases, but many principal problems must be solved beforehand.

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The Internet contains a plethora of medical information potentially valuable for consumers and patients, and the impact of the Internet on health promotion and its potential role for preventive medicine (prevention through information) has been widely acknowledged.

Limited information in the literature is available on how and why patients actually use the new information technologies.

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Much has been speculated about the potential positive and negative impact of the Internet on patients, health care, and health promotion, but no case reports or statistical data are available evaluating this question further. In this article we provide some evidence for the potential benefits but also for the dangers of provision of medical information and Internet consultation by analyzing 209 unsolicited e-mails sent by patients (or relatives or friends of patients) to the physicians of a dermatologic hospital and by presenting some cases to illustrate the potential problems.

The phenomenon of unsolicited e-mails sent to physicians raises several interesting questions, for example: Why do patients turn to the Internet to obtain medical information from the World Wide Web (WWW) or send electronic mails (e-mails) to “virtual physicians,” who are per-
METHODS

For more than 3 years the Department of Dermatology at the University Hospital of Erlangen in Erlangen, Germany, has provided a comprehensive information resource on the WWW. The Web site (http://www.derm.med.uni-erlangen.de) consists of some thousands of Web pages and offers lectures and case reports primarily intended for health professionals as well as an electronic dermatology atlas, providing images about approximately 600 dermatologic diagnoses. Most pages are available in English and German. With more than 2000 visitors per day the Web site is equally popular among professionals and patients from all over the world.

The high popularity confronted us with an unexpected problem—although different disclaimers on our Web pages warn patients not to attempt self-diagnosis and actively encourage patients to see their primary care physician or dermatologist when in doubt about their skin condition, rather than to send e-mails to our physicians (who are listed with their e-mail addresses on the department home page), we still received an average of 1 to 2 e-mails per day from patients asking for information, seeking teleadvice, or requesting help.

For this study, all patient e-mails sent unsolicited to physicians of our hospital between April and August 1997 were systematically collected and analyzed. E-mails from physicians and professionals were excluded from analysis, we further excluded all e-mails that were not written in English or German. This particular period was chosen because the contents of our Web site remained unchanged during that time. After August 1997, we included more information for patients on our site that led to a change of the number and contents of patient e-mails.

E-mails were categorized by using checklists containing possible e-mail contents as listed in Table 1 through Table 3.

The decision on who would have been the appropriate person to answer the request was made by a physician on the basis of the type of request—e-mails containing general requests for information or references (books, Web sites) could have been answered by a librarian or a similarly trained nonmedical individual. More difficult requests such as questions regarding latest research results or e-mails containing specific medical questions were categorized as requiring an experienced physician to answer. While, for example, general questions for alternative or new therapies could have been answered without seeing the patient, concrete verbal lay descriptions of skin lesions or e-mails that do not contain enough information to give any safe advice would have required to obtain further anamnestic or laboratory information or to see the patient before giving any medical advice.

As a matter of principle for this study few e-mails were actually answered individually by senior physicians, we generally replied with a standard e-mail saying that we cannot provide teleadvice.

Two hundred nine e-mails from patients and consumers requesting medical information were analyzed. The length

<table>
<thead>
<tr>
<th>Previous Patient Contact With Physicians</th>
<th>No. (%)</th>
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<tbody>
<tr>
<td>Has not seen a physician</td>
<td>11 (5)</td>
</tr>
<tr>
<td>Gives indication that patient has</td>
<td>117 (56)</td>
</tr>
<tr>
<td>consulted ≥1 physicians before</td>
<td></td>
</tr>
<tr>
<td>Has probably seen a physician</td>
<td>24 (11)</td>
</tr>
<tr>
<td>Has certainly seen at least 1 physician</td>
<td>65 (31)</td>
</tr>
<tr>
<td>Specifically lists multiple physician contacts</td>
<td>28 (13)</td>
</tr>
<tr>
<td>Unknown</td>
<td>69 (33)</td>
</tr>
<tr>
<td>Not applicable</td>
<td>12 (6)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>209</strong></td>
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</tbody>
</table>

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<tr>
<th>Type of Request (Multiple Items May Apply)</th>
<th>No. (%)</th>
</tr>
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<tbody>
<tr>
<td>Wants general information about a given disease</td>
<td>71 (34)</td>
</tr>
<tr>
<td>Contains specific questions</td>
<td>156 (75)</td>
</tr>
<tr>
<td>What is the treatment?</td>
<td>63 (30)</td>
</tr>
<tr>
<td>Requested address of specialist physician or facility</td>
<td>32 (15)</td>
</tr>
<tr>
<td>Are there any new therapies or alternative therapies or research results?</td>
<td>26 (12)</td>
</tr>
<tr>
<td>Is there a cure?</td>
<td>25 (12)</td>
</tr>
<tr>
<td>Gives a list of symptoms and wants to hear a diagnosis or opinion</td>
<td>23 (11)</td>
</tr>
<tr>
<td>Cause of a given disease?</td>
<td>18 (9)</td>
</tr>
<tr>
<td>Prognosis of a given disease?</td>
<td>10 (5)</td>
</tr>
<tr>
<td>Requested addresses of support groups</td>
<td>3 (1)</td>
</tr>
<tr>
<td>How do you diagnose this disease?</td>
<td>3 (1)</td>
</tr>
<tr>
<td>Adverse effects of a given drug</td>
<td>2 (1)</td>
</tr>
<tr>
<td>Looks for a supplier of a given product</td>
<td>1 (0)</td>
</tr>
<tr>
<td>Complications of a disease or treatment?</td>
<td>1 (0)</td>
</tr>
<tr>
<td>Other</td>
<td>15 (7)</td>
</tr>
<tr>
<td>Does not contain any question or request, just asks for “help” or a “suggestion”</td>
<td>11 (5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>For Whom Is the Information Sought?</th>
<th>No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient asks for himself</td>
<td>92 (44)</td>
</tr>
<tr>
<td>Patients asks for someone else</td>
<td>63 (30)</td>
</tr>
<tr>
<td>(child, relative, or friend)</td>
<td></td>
</tr>
<tr>
<td>Unclear or unstated</td>
<td>54 (26)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>299</strong></td>
</tr>
</tbody>
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of the e-mails varied from a single sentence to e-mails with several pages of text and in 2 cases with attached electronic digital images showing skin conditions.

Only 3 e-mails were not from the realm of (human) dermatology, including 1 writer asking about Morbus Sudeck, 1 e-mail about infectious mononucleosis, and 1 e-mail writer describing symptoms of her “dog that is battling with an immune mediated disease.” The other 206 e-mails covered the whole spectrum of dermatology without any obvious preference for any specific disease. Questions about rare conditions (eg, pseudoxanthoma elasticum) were roughly equally as common as ease. Questions about rare conditions (eg, pseudoxanthoma elasticum) were roughly equally as common as questions about common diseases such as psoriasis.

DEMOGRAPHICS

Among those 32 e-mails where we could identify the age of the writer, the youngest patient was 12 years, and the oldest 69 years (mean ± SD age, 31.7 ± 12.0 years; median, 29.5). Most were aged between 20 to 29 years (31%) or 30 to 39 years (25%) years, 19% were in the age interval of 12 to 19 years and 19% in the age interval of 40 to 49 years, only 6% were older than 49 years. Forty-eight percent were male, 31% were female, and in 21% we could not identify the sex of the writer.

COUNTRY OF ORIGIN

In most cases (71, or 34%) the country of origin could not be determined, as the sender did not explicitly provide this information within the mail and the e-mail address was not country specific (eg, @aol.com); however, most senders from this group are probably from the United States. From 46 individuals (22%) we knew that they were from the United States, 50 (24%) from Germany, 22 (11%) from another Western European country, 8 (4%) from South America, 7 (3%) from Canada, 3 (1%) from Australia, and 2 (1%) from Asia. As far as we can tell, no patients from Africa, Middle East, or Central and Eastern Europe sent e-mails.

FOLLOW-UP OF THE E-MAILS

A little less than half of the e-mails (44%) could have been forwarded to and answered by a nonmedically trained professional, eg, to provide addresses or to point the writer to a general information source, or to send a standard information text.

Among the other half (55%), patients could again be split into 2 equal groups: (1) in 51% of the cases the physician could have answered questions without seeing the patient (eg, general questions regarding new treatments); (2) in the other half, answering the questions would have required to see the patient or at least to obtain further clinical information from the treating physician, either (12%) for security reasons (in principle the questions could have probably been answered without seeing the patient, but for ethical or legal reasons one would refrain from giving an advice without having seen the patient) or (37%) because essential information can only be obtained from seeing the patients or having a look at their files.

Thus, 59 (28%) of all 209 e-mails were suitable to be answered by a physician via e-mail, in 27% of the cases any kind of consultation would not have been possible without seeing the patient, and the rest could have been answered by a skilled individual such as a librarian.

LEVEL OF FRUSTRATION

A considerable proportion of e-mail writers (35, or 17%) explicitly or implicitly expressed frustration or disappointment about previous physicians, relative to the proportion of patients who have seen a physician this is almost 35 (30%) of 117.

Most patients (81%) from those who explicitly stated their disease duration (n = 105) indicated that they have a chronic and longstanding problem (>6 months) and most mention at least 1 previous contact with physicians (Table 1). In one third of the cases (33%) it was not explicitly stated and could not be concluded whether the patient has seen a physician (most of these cases were simple requests for general information about a given disease), these have been categorized under “unknown” in Table 1. In 24 instances (“Has probably seen a physician” in Table 1) patients did not explicitly say that they have seen a physician but from the descriptions it could be concluded that they must have seen at least 1 physician, eg, if they used extensive medical vocabulary. A considerable proportion explicitly stated that they have visited multiple physicians; a 34-year-old patient with psoriasis vulgaris from Venezuela even stated that he has been to approximately 50 dermatologists. E-mails were categorized in Table 1 under “not applicable,” when the questions did not contain any question that would have made a physician visit necessary (such as a nonclinical questions, eg, “How does one become a dermatologist?”).

TYPES OF REQUESTS

We have categorized the e-mails into 3 main categories (Table 2): (1) wants general information about a given disease (eg, “Can you send me information about the disease xy?”); (2) contains specific question(s) (eg, “I suffer from xy. How do you generally treat it? Are there any new treatment options available?”); and (3) does not contain any particular question or request (“My aunt has xy. Do you have any suggestions?” or “I suffer from xy, can you help me?”).

The rationale behind these categories is that answering these different categories of questions would involve different workload for the physician or individual who answers them—questions categorized under general information can generally be answered either with a standard reply listing some general information sources or by providing standard texts about diseases, while very specific questions would involve individual and careful research and answering them would raise legal and ethical questions (see the “Comment” section). Questions categorized under asking for “help” are so diffuse that they would involve getting back to the patient asking what exactly he/she wants to get or to know (is not
even clear if the individual is looking for information only or if he/she wants to have an appointment).

Three quarters of the messages (156) contained 1 or more specific questions, mostly about therapy or requests for information about a “specialist” to treat a given condition. As a considerable percentage of patients (15%) was simply asking for specialist names or addresses of hospitals in their area specialized in treating a given disease (patients usually did not make any distinction between dermatologists or other specialists, but simply asked questions like “do you know a specialist for . . .”), we conclude that scientific and professional associations should offer databases on their Web pages helping consumers to find the right person to talk with. Addresses of support groups and organizations providing information should also be included, although only 3 patients directly requested such information.

About one third of the e-mail writers requested information for a relative, in most cases for their child. In some cases the information was requested on behalf of a friend (Table 3).

POSSIBLE REASONS FOR PATIENTS SEEKING HELP ON THE INTERNET

As far as we could tell, possible reasons for patients turning to the Internet rather than (or in addition to) asking their own physician were the following:

• Frustration and/or desperate information seeking from multiple sources as described earlier. One explanation for the high prevalence of frustrated patients among those seeking teleadvice may be that perhaps the anonymity of e-mails encourages open criticism compared with direct patient-physician contact. A probably more important reason is the causal relationship between chronic or incurable disease, frustration (about failed treatments), feeling of helplessness, and a subsequent information-seeking behavior to compensate the feeling of helplessness.

• A lack of trust in one’s own physician or health provider can be observed especially if therapies fail. It has also been noted that with health care systems internationally coming under cost-saving pressure, patients may increasingly become concerned that they receive cost-effective but suboptimal medical care and try to explore alternate sources of expert medical opinion. The hope to find something “new” on the Internet (new or alternative therapies, new research findings) not yet known to the treating physician may also play a role, as 12% of the patients were specifically asking for new therapies.

• Some patients want to be anonymous. In some cases one wonders why the patient asks a simple question by e-mail rather than simply asking his/her physician. For example, a 29-year-old female patient from the Netherlands who has been diagnosed as having urticaria pigmentosa asked whether this disease is malignant and whether she is allowed to go into the sun. In these cases, the relative anonymity of e-mails and, in this example, the fear to ask the treating physician “stupid” questions, may play a role.

• The physician did not give adequate information or the patient subjectively felt ill informed. Sometimes the patients simply have forgotten to ask the physician specific questions during the visit and are ashamed to contact him again.

• Some people are looking for information about diseases that actually do not concern themselves but friends or relatives. Nonclinical questions (such as seeking addresses) where physicians are not believed to be the primary and/or objective source of information, especially when the patient is looking for addresses of specialists.

Irrational hopes, for example a patient from the United States with Hailey-Hailey disease wrote: “I am of German ancestry . . . I would think you if anybody would have greater experience and treatments that could help me, it would come from the land of which it originated for me.”

Interestingly, we did not encounter any patient where physical disabilities, remoteness, or living in a medically underserved area appeared to be the reason for seeking information on the Internet and teleadvice.

As far as we can tell, all patients came from highly industrialized countries with excellent health care systems. This may partly be a reflection of limited access to the WWW in less developed countries and recalls one principal problem of telemedicine that “areas worldwide most likely to benefit from telemedicine are those least likely to afford it or to have the requisite communications infrastructure.”

Still, it is surprising that we did not receive any e-mails, eg, from Central and Eastern European countries, which have reasonable Internet accessibility, therefore other factors such as language barriers or cultural differences may play a role.

Regarding the question how patients found us and why they consulted us especially, we suspect that this is the result of the high “ranking” of our institution in Internet search engines such as AltaVista (http://altavista.digital.com/), which index all Web pages and rank results of queries by potential relevance, sorted based on criteria such as where on the page the query words appear and how often. Our institution is usually ranked on the top of dermatology-related search result lists because of our huge Web-based dermatology database. In this context we noted a common and important misconception among patients and users concerning the relevance of this ranking—some patients misinterpreted this ranking such that we were specialized or have special competencies in the disease they were searching for, or that we were even among the “leading European research centers on this area,” as a patient who searched for psoriasis concluded from his AltaVista search. We conclude that education of the public regarding this special issue is needed.

PROBLEMS OF TELEMEDICINE IN GENERAL AND TELEADVICE IN PARTICULAR

Telemedicine is broadly defined as the use of information technology to deliver medical services and informa-
tion from one location to another as a substitute for face-to-face contact between provider and client. Thus, exchanging medical information via e-mail can be regarded as a simple form of telemedicine.

Widespread use of e-mail to contact physicians and provision of general medical information on the Internet may help to reduce costs of health care.

On the other hand, telemedicine poses a number of problems. Legal issues include problems of confidentiality, liability, and licensing.

Privacy and Confidentiality and Security

In the context of teleadvice, we were surprised how many patients are comfortable to send private details over the Internet, not knowing who is to read the message on the other end and on its way to the receiver. No patient used or requested us to use encryption technology, although encryption software like PGP (Pretty Good Privacy) is easily available. A related security issue is that the patient cannot even be sure that the reply message was actually written by a physician, and vice versa physicians can never be sure whether an e-mail is actually sent by a patient (it might be the bulk e-mail of a pharmaceutical company using a subtle method of praising their products).

Liability

A number of questions are unresolved regarding liability in telemedicine at large, but teleadvice may in particular pose even more problems. If physicians in principle do not answer any e-mails, are they liable under the Good Samaritan law if patients harm themselves because the physician did not reply? If physicians answer all requests, are they liable if they draw wrong conclusions from the limited data the patients provide? If physicians point patients to another information source by giving them a hyperlink, are they liable if this source contains wrong or harmful information? If they answer individual requests with a standard information text about a given disease, are they liable if patients are mislead by not getting specific advice about their own condition? One of our virtual patients seemed to be aware of the problems a physician may run into when giving advice without having seen the patient, so he closed with an interesting “disclaimer.” “I will not take your suggestions or ideas as medical advice but simply as a friend to a friend.”

Licensing

Usually physicians must be licensed by the states or countries in which they practice. If the patient is from country A and the physician in country B, which licensing requirements apply? In addition, advice given across country borders complicates liability issues, as different legal systems and professional and ethical codes of medical practice may collide. For example, we had the scenario of a German physician in our hospital giving advice to a US citizen presently living in South Korea.

Apart from these legal issues, our experience with patients asking for teleadvice shows that we have to add 2 further general issues to the problems list, which is that teleadvice services, especially if they can be easily accessed and are offered for free, are prone to be excessively used by information-seeking patients that could overburden the possibility for easy and near anonymous communication with physicians by asking multiple physicians the same questions over and over again (just to make sure that they are really treated right or that there is really nobody who can cure them). Although the Internet has a tremendous potential for health education and preventive medicine, “the largest untapped resource in health care,” this has to be carefully weighted against possible dangers. Providing publicly accessible medical information on the Internet or providing individual teleadvice could tempt people to diagnose or treat themselves, even when the physical condition would in fact require seeing a physician in person. In 6 cases we received e-mails from patients who attempted self-diagnosis and/or self-treatment, although at least they sought advice from us by e-mail before actually starting a treatment (e.g., “I would like to know what kind of things can I do to fight against psoriasis on fingers, because I saw the photo in your atlas and it seems to be the same”).

It has been pointed out that “the excessive use of teleassistance, when there is neither emergency nor medical isolation, is dangerous because it may affect the integrity and the quality of the traditional medical act.” We found some anecdotal evidence that the effect of the Internet is similar, although controlled studies may be required to explore this question further.

CONCLUSIONS

Aside from ethical considerations there are many reasons why not to ignore unsolicited e-mails sent by patients. Patient e-mails often contain typical questions asked by patients and may therefore provide an excellent learning experience for medical students and junior physicians if discussed with senior physicians. As patients occasionally suggest a possible cause, associations with other diseases, treatments, or previously unknown symptoms, patient e-mails could even provide stimuli for medical research. Analyzing patient e-mails on a broader level may also give interesting insights into quality-of-life issues, consumers satisfaction with health care, and quality of Internet information.

In summary we predict that analysis of patient e-mails can also help physicians to learn from patients, as anonymity of e-mails may encourage patients to address issues they would normally not express in other forms of communication.

On the other hand, the sheer number of inquiries (that is partly a result of this anonymity and easiness of communication) may put a significant burden on providers of medical information on the Internet, which have to be taken into account when opening a Web site. Answering a patient e-mail may take between 5 (if one decides to send out a standard e-mail saying that one cannot respond to e-mails individually) and 30 minutes or more, depending on the problem the patient has. In only 2 of the 209 cases, patients explicitly offered money for getting advice, and especially when dealing with pa-
patients across country lines, reimbursement of teleadvice is—apart from the problems outlined earlier—another unresolved problem.

Further studies are needed to investigate the relatively new phenomenon of physician-patient communication via e-mail. What are the exact demographics and motivations of patients sending unsolicited e-mails? What are the exact clinical and economic outcomes and the cost-effectiveness of providing medical information on the WWW and answering (or not answering) patient e-mails? Can teleadvice over the Internet reduce costs of health care or is it an ineffective or even dangerous approach? In addition it would be interesting to determine to which degree and how the contents of a Web site influences the amount and contents of patient requests—does, for example, extensive patient information rather increase or decrease the number of unsolicited patient e-mails? Further prospective studies may address these questions, although these kind of studies are difficult to conduct. Such further studies could shed some more light on problems of medical communication in the virtual environment, but also on problems of the physician-patient relationship and communication and miscommunication in the real world. As an aside, the phenomenon of unsolicited e-mails raises the general question of how physicians should handle such e-mails, an issue that is not covered by any professional code or recommendation known to us and therefore will have to be addressed.

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REFERENCES


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