

Responses to Unsolicited Patient E-mail Requests for Medical Advice on the World Wide Web

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Context.—The Internet is increasingly used by consumers to seek health and medical information, but online medical advice has not been explored systematically.

Objective.—To explore the attitude of physicians and other providers of medical information on the Internet toward unsolicited e-mail from patients and their reaction to a fictitious acute medical problem described in such an e-mail.

Design.—E-mail in December 1997 and January 1998 to Web sites from a fictitious patient describing an acute dermatological problem. Follow-up questionnaire survey to the same sites.

Setting.—World Wide Web.

Subjects.—Fifty-eight physicians and Web masters.

Main Outcome Measures.—Response rate and types of responses.

Results.—Twenty-nine (50%) responded to the fictitious patient request; 9 respondents (31%) refused to give advice without having seen the lesion, 27 (93%) recommended that the patient see a physician, and 17 (59%) explicitly mentioned the correct “diagnosis” in their reply. In response to the questionnaire, 8 (28%) of the 29 respondents said that they tended not to answer any patient e-mail, 7 (24%) said they usually reply with a standard e-mail message, and 7 (24%) said they answer each request individually.

Conclusions.—Responses of physicians and Web masters to e-mail requests for medical advice vary as do approaches to handling unsolicited e-mail. Standards for physician response to unsolicited patient e-mail are needed.

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THERE HAS BEEN explosive growth in recent years of the Internet and World Wide Web as tools for seeking and communicating health and medical information,¹ with increasing numbers of physicians and health care institutions maintaining Web sites. Physicians or medical information providers who run such sites and post e-mail addresses likely will receive unsolicited e-mail from unknown patients asking for medical information and/or advice. On our bilingual Web site in Germany, patients frequently cross geographic borders to seek such information (about 75% of the unsolicited patient e-mail messages we receive comes from abroad, mostly from the United States²). As our experience likely is not unique,

this situation raises the following 2 key questions: How do such sites react to this unsolicited e-mail? And, should they respond at all?

The American Medical Informatics Association, Bethesda, Md, recently published guidelines for physician-patient e-mail in the context of an established relationship. But apart from some anecdotal reports about “clinical encounters in cyberspace,”²⁻⁶ to our knowledge, there are no studies in the literature investigating the question of how to handle unsolicited e-mail. Our objective in this study was to determine how medical information providers react to unsolicited e-mail sent by patients, to assess the quality of responses given by physicians, to explore how unsolicited e-mail messages sent by patients are perceived by physicians and medical Web masters (individuals who maintain Web pages), and to determine whether there is any consensus on how best to deal with this nearly anonymous form of medical communication.

Methods

We wished to mimic the process by which a patient with a dermatological concern might seek medical advice on the Web and so simulated the search strategy a patient might use to find information on his or her condition. We searched the popular AltaVista (<http://altavista.digital.com>) Web index using the query “+blisters+skin+pain+dermatology.” We viewed the first 100 Web pages and selected all information providers who publish some patient information and/or have dermatologists who could answer the e-mail. We found the following 12 distinct sites: 4 dermatology societies or organizations, 2 commercial sites, 2 universities, 1 dermatologist in private practice, 1 clinical psychologist self-described as specializing in skin diseases, 1 publisher, and 1 hospital. Three of the e-mail addresses extracted from these sites clearly belonged to a physician.

See also pp 1321, 1353, and 1361.

We then visited all academic dermatology Web sites published in a list compiled by Thomas Ray of the University of Iowa Hospitals and Clinics (<http://tray.dermatology.uiowa.edu/AcadDept.html>), except some written in Japanese. As a result, we found 45 Web sites with suitable e-mail addresses.

This process yielded a total of 57 sites that would likely be approached by patients with dermatological problems. In both approaches, we visited the Web sites and looked for an e-mail address belonging to the department, to a physician, or to the Web master.

Usually, we chose only 1 e-mail address from each site, with the exception of 1 Japanese site from which we selected 2 e-mail addresses because of our lack in understanding the Japanese language. If we found several addresses on the site, we selected the e-mail address in the following order of preference: (1) general e-mail address of the department (ie, derma@xyz); (2) the physician responsible for the

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Table 1.—Demographics and Background of Respondents

Demographics	E-mail	Returned Questionnaire
Country		
Austria (n = 1)	0	0
Brazil (n = 1)	0	0
Canada (n = 2)	2	1
Chile (n = 1)	1	1
Egypt (n = 1)	1	1
Finland (n = 1)	1	0
Germany (n = 7)	3	4
Hungary (n = 1)	1	1
Israel (n = 1)	1	1
Italy (n = 1)	0	1
Japan (n = 18)	3	6
New Zealand (n = 1)	1	1
Singapore (n = 1)	0	0
South Korea (n = 1)	1	1
Spain (n = 2)	2	2
Sweden (n = 1)	0	1
Switzerland (n = 1)	0	0
Taiwan (n = 1)	0	0
Turkey (n = 1)	1	1
United Kingdom (n = 2)	1	0
United States (n = 22)	10	7
Characteristics		
Physicians (n = 41)	26	25
Dermatologists (n = 37)	22	23
Department heads (n = 11)	6	7
Web masters (n = 6)	1	4
Unknown (n = 11)	2	0

site; (3) e-mail address of the head of the department; (4) e-mail address of any other physician in the department; (5) e-mail address of the Web master.

Clinical Problem

Between December 1997 and January 1998, we sent an e-mail message with the following text to the selected addresses:

Hello,

I am a 55-year-old male and have a sudden skin problem.

During the last 4 days, I had a little fever and headache. There was also a burning pain and tingling and extreme sensitivity in one area of the skin of the chest. Since yesterday, suddenly, multiple, fluid-filled, painful, red blisters appeared on the same skin area on the chest, on a broad streak of reddened skin. The skin eruptions are very painful, and my wife says the groups of blisters look a lot like chickenpox, though they are only on that girdlelike skin area.

I am on Sandimmune [cyclosporine] since I had a kidney transplant some time ago.

What is this? Is it dangerous? What is the therapy? Do I have to see a doctor?

Please reply!

*Thank you very much,
Peter*

With this description, we tried to suggest a herpes zoster infection, caused by varicella-zoster virus reactivation due to

immunosuppressive treatment (cyclosporine). In this case, early treatment with acyclovir is essential to prevent severe and possibly deadly complications.⁷⁻¹⁰

Because no patients were involved in our study and no subjects were treated or put at risk, our institution does not require institution review board notification, review, or approval of the research protocol (B. Fleckenstein, written communication, September 10, 1998). We considered our approach to be an appropriate assessment of quality in lieu of other means of testing the quality of information on the Internet. After the study was completed, we informed those who responded that the "patient" query they had received was fictitious and was part of a research project that would report their responses without identifying them.

Questionnaire Survey

Between 12 and 18 days after we sent the patient e-mail, we distributed a 9-item questionnaire, using a different e-mail sender address, to the same addresses, without disclosing that the previous e-mail had been a part of our study. We asked how many unsolicited e-mail messages the site received per week, what the response policy to such requests was, and what was the respondent's personal views on the topic. We asked them to return the questionnaire by e-mail. If we received no reply, we re-sent the questionnaire after 5 weeks and again after 9 weeks.

Results

Demographics and Backgrounds of Our Responders.—We sent the fictitious patient e-mail to all 58 addresses; 2 bounced back because of technical reasons. We sent the questionnaire to 53 of the 58 information providers. We excluded the 2 nonworking addresses and 3 information providers from the United States, Canada, and Germany that actively solicit patient e-mail since we wanted to study how unsolicited e-mail was handled (Table 1).

Responses to the Fictitious Patient E-mail Messages.—Twenty-nine (50%) of the individuals replied; 26 (89%) of the respondents reported that they were physicians. All but 2 of the respondents, or 93%, urged the fictitious patient to see a physician; the 2 who did not refused to give any advice at all. Seven (26%) of those who advised the patient to see a physician refused to give additional advice. Of the remaining 20 respondents, 18 mentioned a diagnosis and 17 specifically mentioned herpes zoster (the other mentioned Stevens-Johnson syndrome or toxic epidermal necrolysis as possible diagnoses). Thirteen respondents, including the provider who did not mention herpes zoster, expressed the diagnosis with

caution. Five respondents explained possible causes, and 9 pointed out possible complications. Finally, 5 (all of whom had mentioned the diagnosis of herpes zoster) provided specific advice about therapy, which consisted of taking acyclovir, valacyclovir hydrochloride, and famciclovir (Tables 2 and 3). The usual response time was between 1 and 2 days.

Questionnaire Results.—Twenty-nine (55%) of the 53 to whom we sent questionnaires replied (Tables 2 and 3), including 17 (32%) who also previously replied to the fictitious patient e-mail message. We further asked how many unsolicited patient e-mail messages these sites receive per week. Responses ranged between 0 and 50, with a mean value of 4.4 (SD, 9.47) and a median of 1 e-mail message per week.

Except for 2 cases, we noted no obvious discordance between actual behavior in the fictitious patient experiment and the policy stated in the questionnaire. The questionnaire results corresponded well with the results of the experiment, indicating that about half of physicians answer unsolicited e-mail requests.

Comment

The study found a striking lack of consensus among medical information providers on the theoretical and practical handling of unsolicited patient e-mail messages and their judgment of this topic. About one third of those who replied explicitly refused to answer patient requests individually, arguing that it would be impossible to make a diagnosis via e-mail without an examination, as well as arguing that they lacked the resources and/or mandate to reply to these kinds of inquiries. The remaining two thirds attempted to help individually, 5 of whom gave detailed treatment advice.

Our small sample size precludes stratifying answers by country or other characteristics. Further, the results cannot be generalized to other specialties or sites. Also, the response rate to the fictitious patient e-mail requests and the information provided likely depend on the clinical contents of the e-mail (eg, the urgency and clarity of the description). Another clinical problem might produce different results.

There likely are many reasons why patients turn to the Internet for medical advice, rather than asking their own physicians.² However, our study suggests that patients approaching unknown physicians to request e-mail advice must be aware that there is no guarantee that such information will be accurate, timely, or appropriate.

First, only half of the physicians or Web masters responded to our fictitious patient e-mail, even though the problem being described clearly was a medical emergency; in chronic medical problems,

Table 2.—How Medical Information Providers on the World Wide Web Report Handling Unsolicited Patient E-mails*

Response to Questionnaire Question "How You Handle Unsolicited Patient E-mails"	Information Provider Who Responded to Fictitious E-mail	Information Provider Who Did Not Respond to Fictitious E-mail	Total, No. (%)
Answer each e-mail individually	6	1	7 (24)
Reply with standard e-mail	2	2	4 (14)
Reply with standard e-mail, but make exceptions	1	2	3 (10)
Never answer patient e-mail	1	2	3 (10)
Never answer, with exceptions	2	3	5 (17)
Forward patient e-mail to a third party	2	1	3 (10)
Other	3	1	4 (14)
Total Replies to Questionnaire, No. (%)	17 (59)	12 (41)	29 (100)

*Percentages do not total 100 because of rounding.

Table 3.—Responses From 29 Medical Information Providers on Different Issues Regarding Unsolicited Patient E-mail

Response	Yes, No. (%)	No, No. (%)	Don't Know, No. (%)
We published a disclaimer on our Web site saying that patient e-mail is not answered	4 (14)	25 (86)	...*
There is a written or oral institutional policy or guideline on how to handle unsolicited patient e-mail	4 (14)	25 (86)	...
We consulted legal advice regarding the question of answering unsolicited patient e-mail	2 (7)	26 (90)	1 (3)
It is an appropriate and success-promising strategy for patients who are seeking medical advice to approach physicians (who are personally unknown to them) via unsolicited e-mail	10 (34)	18 (62)	1 (4)
There are cases in which it might be appropriate/helpful for the patient to approach a physician via e-mail and where a visit to the physician can be avoided	16 (55)	10 (34)	3 (11)
Unsolicited e-mails from patients represents a significant unresolved problem on the Internet	18 (62)	11 (38)	...

*Ellipses indicate that response is not applicable.

which constitute the majority of unsolicited e-mails queries,² the response rate may be even lower. Second, even among those who replied, the response time often was long (up to 10 days). For a real immunosuppressed patient experiencing herpes zoster, waiting 10 days for advice could have been fatal.

Physicians who do answer unsolicited patient e-mail requests seem to have several reasons for being cautious. Aside from the problem that the sheer volume of e-mail received can hardly be handled if patients overuse easy and anonymous access to medically qualified personnel, the danger of misdiagnosing is imminent without access to a complete patient history and physical examination.

The legal consequences of providing incorrect, incomplete, or inappropriate advice under these circumstances are unclear. Our study suggests that making a diagnosis via e-mail is possible in principle, as none of the respondents offered misinformation, although 1 responding physician considered Stevens-Johnson syndrome and toxic epidermal necrolysis as possible diagnoses, which may be the result of the physician's personal interest in severe skin reactions.

Confidentiality and security issues also are crucial. Unencrypted e-mail messages can be read by third parties as easily as postcards, so patients who send out e-mail to individuals unknown to them

can never be sure that a physician really is behind the published e-mail address. Physicians could also be misled, for example, by commercial enterprises that might use fictitious patient e-mail as a subtle means of praising their own products or discrediting those of a competitor.

In addition, both parties can never be sure whether e-mail actually reached the intended recipients, as most Internet-based e-mail systems do not provide confirmation that a message was delivered. Even if the software returns notification of receipt, it cannot ensure that the message was actually read and understood.¹¹ Again, patients waiting for answers from physicians who do not read their e-mail messages may waste precious time.

Because the Web is a global, unregulated medium, additional cross-border issues arise. Language problems on both sides may create misunderstandings and patients may presume that the standards of medical training in other countries are comparable to those of their own, which may not always be the case. Physicians who give e-mail advice have to take into account different ethical, cultural, or economic backgrounds of patients as well as variations in health care settings and delivery systems, which might preclude the availability of certain therapeutic or diagnostic procedures.¹² The international nature of the Web also poses licensing issues, raising the question of whether a

physician is allowed to counsel out-of-area patients at all.

Although guidelines recently have been proposed for clinical use of e-mail with patients, these suggested protocols apply within an established patient-physician relationship.¹¹ We, therefore, propose that additional guidelines be developed to advise physicians on how to handle unsolicited e-mail requests from patients. The expected growth of the Internet and its potential applications in health communication make the need for such guidelines especially pressing. In the absence of outcome data for patients using online medical advice, such guidelines should address clinical and ethical issues as well as legal ramifications and concerns regarding confidentiality.

Until such guidelines are forthcoming, we suggest that medical institutions that maintain Web sites develop standardized policies for handling the unsolicited patient e-mail that they can expect to receive. We recommend that such policies, at a minimum, make a provision for posting a disclaimer clearly indicating that unsolicited patient e-mail may not be answered and is not a substitute for obtaining medical advice in person from a health professional.

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