Web Relationships Between Physicians and Individuals Seeking Information on Hepatopancreatobiliary Diseases

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**Hypothesis:** The Internet has led to widespread Web consulting, the proportions of which are not yet known; there is not yet agreement on its management.

**Design:** We verified the typology and needs of people and patients of a single-language population inquiring about a homogeneous group of diseases treated in tertiary reference centers and their reason for writing. Data were extracted and coded from e-mail messages received over 27 months by a noninstitutional Web site devoted to surgically treatable hepatopancreatobiliary diseases. Consultation activity was verified by the number of answers and subsequent messages.

**Main Outcome Measures:** One thousand forty-seven users sent 1788 messages to one of the Web site addresses; 1179 (94.6%) of them inquired about clinical problems. Data were collected on the demographics of senders and patients, the nature of the clinical problem, and the reasons for the messages.

**Results:** A mean of 2.1 messages per day were received. Queries were sent by patients in 260 instances (22.1%) and by others in 750 (63.6%). Two hundred thirty-seven (20.1%) e-mails had medical enclosures. The presence of a malignant disease was reported in 705 messages (59.8%). Description of previously undertaken therapy was present in 613 cases (52.0%). An answer was given to 1177 first messages (94.4%) and a follow-up message was received from 401 users (34.1%). Second messages were characterized by a shorter time to receive an answer (mean, 2.5±3.6 days vs 3.5±5.3 days). Each user sent a mean number of 1.4±0.7 messages (range, 1-8).

**Conclusions:** Web consulting is a powerful tool for patients and health professionals that emerged owing to physician communication problems. Nevertheless, the Internet is still pushing physicians toward a reconsideration of the principles of medical ethics and a reevaluation of rules and regulations to deal with these new communication methods.

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The increasingly easy access to the World Wide Web has led to an increased diffusion of health news over the Internet. One third of Europeans and 43% of Americans already use the Internet to get health information. Information can be shared by professional medical systems and physicians to advertise their activity, by groups of patients suffering from a common specific disease, and by individuals looking for treatment for themselves or for relatives.

**See Invited Critique at end of article**

During the late 1990s, there was real enthusiasm for the introduction of e-mail as a vehicle of communication between patients and physicians. Internet use has been welcomed just as the use of regular mail and telephones was in the past. Besides the routine patient-provider communication, the sending of e-mails to an interactive health Web site raises the problem of unsolicited messages and Web consulting. We report on a large series of Internet-based consulting generated by a single surgical Web site that has been analyzed from a clinical point of view and found not to have a marketing-oriented purpose. The analysis takes into consideration the interaction of a single-language population for a homogeneous group of diseases routinely treated by the researchers (physicians working in a tertiary reference center). Data were collected on the demographics of senders and patients, the nature of the clinical problem, and the reasons for the messages, obtained without specific request and with full respect for the privacy of the people involved.

**METHODS**

In February 2002, a Web site devoted to surgically treatable hepatopancreatobiliary diseases...
The second institution was the local College of Physicians. In a communication dated November 10, 1999, the Italian College of Physicians stated that Internet publicity has to respect the dictates of law No. 175, as well as article 53 of the Medical Code of Ethics. For these reasons the entire contents of the Web site were submitted to the College of Physicians of Bologna, which expressed a positive opinion on its publication.

WEB SITE DIFFUSION

There were no efforts to promote the existence of the Web site through media or other electronic systems. The address was submitted to the main Italian and international search engines and is easily reachable by keyword searches. A few other Web sites decided to place a hyperlink to this Web site in their own pages. From March 2, 2002, to June 30, 2004, the home page was visited 40,648 times. At the end of the study period the entire Web site had an average of 45 visitors per day, with visitors reading an average of 1.54 pages per visit.

MAIL COLLECTION

Users were given the possibility to send questions to the site Webmaster or to individual surgeons. No fees or personal data were asked of the visitors to gain access to the Web site. Providing personal data was absolutely optional, left to the discretion of the visitor, and handled in compliance with the Italian law on privacy (Italian Law No. 675 of December 31, 1996, titled, Protection of People and Other Subjects in the Handling of Personal Data).

MESSAGE CODING

All queries were read on the same day they were received and an effort was made to give an answer in the shortest time possible. I then reviewed the messages for coding to reduce bias due to text misinterpretation. Duplicate or empty messages were discarded.

The following characteristics were analyzed and recorded for the first message sent: date of the message; type of inquiry (generic vs clinical); sex, age, and domain extension of the sender; address to which the mail was sent; whether or not an answer was given; date of the answer; and total number and date of possible subsequent messages sent by the same person on the same topic. For messages with questions related to clinical situations, the following data were also recorded: sex, age, and degree of relationship to the patient; disease organ (liver, biliary tract, or pancreas); type and subtype of the disease; kind of disease (benign vs malignant); presence of e-mail enclosures; main subject of the message (onset of symptoms, uncertainty in the diagnosis, therapy, or prognosis of the disease); approach to therapy (first opinion, second opinion, failure of a previous treatment, or general advice); therapy already followed or already proposed; and therapy under inquiry. In messages regarding patients with malignant disease, care was taken to identify any signs of advanced disease, if possible (peritoneal dissemination, vessel infiltration or thrombosis, or distant metastases).

All the discharge or case history summaries, and laboratory, radiographs, or pathology reports that were added in any form to the e-mail message were treated as enclosures. All enclosures, together with the personal data included in the message, were treated in accordance with the Italian law on privacy.

STATISTICAL ANALYSIS

Messages and answers were stored in the Netscape Communicator 4.51 mail client (Netscape Communications Corp,
Mountain View, Calif) and processed with the SPSS statistical package (SPSS Base 11.0; SPSS Inc, Chicago, Ill) after coding. When some of the data could not be identified in the message they were treated as missing in the analysis.

Results were expressed as mean±SD and compared using the t test; analysis was performed to evaluate categorical variables. A P value less than .05 was considered statistically significant.

RESULTS

Between March 11, 2002, and June 30, 2004 (842 days), a total of 1788 messages were received at one of the Web site addresses, giving a mean of 2.1 messages per day (Figure). Of these, 1247 were censored as first messages and they are the main subject of the study.

The majority of the senders’ e-mail addresses had the Italian extension (.it) in the address domain (1072 [86.0%]); 141 (11.3%) had .com, 14 (1.1%) had .net, 1 (0.1%) had .org, and the remaining 19 senders (1.5%) had a variety of domain names. Messages were sent directly to the personal addresses of the authors in 96 cases (7.7%). Table 1 reports the demographic information of the senders. The mean age of senders was significantly lower when the message came from the patient (38.6±12.3 years vs 55.6±17.5 years; P<.001). There was no difference in gender distribution whether or not the sender was the patient.

Two hundred thirty-seven queries (20.1%) had medical enclosures. There was no difference in the presence of enclosures by gender. Enclosures were present in messages from senders with an older mean age (41.5±11.9 years vs 37.7±12.2 years; P<.05) and when dealing with older patients (58.1±15.0 years vs 55.0±18.1 years; P<.05).

Table 2 summarizes the organs and diseases that were the subject of inquiries. Patients wrote more frequently than others regarding symptoms (4.7% vs 2.7%; P<.05). Senders who were not the patients included enclosures more frequently than patients (14.8% vs 6.3%; P<.01), after the failure of a previous treatment (12.7% vs 1.2%; P<.001), and inquired more frequently about cancer (56.8% vs 3.3%; P<.001), diagnosis-related problems (8.5% vs 4.2%; P<.05), therapy-related problems (53.7% vs 11.1%; P<.001), and receiving a second opinion (27.9% vs 6.5%; P<.001).

NATURAL OF THE DISEASE

Malignant disease was reported in 705 messages (59.8%), and a benign disease was reported in 466 cases (39.5%), while in 8 cases (0.7%) these data could not be determined. The mean age of senders who wrote for others did not differ according to the nature of the disease. On the contrary, the mean age of senders who wrote for themselves varied depending on the nature of the disease, with younger senders (aged 40.5±12.7 years) dealing with benign diseases and older senders (aged 55.3±12.9 years) with malignant diseases (P<.001). The mean age of the patients was higher in those inquiring about malignant diseases (63.4±11.9 years vs 44.0±18.1 years), without differences in who the sender was.

The main topic of messages dealing with cancer was therapy (44.8% vs 15.4%; P<.001), and usually included asking for therapy solutions (45.5% vs 14.7%; P<.001). According to our criteria, of the 705 messages dealing with malignancies, 327 (46.4%) met criteria con-
sistent with advanced disease and 108 (15.3%) were consistent with limited disease; the remaining 270 (38.3%) were not assessable. Messages reporting advanced malignancies more frequently included enclosures (12.1% vs 9.5%; \( P/H11021 < .05 \)).

TREATMENT ALREADY FOLLOWED

Descriptions of previously undertaken therapy were included in 613 cases (52.0%). The most common was medical treatment in 166 cases (27.1%), chemotherapy in 146 (23.8%), hepatic resection in 78 (12.7%), operative endoscopy in 46 (7.5%), explorative laparotomy in 45 (7.3%), percutaneous ablation in 37 (6.0%), other surgery in 34 (5.5%), cadaveric liver transplantation in 32 (5.2%), transarterial chemoembolization in 25 (4.1%), and living-related liver transplantation in 4 (0.7%).

REQUESTED ADVICE

Table 1 summarizes the categorization of the main questions contained in the messages. Senders other than patients more frequently requested information for second opinions (27.9% vs 6.5%; \( P < .005 \)), malignancies (23.1% vs 9.6%; \( P < .001 \)), advanced diseases (20.7% vs 17.6%; \( P < .05 \)), and therapy-related problems (28.2% vs 4.2%; \( P < .001 \)).

TREATMENT INQUIRIES

A total of 597 messages (50.6%) requested advice on specific therapies. Liver resection was the most frequent, with 269 messages (45%), followed by cadaveric liver transplantation in 133 (22.3%), medical treatment in 52 (8.7%), living-related liver transplantation in 41 (6.9%), chemotherapy in 25 (4.2%), percutaneous ablation therapy in 19 (3.2%), and other therapies in 58 (9.7%).

Senders asked whether liver resection could be appropriate after the patient had undergone chemotherapy (10.3%), a previous resection (5.1%), medical therapy (4.2%), or after no prior treatment (17.3%). Inquiries were also made about cadaveric liver transplantation after medical therapy (8.8%), chemotherapy (2.9%), a previous transplant (2.5%), and after no prior treatment (4.4%).
CONSULTING ACTIVITY

An answer was given to 1177 first messages (94.4%) and not given in 70 cases (5.6%). The mean time for an answer was 3.29 ± 5.0 days, ranging from 0 to 58 days (median, 2 days).

Following an answer, a second message was received in 259 cases (22.0%). An acknowledgment message was received from 186 users (15.8%). As a total, 401 single users (34.1%) sent at least 1 further message. The second message was received 27.1 ± 64.6 days (range, 0-528 days) after the first and 22.7 ± 56.5 days (range, 0-412 days) after the answer was given. Second messages were characterized by a shorter response time (2.5 ± 3.6 days vs 3.5 ± 5.3 days; P < .005). This difference was not noted for acknowledgment messages. Second messages were sent more frequently by users who were not patients (27.9% vs 6.5%; P < .005), when dealing with malignant diseases (23.1% vs 9.6%; P < .05), and for therapy-related problems (28.2% vs 4.2%; P < .001).

A third message was sent by 63 users (5.4%). The third message was received 88.0 ± 136.2 days (range, 2-648 days) after the first one and 68.7 ± 133.3 days (range, 0-647 days) after the second. In total, 1247 users sent 1788 messages, with a mean number of 1.4 ± 0.7 messages (minimum, 1; maximum, 8; median, 1).

The design of the study and the absence of an institutional connection with the Web site prevented the evaluation of a possible increase in the volume of outpatient activity or in the number of surgical procedures.

There are several aspects of electronic communication that need to be considered by health professionals. The most common considerations are the rules for publication of Web sites, the use of e-mail as an instrument for the patient-physician relationship, and the management of unsolicited e-mail messages and Web consulting. Despite the widespread existence of these problems, very few reports are available in the scientific literature. Most of these have been published in highly specific journals, the vast majority of them coming from the United States. Only sporadic reports are from European countries.12-14 The only consistent forum appeared in 1998 in a single issue.3,5,12-15 For someone who is new to the Web it is difficult, if not impossible, to get an idea of how the medical community wants to present itself to the vast stage of Internet users. But while some guidelines have already been published for the first 2 topics,19,20 less information is currently available on the origin and the management of unsolicited mails. Table 3 summarizes the few reports already present in the literature. Most of the remaining reports based their data on post-counseling surveys.14,23

With 1788 messages received over 27 months, this is the most consistent series of consulting e-mails reported. It also offers the most accurate analysis of the users and the patients who asked for a Web opinion, because it investigates many aspects of those who ask for suggestions on their own health or the health of relatives.

The data we present here can give rise to several analyses of the people who are consulting the Internet on health matters and on what they want. We have to stress that specific topics of the Web site are diseases that are not the subject of primary care but are usually treated by specialists of tertiary referring institutions.9 For these diseases, more than others, a correct referring system is fundamental.

There is no doubt that one of the major causes at the root of this phenomenon is the presence or the persistence of difficult-to-treat diseases. More then half of the patients mentioned in the received messages had already had at least 1 kind of treatment for their disease. Sixty percent of all the messages concerned neoplastic conditions and half of them reported features of already advanced diseases. The Internet is accessible and surfing on the Web and sending e-mail is a very easy way to try to find the most appropriate solution to a life-threatening situation; but what emerged from the repeated reading of our messages, when received and during coding, is that their true origin lies in a substantial lack of satisfactory communication between patients and their health providers. While this aspect could not be easily translated into categories, most of the patients who were the subject of our messages already had a diagnosis, an indication for therapy, or had already been treated for a disease (surgically in 24.1% of the cases and with chemotherapy in 23.8%). Senders were nevertheless still looking for greater clarification on the nature of their illness, for support or an alternative to the proposed therapy, or for further treatment in the case of failure. They do this very easily, without worries of any legal- or privacy-

Table 3. Reports of Web Consulting Present in the Scientific Literature

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<th>Source, Language, Specialty</th>
<th>Study Period, mo</th>
<th>No. of Messages Received (Rate)</th>
<th>No. of Messages Analyzed</th>
<th>No. of Messages Answered (%)</th>
<th>Senders Analyzed</th>
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<td>Widman and Tong21 English Cardiology Yes 12 70 (5.8/mo) 70 70 (100) Yes No</td>
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<td>Eysenbach and Diepgen12 English + German Dermatology Yes 6 201 (33.5/mo) 201 Few Yes No</td>
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<tr>
<td>Borowitz and Wyatt16 English Pediatric gastroenterology Yes 33 1239 (37.6/mo) 1239 Yes No</td>
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<td>Labir et al13 English + German Mixed No 8 15 456 (5.3/mo) 1500 901 (60) Yes No</td>
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<td>Shuyler and Knight12 English Orthopedics Yes 2 1587 (793.5/mo) 793 Few Yes Yes</td>
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<td>Present study Italian HPB surgery No 27 1788 (66.2/mo) 1247 1177 (94.4) Yes Yes</td>
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Abbreviation: HPB, hepatopancreatobiliary.
related considerations: one fifth of our first messages had clinical enclosures and this proportion increased when considering messages dealing with advanced malignant diseases. A large percentage of them were looking for more than a simple answer, because in 34.1% of the cases, a second, unrequested message was received.

If perfect communication existed between patient and physician, there would not be any need for health searching over the Internet. Obviously, this is not the case. On one side, there is uncontrollable and fully justifiable search by the patients themselves or by their relatives for health problem solutions, even for irreversibly deteriorated clinical situations. This is not controllable or correctable by health professionals. On the other hand, our analysis revealed that the need for an answer from a physician very often remains unsatisfied, regardless of the kind of need.10 On several occasions the feeling was that the relationship between the patient or his or her relatives and the physician was unfinished and left hanging in the balance. Electronic messaging and Web consulting represent the obvious continuation of the relationship.

It could be argued that our Web site received messages from highly sensitized people, representing a strict minority of cases; but the number of similar Web sites (with or without advertising; whether or not commercial or interactive) and newsgroups easily reachable through the most common search engines give an idea of the magnitude of the problem. Even our major newspaper has recently opened separate forums for major diseases, including those treatable only in tertiary referring centers.24

It is both inappropriate and beyond the scope of this article to put forward possible criticisms on the use of the Internet for health-related problems (Table 4). In fact, the use of e-mail was quickly welcomed when applied to medical communications,2 but the appearance and the continuous growth of unsolicited e-mails and Web-based inquiries should create new concerns for the medical community on the effectiveness of its communication with patients and on its own ability and capacity to interact with colleagues as a full and unique referring network. There are 2 main points physicians should consider when thinking about Web-based consulting: (1) the possible structural modification of the relationship between patient and primary physician (“Will I still trust my family doctor if I am able to find more appropriate or updated therapies for my disease from a Web consultation? Should I go to the physician suggested by my family doctor if I can have an e-mail consultation with one who appeals to me more?”)25 and (2) the chance that the decision of choosing a treating physician would be influenced more by the attractive appearance of a Web site or by the promptness in answering e-mail, as emerges from this study, in comparison with the appropriateness, the experience, and the skill of a named physician.26

What has changed in the 7 years since the first report on this phenomenon?21 The time that has passed is long for the Internet, but only a moment in terms of time for the medical communication system to change. Six years ago some hospitals and state agencies promoted the deletion of these messages.2 Is this still applicable?

The further increase in patients consulting the Internet should encourage physicians to change their attitude.2 If this is not the case, patients will change providers; the Internet patient already makes this change on the basis of nonprofessional considerations.25

The medical community does not seem able to properly deal with the problem,7 nor to have the tools to effectively deal with it. Perhaps it is no accident that many of the articles on this subject are found in the unspecialized press instead of in major scientific journals.19 Even the HON code does not seem to represent a fully satisfactory tool. In this way, today the Internet is pushing us towards a reconsideration of the principles of medical ethics and a re-evaluation of the rules and regulations.7

In conclusion, we have confirmed that Web consulting is a powerful tool for both patients and health professionals. Unfortunately the communication problems with the physicians themselves are the main reason why patients surf the Internet searching for the best consultations. In the last few years nothing has changed in medical practice to achieve a rational but also ethically correct management of the resources made available by the Internet.

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REFERENCES


A
ccess to electronic health information and communication is no longer a future anticipation of patients but a current expectation. In this issue, Grazì breaks new ground by reporting his observations of electronic communications to surgeons via a European Web site written in a non-English language (Italian), related specifically to a non–primary care topic, surgical hepatopancreato-biliary disease, and in which the physician recipients had no prior clinical relationship with the patients. Almost all reports to date in the scientific and lay press about e-mail and Web messaging between patients and providers have focused on primary care in the United States and on communication written in English.

Remarkably, given the relative nonavailability of physician-patient electronic messaging in Europe, the Web site was visited 40,648 times over 27 months, and 1247 patients or proxies sent 1788 electronic messages. The senders’ ages ranged, in years, from mid 30s (primarily for benign conditions) to the 60s (primarily for cancer).1-3 Surgeons who believe that their members will provide private health-related information, the apparent need for second opinions and clarification of treatment or disease-related outcomes, and the frequency with which users access Web-based resources. Although many uncertainties remain about Web-based consulting, electronic communication, and Internet-based information, surgeons should consider offering this mode of communication to their patients, and respond when they use it.

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