A 67-Year-Old Man Who e-Mails His Physician

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DR SHIP: Mr S is a 67-year-old retired public service worker who lives in the Boston area with his wife. He has Medicare and indemnity insurance.

Approximately 4 months ago, Mr S started to communicate by e-mail with his hospital-based primary care physician Dr G, using the hospital's secure Internet site for patients. Previously, Mr S would call his physician with questions and leave a message. He now finds electronic communication both easier and faster. He has not encountered problems with this form of communication and has few concerns about privacy. Mr S tries to keep his e-mails brief because he feels that his physician's time is valuable. Mr S understands that it takes time for his physician to respond to e-mail questions and says he would be willing to pay additionally for this. However, he is not sure how much such service is worth.

Mr S has a medical history significant for prostate cancer, which was resected several years ago, osteoarthritis, allergic rhinitis, obstructive sleep apnea, and hypertriglyceridemia. His medications include gemfibrozil, 600 mg twice a day; naproxen sodium, 500 mg twice a day; aspirin, 81 mg/d; and budesonide nasal spray, 2 sprays in each nostril daily. He has no drug allergies. He smoked one pack of cigarettes per day for 15 years and quit at age 35. He drinks alcohol socially.

Mr S wonders if electronic access to his medical record and e-mail communication could be expanded to all his physicians.

MR S: HIS VIEW

Formerly, I would pick up the phone, call the health service, pose a question, and ask that my physician get back to me by phone. This way, I go right in. I can e-mail specific items that I would like to know about, different appointments that I might have, or problems in my health I might think of. And he e-mails me back, and so far it's worked out very well. e-Mail is great because you can sit down and you can compose something or write it out so you've touched on everything, whereas, with a telephone conversation you might get off the telephone and 5 minutes later, say, "Gee, I wish I had said that."

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I probably e-mail my doctor once every 2 weeks. If I have a concern, it might be more often than that. I think that health issues are important, and by e-mailing my doctor and getting responses, I can print them out and refer to them later. If the message is just about, "What do you think of this?" or I might have read an article and want some ideas, I'm not too concerned [about response time]. If it's something with my general health, I'd like to see the doctor respond within 1 or 2 days.

I haven't tried to access all [parts of] my patient records. I think it would be helpful, because I think it would give me an idea of what my doctor's thoughts were about my care. I think it is part of the whole process of interacting with the doctor. I think if a patient had access to his chart and he found something in there which he had concerns about, then it would be helpful to e-mail the doctor and say: "I have a concern that this is not correct." But I don't think the patient should be able to edit out anything on his own, because I think those are important issues that the doctor has to look at.

I know that on the present PatientSite, some physicians are not involved at all, and I'm just wondering if it's just the newness of the program or if they're too busy. I think if it could be expanded to other doctors that would be helpful. (Author's note: Beth Israel Deaconess Medical Center maintains a Web site that enables patients to view their medication and results of their diagnostic studies; request prescriptions, appointments, and referrals; and communicate with their physicians.[1])

DR G: HIS VIEW

Generally, so far, a lot of these e-mails replace a conversation I might have had with the patient on the phone anyway. Before I started doing a lot of e-mail with patients, I know [my colleagues and I] had concerns that we'd receive "rambling novels" of e-mails. I have not found that to be

true. My perception is that an e-mail interchange with the patient takes less time than a phone communication. The reason is that the patient actually has to think a little bit more about what their question is when they e-mail me, so it tends to be more focused. I think in an average day I probably spend 10 to 20 minutes on e-mail with patients. At this point, I'm not convinced it saves me time, but I'm not convinced it costs me time either. For some issues, it saves me time over the phone, but it doesn't obviate the need for phone calls entirely.

I have had increasing numbers of e-mails from patients asking me about things they saw on television or read, or perhaps their cousin is taking this drug instead of the one they're taking. I think in that case an e-mail adds value for the patient, although it probably creates something for me to do that I wouldn't have had to do if this medium didn't exist. To the extent that these questions are relatively simple, it's probably not too bad. However, having said that, I do feel strongly that physicians have to start getting reimbursed for doing this service. One thing that is neat about e-mail is its intrinsic record. If you needed to prove to an insurance company that there was an interaction, it's easy to do.

Some people have advocated letting patients actually add to or edit their record. I feel fairly strongly that that's not something I'm interested in having patients do, although I certainly would support people's ability to correct inaccuracies in their record. The main reason is not so much that I have any issue with them looking at my notes, but my understanding is that if I allow them to look at my notes, then they can look at anyone's notes. I really don't want to find myself trying to explain why other doctors wrote what they wrote. I also don't want to start to get into having a patient version of the record and a doctor version of the record. I know some people are interested in that, but as a busy primary care doctor that scares me a bit.

I think it is a concern that a patient might find out something really worrisome directly from the Web site, rather than from the physician. However, I have personally never had anyone come across something that really was troubling before I knew about it. There's a separate issue. Is it good for patients, and does it improve their care? I suppose, by definition, they like having the information or else they wouldn't look at it. But does that help them to understand their medical conditions, and ultimately does it lead to them being healthier? That is the really big question.

AT THE CROSSROADS: QUESTIONS FOR DR SLACK

How has e-mail access to clinicians affected patient-physician communication, patient care, and physicians' lives? What qualitative and financial issues are raised by electronic access and e-mail communications? What issues are raised by patients' electronic access to their medical records, and how does such access improve and/or complicate care? What

other forms of patient communication with computers may prove helpful? What do you suggest to Mr S?

DR SLACK: Mr S and Dr G speak approvingly of computer-based communication in primary care medicine. Given the enormous place that computers occupy today in so many of our lives, it is difficult to remember that barely more than a quarter of a century ago, this technology was all but unheard of outside of a small circle of computer specialists.

e-Mail in Medicine

e-Mail first emerged in clinical facilities in the 1970s, in conjunction with early hospital information systems.[2] At the time, few foresaw the extent to which e-mail would revolutionize communication.[3] In 2 Boston teaching hospitals, a home-grown e-mail system designed originally to expedite communication between computer system users and developers, rapidly evolved into a cybermedicine lifeline that greatly enhanced communication.[2,4] Ten years after its introduction, physicians, nurses, and other clinicians at these 2 hospitals were reading over 40 000 messages per week.[4] Since the 1980s, e-mail between clinicians has been reported with increasing frequency.[5-9]

There is no way to know when or where the first e-mail message was sent between a patient and physician, but it likely occurred in the dawning days of the Internet; the first published reports appeared in the 1990s.[10,11] When an immediate response is not required, e-mail enables communication between Mr S and Dr G at any time, at their own convenience, and without untimely interruptions. In a medical emergency, there is no substitute for the pager and telephone, but emergency situations aside, Mr S feels that e-mail enables him to be more thoughtful, inclusive, and succinct with his messages to Dr G. In addition, both Mr S and Dr G can save copies of their messages for later review.

Studies reported thus far tend to support Mr S's assessment. In surveys of people who, for the most part, were not yet communicating by e-mail with their physicians, the majority of those who responded were in favor of doing so— 65% of 87 adults questioned in a university-based clinic,[10] 70% of 476 adults questioned in 2 university-affiliated primary care settings,[12] 74% of 325 parents questioned in a group of pediatric clinics,[13] and 65% of 954 users of a medically related Web site who were questioned online.[14] In an online survey polling patients already using e-mail with University of California, Davis clinicians and other medical staff members, of 232 who participated (response rate, 37%), 25% were satisfied and 61% were very satisfied with this use.[15] Of the 6% who were dissatisfied, the principal reason given was a delay in the clinic staff's response time. Six of the 8 clinicians interviewed as part of the study indicated they were satisfied with their use of e-mail with their patients. The most messages any clinician received was 6 per day.

Mr S would like e-mail access to all of his physicians, but not all of them have as yet agreed to communicate online with their patients. Some physicians who have responded

to surveys have expressed concerns that patients will overwhelm them with messages.[12,16] On the other hand, a mail survey (response rate, 88%) of 178 physicians in university-affiliated ambulatory clinics who had used e-mail with their patients (with a mean of 7.7 messages received per month) found that 60% were "satisfied" with their messages "all or most of the time," 29% were "satisfied" "some of the time," and 55% believed that compared with telephone calls, e-mail with patients "saves time."[17] Still, there are few studies from which to generalize, and whether physicians of the future will be overwhelmed by incoming messages remains an open question and a source of concern. Mr S sends Dr G a message about once every 2 weeks. Dr G in turn spends between 10 and 20 minutes daily communicating with patients by e-mail. By recent count, 160 of Dr G's fellow physicians affiliated with Beth Israel Deaconess Medical Center handle an average of 1 message per day for each 100 patients among the 17 666 total patients in their practices using the medical center's Web site.[1] However, usage ranges from 1 physician who receives messages from as many as 20 per day, to other physicians who rarely communicate via e-mail and only with reluctance.[18] In Dr G's experience, superfluous messages are not a problem. He interprets lengthy or complicated messages as a signal to telephone the patient or to schedule an office visit. Dr G also believes that the time he spends responding to e-mail from his patients is about equal to the time he saves in telephone conversations with them.

Physicians also have concerns about breaches in confidentiality,[12,13,16] although messaging systems that use secure Web sites can effectively fend off unwarranted intrusions. The physicians and patients in the University of California, Davis, study used a secure, Web-based messaging system,[15] as do Mr S and Dr G.[1] Reports of use of these systems are thus far, few in number. On the other hand, this technology should become more available at lower costs as health-related institutions increasingly use the Internet for communication with patients.

Dr G feels strongly that medically related e-mail should be considered an integral component of a patient's care, and that whoever pays for the care should also pay for such services. Other physicians agree.[16,17,19] In response, insurers have begun to consider methods of reimbursement, such as an annual subscription rate with unlimited use for the patient and a stipend for the physician, and, alternatively, as a fee to the physician for each use, with or without a co-payment by the patient.[20-22] On a trial basis the University of California, Davis, physicians have received $25 from an insurer for each online communication with a patient.[15,23] Still, as with all current and proposed plans for medical payment, the future is uncertain.

Legal issues may arise with e-mail between patient and physician. As an additional, complementary record of good medical care, e-mail could be used in support of the physician in the courtroom. Of 178 university-affiliated physicians who responded to a survey, 40% agreed that e-mail "enhances documentation for medicolegal purposes"; 32%, however, disagreed.[17] To date, no malpractice suits have been reported in conjunction with the use of e-mail in medical practice.[24]

Whether e-mail between patient and physician will improve the quality and efficiency of patient care remains to be determined. In a recent study in 2 university-based primary care clinics, where 24 staff physicians and 74 resident physicians were randomly assigned either to an intervention group, whose members used e-mail with their patients, or to a control group, the investigators found no significant difference over a 10-month period in either the number of phone calls to the clinic or the number of missed appointments.[25]

Clearly, however, e-mail between patient and physician is on the rise,[19,26] and guidelines for appropriate topics, content, turnaround time, and documentation are now available to help patients and physicians use this new technology with protection of both sender and receiver.[27,28] Preliminary evidence from the 2 primary care clinics[25] indicates that guidelines can be effective. A content analysis of 273 messages (randomly selected from 3 007 messages) revealed that patients, who had been advised in advance to focus the content of their messages, to limit the number of requests per message, and to avoid urgent requests or highly sensitive content, for the most part, adhered to the guidelines. There were no urgent messages; sensitive content pertained primarily to psychiatric medications; single requests were the rule, and the tone was "generally formal, concise, and courteous."[29]

In spite of the uncertainties,[30] I believe that e-mail will for the most part prove to be convenient and efficient for those patients and physicians who acclimate to its use. A related issue, also of importance to Mr S and Dr G—whether the shared medical record will help in important ways to improve communication between patient and physician—remains to be determined as well.

The Medical Record Shared

Until the past few decades, the time honored, hand-written medical record was in most medical centers a classified, "eyes only" document, restricted to use by clinicians, administrators, accountants, and lawyers.[31,32] Information in the hands of the patient was deemed dangerous as the patient might misunderstand, misinterpret, or be unduly traumatized by the medical message. Patients were to receive only limited information, parsed out with utmost care. With the best of intentions, some physicians used deliberately complex terminology in the presence of patients—"supratentorial" for psychiatric, "mitotic bodies" for cancer, and "hydroxylated radicals" for alcohol—to protect patients from fully understanding their conditions. Prescriptions were written in Latin, which, in fact, helped to prevent communication.

On the other hand, information in the paper record was all too often disorganized, illegible, and hence incompre-

hensible to the physician as well. Not until the 1960s, when Weed presented the case for a "problem-oriented" record that would "guide and teach," would there be a considered effort throughout the United States to reorganize the medical record into a more functional document.[33,34]

In 1970, I proposed that patients and physicians alike would benefit if medical records were declassified, shared, and developed jointly by patient and physician.[34] A digital computer, programmed to interact directly with a patient to take a medical history, offered the opportunity to experiment along these lines.[35] The first patient to be interviewed by the computer became quickly engaged, and later, when his summary began to print, in a legible but otherwise conventional format, he asked, "May I read that?" and in a break with longstanding tradition, he read his medical record and discovered errors that needed correction. The computer interview had been, and in our experience, would continue to be a convenient, acceptable means to share the medical record at a time when sharing was controversial and resisted in the traditional setting.

In 1973, Shenkin and Warner proposed federal legislation to require physicians and their clinical facilities to provide patients with their medical records.[36] They predicted that such openness would improve the patient-physician relationship, as well as the accuracy of records and the quality of medical care. In the ensuing decades, even without legislation, physicians both in the United States and abroad became increasingly interested in the effects of sharing medical records.[37-39] In a comprehensive review of the literature[40]—12 studies in the 1970s, 21 in the 1980s, and 23 since 1990—Ross and Lin found 7 studies, including 3 that used controlled trials,[41-43] that showed improved communication between patient and physician when records were shared, and 10 in which patients who read their records found errors in need of correction. Although patients in psychiatric settings were frequently disturbed by what they read,[44] Ross and Lin concluded that the shared records did not generate substantial anxiety or concern in most studies. They cautioned, however, that the studies were of limited quality and would serve more to help generate hypotheses for future research than to provide direction for current clinical practices. Still, the results are encouraging, and the outcomes might have been substantially more favorable had the records been prepared with the expectation that patients would read them, which apparently was not the case in most of the studies.

In 1980, investigators brought together 2 physicians, a nurse practitioner, and a social worker who agreed to co-author their medical records with their patients.[45] The records evolved with a high degree of satisfaction among all participants. The clinicians' early apprehension about exposing their patients to what had been confidential information gave way to a gratifying improvement in communication. The principal problem for the clinicians was the additional time required during the coauthorship.

Regardless of study results, shared records are here to stay. In 1990, the British paved the way with the Access to Health Records Act,[46] and the proposal originally put forward by Shenkin and Warner has come to pass in the United States with the Federal Health Insurance Portability and Accountability Act (HIPAA) of 1996, which requires that patients must be able to see and get copies of their records and request amendments.[40,47] Logistical difficulties associated with access to the paper record have now replaced the more traditional concerns as the principal barrier to the shared medical record.

The Computer and the Medical Record

The digital computer appeared on the hospital scene in the 1960s, first in financial offices and then, with the rudiments of an electronic medical record, in laboratories and clinical departments.[48] In subsequent decades, workers in the United States and abroad turned with increasing activity to develop and implement cybermedicine systems to help in the practice of medicine.[49] Although progress has been slow—most computing in US hospitals remains financial rather than clinical, the electronic medical record is still more the exception than the rule and the computing is all-too-often undependable[50,51]—there are cybermedicine systems in both the United States and internationally that have proved highly useful to physicians in the care of their patients.[52-59]

At any time of day or night, Dr G and his colleagues can sign on to their computing system to obtain results of diagnostic studies; access biomedical literature,[60] read advice, alerts, reminders, and e-mail; and receive assistance in the day-to-day practice of medicine from terminals located throughout the hospital, in ambulatory clinics, in private offices, and in their homes.[2,9,61,62] The benefit of cybermedicine for the clinician raised the question of whether it could help the patient as well. The response was to begin to create secure Web sites that could give Mr S, and other patients with Internet access, a messaging system that would be a secure way to communicate with their physicians; a means to view their medications, upcoming appointments, and results of their diagnostic studies; and request prescriptions, appointments, and referrals.[1,63-66]

Mr S likes to access the results of his laboratory and radiographic studies over the medical center's PatientSite.[1] He would also like to access Dr G's narrative, but physicians' notes, even when part of Mr S's electronic record, are not yet available via PatientSite. Dr G would be comfortable if his patients read his notes, but not the notes of other physicians, because he would have no control over such records. If in the future physicians' notes were prepared in electronic form with the expectation that patients would read them, and with due consideration of patients' feelings upon reading the notes, Dr G's concerns could be mitigated. Early results in a recent study at the University of Colorado showed that physicians' concerns tended to abate once their patients were granted access to electronically recorded narrative notes.[67] Mr S and his fellow patients would then have

ready access to their write-ups in a legible, comprehensible form, and the advantages of shared records could be substantially augmented. Upon reading the notes, patients could relay questions, comments, and suggestions to help their physicians with the accuracy of their records.

Studies to date of the shared medical record have focused primarily on the patient's perspective. For the busy physician, an increase in the time required in dialogue with the patient, and the dilemma of how best to record controversial and potentially litigious issues, could present formidable problems. On the other hand, shared electronic notes, if well documented, mutually understood, and agreed upon by patient and physician, could actually improve the quality and efficiency of the clinical transaction and serve as a protection against unwarranted lawsuits.

Possibilities for the Future

Although dialogue between patient and physician is the mainstay of clinical medicine, practitioners face problems when it comes to dialogue with their patients.[68] Incomplete histories and insufficient counseling can result from limitations in time beyond the physician's control. As one possible solution, Bachman has argued for greater use of computer-based medical histories in clinical practice.[69] In support, he reviewed 61 studies from 1966[35] through 2001,[70] in a diversity of geographical and clinical settings, some controlled, some descriptive, that indicate that dialogue between patient and computer has the potential to yield histories on a wide variety of medical and psychological problems. Patients were positive about the computer interviews in 43 of the 45 studies that included their assessment. Physicians' responses were positive about the process in 10 of the 18 studies that included their assessment, mixed in their reaction in 6, critical (less accurate) in 1,[71] and negative in 1.[72] The computers' summaries were more inclusive of sensitive information than were the physicians' summaries in 25 of the 28 studies in which comparisons were made. On the other hand, false positive information was a problem in some of the studies.[35,73,74]

As a practical matter, it has been hard for clinics to provide the computers, protected space, and administrative overhead required for these interviews. Now, however, with the availability of the Internet—Mr S and more than 100 million other individuals already use the Internet to obtain health-related information[75,76]—it should be possible to deliver to patients, in their homes, interactive, private interviews that obtain their medical histories and, with a possible savings in physicians' time, incorporate the results into patients' electronic medical records, readily available to both patient and physician. The interviews could also offer health-related information and links to additional reputable medical Web sites that could help relieve Dr G and his fellow physicians of some of the time currently devoted to responding to patients' questions. More research is needed, however. Whether computer-based interviews will prove to be economically feasible, clinically worthwhile, and acceptable to patients and physicians remains to be studied.[77] But now with the Internet, such studies are at least possible.

In the future, the interactive computer could supersede even the telephone consultation for some common medical problems. It can be argued that the largest, yet most neglected health care resource worldwide is the patient or prospective patient, and that the interactive computer is well positioned to help patients to help themselves.[78] Years before the availability of the Internet, a computer program for women with urinary tract infections took a history of the present illness, performed a review of systems, provided instruction for the collection of a urine specimen,[79] interpreted laboratory data, presented options for therapy, addressed the patient's priorities, incorporated the patient's decisions into choices about therapy, wrote a prescription (signed by a physician), wrote documentation for the chart, scheduled a follow-up visit, and wrote a summary (with reminders) for the patient.[80] In a preliminary trial of 36 women who completed the program (10 others were referred by the program to a physician for further evaluation), 35 decided to take the treatment of choice at the time, sulfisoxazole for 10 days , and 1 decided to wait for the results of her culture, which were negative. The patients reacted positively to the program, and when asked, "How has it been to decide for yourself about sulfa?" 30 found it to be "a good thing." Clearly, much more research is needed. But if programs such as this can be demonstrated by careful study to help patients to help themselves, these programs could be made available over the Internet to people in their homes, as well as in other protected and convenient places.

In these litigious times, physicians understandably worry that shared medical records and electronic communication will make them more vulnerable to litigation.[24] It is possible, however, that the opposite will prove true. As Shaw once observed, poorly informed and subservient patients have tended to regard their physicians as omniscient and are incredulous when outcomes are unfavorable.[81] Perhaps the more we welcome our patients as colleagues, and the more they participate in medical decisions, the more they will share with us the responsibility for these decisions, and the more physicians will be free of the inappropriate liability that accompanies medical paternalism.[82]

Finally, what of the digital divide? Although personal computer access started out in the hands of a few, it is now available to many more people; the computer is becoming democratized as well as democratizing. As with all health-related information directed to the patient, users of the Internet must be careful to consider the source and seek additional opinions; misinformation co-mingles with the useful and well founded. Despite potential hazards, it is possible in the future for well-developed, well-studied, and interactive programs addressing the individual needs of patients to be a powerful form of adjunctive therapy in primary care, available to ever-wider segments of the population.

My advice to Mr S and Dr G is for them to stay on course. They are among the pioneers in the use of electronic communication between patient and physician. I hope that they will continue to find their online programs helpful; to try new programs as they become available; and to offer advice and suggestions to physicians working in the field. There are real dangers with the misuse of electronic communication in medicine such as depersonalization, true dehumanization, breach of privacy, and a disruptive wedge between patient and physician, and we must keep our guard up. On the other hand, if used wisely and well, this powerful new technology has the potential to make the practice of medicine more satisfying for the physician, to augment the relationship between the patient and physician, and to improve the quality of medical care.

QUESTIONS AND DISCUSSION

A PHYSICIAN: In my opinion, the focus on confidentiality is much ado about the wrong thing. I suspect privacy is gone forever, and we should spend our time working on how to deal with a lack of privacy, rather than trying to preserve it. Although physicians are incredibly concerned about confidentiality and privacy, many patients are more interested in learning about their illness than keeping everything private. What do you think is going to happen with this issue of confidentiality?

DR SLACK: I believe confidentiality is very important, but people do differ in the importance they place on this. We have devoted much effort in our hospitals to protect the confidentiality of information within our walls with passwords and audit trails.[2,4,9,83] In some ways, we can protect the privacy of electronic records better than paper charts. Now, of more concern to me than the protection of confidentiality within the walls of a hospital is the protection once clinical information leaves the hospital. For purposes of reimbursement, hospitals and clinics are required to send confidential clinical information—diagnoses at a minimum—linked to charges, to a broad array of third-party payers, strangers if you will who are beyond the control of the hospital, doctor, and patient. I suggest that we stop sending confidential clinical information to the payer.[84] We can develop a system that would group charges on the basis of mutually agreed-upon costs for preventive, diagnostic, and therapeutic measures, and the charges, separated from their clinical antecedents, would then be sent on to the payers, with provisions for internal review as well as for review by independent, external auditors to ensure the legitimacy of the charges.

A PHYSICIAN: For specialists, I think our local PatientSite approach needs to be considered differently. For example, in oncology, speaking for many of my confreres, we have certainly eschewed paternalism. But in some instances, our patients using PatientSite find their CT scan or MRI results before we have had a chance to review them and articulate a plan. What usually follows is a lot of time on our part just calming someone down or dealing with an appropriate grief reaction. The machine simply cannot substitute for the empathic consideration of a caring doctor.

DR SLACK: I agree entirely and provisions have been built into PatientSite to delay access to emotionally charged information. Thoughtful people are working on this issue. The law now says that any patient who asks for a record can have it at any time. So we must collectively solve this issue to serve and protect both patient and doctor.

A PHYSICIAN: One downside to sharing medical records with a patient is that the medical record, as written by the doctor, does not contain everything that the doctor is thinking. The reason is that often the doctor is uncertain. We fail to recognize the importance of uncertainty, but the patient doesn't like uncertainty. The patient is very anxious—much more than the doctor. How would you address that?

DR SLACK: I would suggest an uncertainty folder for the physician, which belongs only to him or her, and is not available to the patient. This would be the written equivalent of "mental notes," shared only at the discretion of the physician, not part of the medical record, not subject to subpoena, and erased when no longer useful.

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