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What Do Patients Do with Access to Their Medical Records?

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Abstract

We sought to study the phenomenon of patients having access to their own medical records in order to determine the impact on them and on their relationship with their health care providers. We created the Patient Clinical Information System (PatCIS) to interface with the clinical data repository at New York Presbyterian Hospital to allow patients to add to and review their medical data. We also provided educational resources and automated advice programs. We provided access to the system to thirteen subjects over a nineteen-month period and reviewed their activities in the system's usage log. We also collected data via questionnaire and telephone interview.

We found that patients varied in their use of the system, from once a month or less to one or more times per day. All patients primarily used the system to review laboratory results. Both they and their physicians believed that use of the system enhanced the patients' understanding of their conditions and improved their communication with their physicians. There were no adverse events encountered during the study.

Keywords

Consumer Informatics, Electronic Medical Records, Personal Health Records, World Wide Web

Introduction

Patients in the US have the right to review their medical records. Although preliminary studies in the US and elsewhere have shown that provision of psychiatric records to patients is generally met with a positive response,[1-4] the overall effect of such access on patients' understanding of their conditions and their relationships with their providers is unknown. With the increased availability of electronic medical records, researchers are experimenting with the provision to patients of some or all of their records via mechanisms such as the World Wide Web.[5-8]

We have developed a Web-based interface to the New York Presbyterian Hospital clinical data repository intended for use by patients to review their own records. Called the Patient Clinical Information System (PatCIS), it serves as a framework for a variety of applications for data entry, data review, education, and advice. We have previously reported on early experience with PatCIS usage [9] and user experience [10] during its pilot period. In this paper, we report on the usage of and experience with PatCIS by 13 subjects over a period of 19 months.

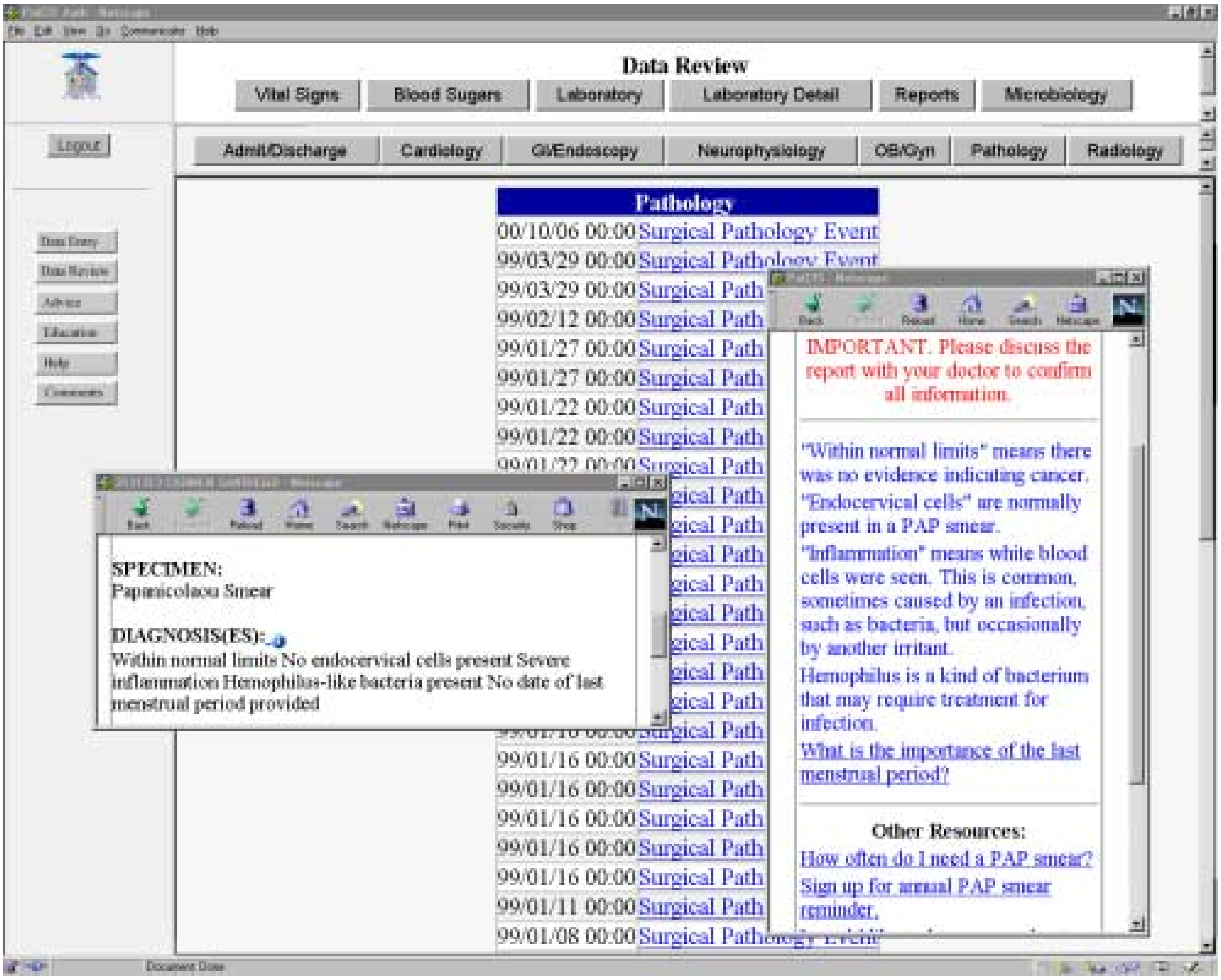
Materials and Methods

PatCIS Architecture

The architecture of PatCIS has been described elsewhere.[11] Briefly, it is a Common Gateway Interface (CGI) program that presents a set of applications to patients, organized into the following categories: Data Entry (writing information into the clinical record), Data Review (reading information stored in the clinical records), Education (information resources on various topics), and Advice (application of patient data to online guidelines), by referencing a table of application names and CGI references. We also incorporated “infobuttons,” which pass patient-specific information to programs that generate patient-specific educational messages.[12]

When users select a button with the application name, the CGI reference is passed to PatCIS, which carries out several steps:

- Timeout: Checks for the time since last activity and, if greater than 5 minutes, requests reentry of the password
- Security: Verifies the session is valid and that no session parameters (user ID, medical record number, IP address of the user's browser) have been altered
- Logging: Records the requested function in the usage log
- User function: calls the requested CGI and passes the results back to the user's browser



Pathology

00/10/06 00:00 Surgical Pathology Event
99/03/29 00:00 Surgical Pathology Event
99/03/29 00:00 Surgical Path
99/02/12 00:00 Surgical Path
99/01/27 00:00 Surgical Path
99/01/27 00:00 Surgical Path
99/01/22 00:00 Surgical Path
99/01/22 00:00 Surgical Path
99/01/16 00:00 Surgical Path
99/01/16 00:00 Surgical Path
99/01/16 00:00 Surgical Path
99/01/16 00:00 Surgical Path
99/01/16 00:00 Surgical Path
99/01/11 00:00 Surgical Path
99/01/08 00:00 Surgical Pathology Event

SPECIMEN:
Papanicolaou Smear

DIAGNOSIS(ES):
Within normal limits No endocervical cells present Severe inflammation Hemophilus-like bacteria present No date of last menstrual period provided

IMPORTANT. Please discuss the report with your doctor to confirm all information.

"Within normal limits" means there was no evidence indicating cancer.
"Endocervical cells" are normally present in a PAP smear.
"Inflammation" means white blood cells were seen. This is common, sometimes caused by an infection, such as bacteria, but occasionally by another irritant.
Hemophilus is a kind of bacterium that may require treatment for infection.
What is the importance of the last menstrual period?

Other Resources:
How often do I need a PAP smear?
Sign up for annual PAP smear reminder.

Figure 1 – A typical PatCIS screen. On the left are general classes of functions. Here, the subject selected "Data Review," which produced the list of buttons at the top of the screen. The subject then selected "Reports," which produced a second list of buttons. The subject selected "Pathology" to obtain the list of reports. When the subject selected a report, the small window on the left was displayed, showing the details of the report. This particular report contains an "infobutton" that, when selected, provides explanatory information (small window on right) about the findings in the

In some cases, the documents returned by the CGIs contain links and function calls. When these documents are created by CGIs that are part of PatCIS, they too will call the PatCIS CGI, repeating the process above. Figure 1 shows a typical PatCIS screen.

Review of Log Files

To determine how subjects used PatCIS, we examined the log files from April 1999 through October 2000, inclusive (19 months). We considered a session to start with a successful log on, followed by use of one or more PatCIS functions. Sessions were considered to have ended at the time the subject selected the "log out" function or, if the subject did not use the log out function prior to the next log on, the time of the last function in the session. Session

activities were tabulated based on the function or CGI call the subject selected. Figure 2 shows a sample of a log file.

On-line Questionnaires

We surveyed subjects with two questionnaires. Subjects completed the first questionnaire the first time they logged on to PatCIS. These questionnaires assessed subjects' demographics, subjects' perceptions of their relationship with their health care provider, expectations about the system, and prior computer experience. We e-mailed the second questionnaire to subjects after nine months of system usage and assessed the usability of the system and changes in subjects' perceptions about their expectations and their relationships with their providers.

Telephone Interviews

Phone interviews were conducted with subjects and their physicians after nine months. Interviewers sought to determine subjects' perception of the usefulness of various PatCIS features, to understand patterns of use, to identify

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sandcar!Fri Oct 27 11:32:22 2000!cim.cpmc.columbia.edu!|patcis^login
sandcar!Fri Oct 27 11:32:24 2000!cim.cpmc.columbia.edu!|patcis^Data Review
sandcar!Fri Oct 27 11:32:28 2000!cim.cpmc.columbia.edu!|patcis^Data Review^
     Laboratory Detail^lab_detail.cgi
sandcar!Fri Oct 27 11:32:30 2000!cim.cpmc.columbia.edu!|patcis^Data Review^
     Laboratory Detail^labSum.cgi
sandcar!Fri Oct 27 11:32:35 2000!cim.cpmc.columbia.edu!|patcis^logout
```

Figure 2 – Sample records from PatCIS usage log, showing a simple session in which a subject (user ID "sandcar") signed on, selected the "Data Review" button (Figure 1), the "Laboratory Detail" button, a single test result (to produce a summary report), and then logged off. The session took 17 seconds.

impact on subjects' decision making, and to characterize any influences on the patient-provider relationship.

Results

Subject Enrollment

Thirteen subjects were enrolled between April 1999 and October 2000. One subject never used the system. Another subject dropped out of the study after five months, due to retirement from employment (with attendant loss of computer access). Follow-up periods for the remaining 11 patients were considered to be from date of enrollment through October 2000. The average follow-up period for all 12 active subjects was 10 months.

Subject Characteristics

Eight of the thirteen subjects were male. Two of the male subjects listed their ages as ">65," while the rest of the subjects listed "40-64." Eight of the ten subjects who answered the question about educational level had a college degree or higher. All of them reported using computers for more than two years on a daily basis. They unanimously agreed that the Web was likely to improve communications between patients and providers, and all but one agreed that the Web would change health care.

Table 1 – Number of active PatCIS sessions by month

Subject:	1	2	3	4	5	6	7	8	9	10	11	12	13
Apr-99	1												
May-99	2	0	7										
Jun-99	0	0	24										
Jul-99	0	0	11	0	0								
Aug-99	1	0	15	6	0								
Sep-99		0	8	7	0	4							
Oct-99		0	7	3	0	3	0						
Nov-99		0	3	13	0	0	0						
Dec-99		0	8	7	0	1	0	9					
Jan-00		0	13	19	0	1	0	3					
Feb-00		0	1	15	0	0	0	6					
Mar-00		0	7	43	0	4	0	3					
Apr-00		0	4	0	0	1	0	3					
May-00		1	9	9	0	1	2	3	0	1	1		
Jun-00		0	5	45	0	2	0	2	0	0	0		
Jul-00		0	5	13	0	4	0	2	0	0	0	1	
Aug-00		0	7	10	0	0	0	2	2	0	0	0	3
Sep-00		0	12	18	0	8	0	3	3	0	0	0	0
Oct-00		0	12	14	0	0	0	1	1	0	0	0	1
Totals	4	1	158	222	0	29	2	37	6	1	1	1	4

System Usage

Twelve subjects logged on a total of 630 times during the study period. These included 131 failed log-on attempts of which 61 (46.6%) were due to 5 events in which subjects tried repeatedly to log on with incorrect user IDs or passwords. In each case, the subject persevered and ultimately logged on successfully. The remaining failed log-on attempts were isolated events scattered across all subjects throughout the study period. In an additional 33 log ons, subjects did not select any functions. The activities occurring in the remaining 466 sessions were studied.

Active subjects had between 1 and 222 active sessions

Table 2 – Activities in 466 PatCIS sessions

Data entry: 73 total
- 34 vital signs
- 39 diabetes flow sheets

Data review: 1831 total
- 1518 laboratory results
- 36 vital signs
- 35 diabetes flow sheets
- 212 reports (incl. 81 radiology, 35 pathology)
- 30 Microbiology

Advice: 6 total
- 5 cholesterol guideline
- 1 mammography guideline

Education: 53 total

Other: 135 total
- 10 newsgroups
- 83 infobuttons
- 2 comments
- 10 e-mail to physician
- 17 disclaimer
- 13 help

Total: 2098

(average: 38.8) during the study period, with between 0 and 45 sessions per month (average: 4.0). Table 1 shows the distribution of active sessions for all subjects during the study period.

The session duration ranged from less than one minute to 66 minutes (average: 5.7); 391 (83.9%) of the sessions were ten minutes or less, 58 (12.4%) of the sessions were eleven to twenty minutes in duration, with only 17 (3.6%) being longer than 20 minutes. During the sessions, subjects carried out a total of 2098 actions (shown in Table 2). This represents an average of 4.5 actions per session: 320 sessions (68.7%) had five or fewer actions, 102 sessions (21.9%) had six to ten actions, and 44 sessions (9.4%) had greater than ten actions (31 maximum).

User Experience

Of the eight patients who were in the study nine months or more, five responded to the follow-up questionnaire. One of these was Subject 5, who never actively used the system. He was therefore unsure about the benefit of PatCIS. Responses from the other four patients are shown in Table 3.

These five patients were also interviewed by telephone. Those that used the system reported that the system was easy to use, easy to understand, and improved their health care by allowing them to take a more active role. They experienced some difficulties with some of the system features (particularly the graphing function) and some problems with system response time. Their overall impressions ranged from “very impressed, a step in the right direction” to “excellent program.”

Table 3 – Number of subject responses (using a five-point scale) on the follow-up questionnaire

Question	SD	D	U	A	SA
I find PatCIS useful			1	1	2
I am willing to enter my own data into my record using the WWW				3	1
I am willing to review my own health information using the WWW				2	2
PatCIS has improved my interactions with health professionals				1	3
PatCIS has improved my understanding of health and illness		1			3
PatCIS has changed how my health care is managed			1		3

SD=Strongly Disagree, D=Disagree, U=Unsure, A=Agree, SA=Strongly Agree

Clinician Experience

All three of the physicians who provided subjects for the study were interviewed. They were generally aware that their patients were using PatCIS and that it was helping them understand their illnesses better and gain better control over their own care.

Discussion

At the outset of this study, we were concerned with three cognitive issues related to the use of PatCIS:

1. Would patients be able to use the system?
2. Would patients be able to understand their records?
3. Would use affect the clinician-patient relationship?

Usability

The PatCIS project was created to give patients access to their medical records and to observe the results. No attempt was made to provide a comprehensive framework for a patient-centric view; the clinical data are presented in the same manner that is used to present to clinicians. Nor was any attempt made to provide training or guidance in the use of the system, under the assumption that such support would not be feasible if the system were to be made generally available. Despite these potential obstacles, the majority of patients who have tried PatCIS have used it successfully. The resulting experience extends our knowledge about patient access to electronic medical records.

As shown in Table 1, the ways in which subjects used PatCIS varied greatly. Some patients had one or two active sessions and then did not use it further during their remaining follow-up periods (4-6 months), while others used it on a monthly, and sometimes daily, basis. This variability may reflect differing perceptions of usefulness, but the interview data do not support such a conclusion. Another possibility is that the variation in usage is due to variation in the accumulation of new health data: a patient who has laboratory tests done once a year may have little reason to check his or her record more often than that, whereas a patient who has weekly laboratory tests may log on much more frequently. Patient comments support this conclusion.

Despite a variety of reasons stated for wanting to use the system, our subjects were consistent in being primarily interested in reviewing laboratory results; as shown in Table 2, this accounted for over 72% of their activities. Based on the subjects’ comments, we believe this reflects the high volume of laboratory results in the medical record, compared to other data.

Understandability

Our subjects generally seemed to understand the information they found in their records. Apparently, they did not require educational resources or infobuttons to do so. Although this result is encouraging, it must be interpreted with caution. The subjects in our study were a highly-selected group: they were patients of physicians willing to participate, they were selected by these physicians as being good candidates, they were self-selected by agreeing to participate, and they were able to overcome technological barriers to access (since they were required to enroll on line).

Patient-Clinician Relations

Prior to the study, we conjectured many potential positive and negative impacts that PatCIS use might have on the relationship and interactions between patients and their health care providers. Subjects and clinicians were unanimous in their belief that PatCIS contributed to improvement of both. In particular, both patients and physicians indicated that PatCIS improved the level of communication during patient-physician interviews. No adverse events were reported.

Conclusion

This study demonstrates that patients can be given access to their electronic health records via the World Wide Web and that such access can improve their understanding of their health and their communication with their health care providers. These outcomes suggest the potential for systems such as PatCIS to have beneficial effects on health outcomes through shared workload between the doctor and the patient, resulting in better communication and negotiation. A challenge for future studies will be to extend access to patients from all educational, economic and social backgrounds.

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