The Role of Patients in Transiting Personal Health Information: A Field Study

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Abstract

Recent consumer health informatics initiatives advocate individual access and management of personal medical records. However, little is known regarding the impact of personal access of health information on clinical practice. This paper introduces a field study investigating the usage patterns of personal health records in medical consultations. The self-managed records provide patients with a strong sense of ownership and control over their own health information. Personal medical records have been used primarily for transiting information among different providers. This behavior changed patient-provider communication into a records sharing. Doing so effectively eliminated the potential errors in the verbal reporting process. This study indicates that patients can be effective contributors to their own health and suggest the design of health information systems to rethink the role of patients in the healthcare process and shift the responsibility of healthcare to the patients' side.

Keywords:

Medical records, Physician-patient relations, Cooperative behavior, Access to information, Consumer health information, Information management

Introduction

Recent consumer health informatics initiatives encourage individual access and management of medical records using Personal Health Record (PHR) system. PHR has been previously defined as personal notes documenting important medical information such as medical history and current medications [2, 3]. A large-scale survey [1] shows that approximately 40% of people maintain some form of paper medical records, while only 1.5% use computer tools to manage their health information.

Online PHR is therefore "*an electronic application through which individuals can access, manage, and share their health information and that of others for whom they are authorized, in a private, secure and confidential environment* [4]." PHR is believed to be able to improve patient-provider communication and empower patients to engage into their own health [5-7].

While the focus of current PHR study is usually on the patients' side, accessing and managing personal health information also affects the way in which medical consultation is conducted. The information contained in patients' records is crucial for physicians to make correct medical decisions and to apply optimal care. This information, however, is often managed by individual healthcare organizations where a patient previously sought care. It is notable that to date, there is little information as to how personal managed health records manage in actual clinical practice [4].

This paper describes an observational field study that was conducted in urban China, a place where patients are responsible for maintaining their outpatient medical records. We shadowed doctor-patients interactions in consulting rooms in order to understand the usage patterns of paper-based PHR in the medical consultation process. Our observations suggest that for patients, their medical records are transitional artifacts that carry critical information among the multiple physicians they visit. Using personal health records has turned the question-answering mode of clinical interviews into an information-sharing practice. This ensures the accurate medical history is communicated to the providers. It also fosters an effective collaboration between patient and provider where part of the responsibility is shifted to the patients' side. Maintaining their own health records provides a sense of control among patients and encourages them to be more involved in their own health. These findings can be used to direct future PHR system design and to impact chronic disease management.

Methods

This observational study was conducted in an outpatient department of a large hospital located in urban China. The primary reason this field site was chosen is that outpatient (ambulatory) medical records are routinely kept by individual patients in current Chinese medical practice. We obtained IRB approval from the university the researcher is affiliated with, and the approval of the scientific review board of the hospital being studied. All the participants' names are pseudonyms in order to protect their confidentialities.

Participants

The hospital where this study was carried out is well known for its medical expertise in the fields of ophthalmology (eye) and otorhinolaryngology (ENT). Most patients in these two departments are non-locals looking for second opinions or hoping to be treated for diseases that are untreatable elsewhere. By contrast, the other departments consist mainly of local patients. The whole hospital is under resourced due to the large demand of patients care. To observe the medical records usage patterns in both the departments of expertise and non-expertise, we recruited four doctors from the outpatient departments, including two internal medicine physicians, one eye doctor and one ENT doctor. A total of seventy-six patient consultations were observed during the study.

Data Collection and Analysis

The field observations were intended to identify usage patterns of patients' self-maintained medical records during the consultation process. A total of 40 hours of observations were performed in the consulting room. Each observation session lasted for 4-5 hours. Usually, the researcher sat in an unobtrusive location within the consulting room (Figure 1). The research activities included jotting down brief observation notes, asking questions when patients/physicians were available, and tracking down critical incidents during the observations. Detailed observation notes were transcribed after each session. The researcher is a native Mandarin speaker and previously majored in medicine. This ensured proper understandings of the patient-physician interactions in the consulting room. Overall, over 120 observation notes were summarized.
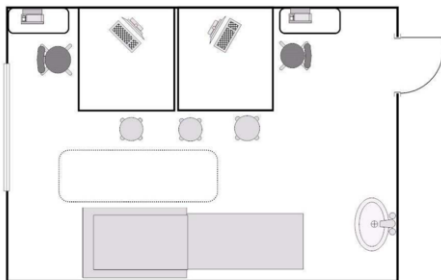

Figure 1- The physical layout of the medical consultation room. The physician sits on the left side at a desk. Student 1 was at the right side desk entering information into the HIS system. The three horizontal chairs were for: patient, student 2, and the observer (from left to right).

The observation notes were coded using an iterative open coding scheme [8] to extract the medical records usage patterns in the consulting room. These findings were verified with participating doctors and other clinicians in the hospital.

Results

In this section, we report medical records usage patterns in the consulting room sequentially following the general clinical workflow in the following three steps: sharing records, checking records and making decisions.

Sharing Records

Keeping one's own outpatient medical records are a predominant phenomenon in Chinese medical practice where patients receive their own records in almost every healthcare organization. Similarly, patients in the current study have full access to their medical records. ***Full access*** means that patients are able to maintain all their medical information generated in healthcare settings, including diagnoses, prescriptions, clinical notes, lab results, and even hardcopies of radiology images. The hospital in urban China is equipped with a Hospital Information System (HIS) where doctors can enter medical orders and diagnoses directly to the HIS system. To ensure that patients have full copies of their medical information, the information typed in the HIS system is always printed out and attached to a medical records book that is used to document their other health information. The records book is used in all healthcare organizations in the region. Patients then keep the records book at home as their own personal health information.

Figure 2- In the Eye consulting room, a family member holding a CT image the patient received from his local hospital – thousands miles away from the study site.

These self-maintained medical records are brought back to the consulting rooms by patients later on. Carrying medical records is a way for patients to share past medical history with current doctors. During observations, patients often came in with a stack of medical record books that they had collected from different healthcare providers or from different time spans, such as from the earliest disease onset to the most recent treatment. In our study, 74 out of 76 patients brought in their own personal medical records.

Xiaoxia is local patient with 20 years of diabetes treatment who also suffers from multiple complications of her illness. She told us why she carries her medical records with her at all times:

> "*I need to go to hospitals frequently. Sometimes when I felt uncomfortable or when I suddenly have a couple of hours free time during work, I just go*

to see a doctor. This small book is easy to carry and I always put it in my purse. That way I don't need to go back home to pick up my records and I can go whenever I want to!"

Later on in the consultation, she took out a couple of medical record books that she recently received from other doctors, including a cardiologist, physician from the community hospital and a Chinese medicine doctor to show her physician. In Xiaoxia's opinion, having medical records is a requisite to seeing her doctors and carrying her records is a convenience that allows her to stay healthy.

Checking Records

Patients have to turn in their most recent medical records to the receptionist with their registration numbers before entering the consulting room. They are allowed to keep with them other medical records, *e.g.* medical records from the past year or smaller pieces of information prepared at home, *e.g.* glucose readings in the past two weeks. The medical records the receptionist takes are then put on the physician's desk for review. The physician's work starts with the placement of the records book on the desk. For the first few minutes of the consultation, the patient just sits quietly and waits for their doctor to review their records.

The review process of the medical records starts from the most recent medical visit, then traces back to earlier visits until doctors get an overview of the patients' situation. In the cases of the Eye and ENT departments, where most patients present with relatively severe diseases, the assistant often requests patients hand in all their past medical records along with original radiology images. The Eye/ENT doctors then carefully examined this information and observe the images before the patient begin reporting their symptoms.

After reviewing the recent records, patients start communicating with their doctors verbally about their feeling and symptoms as well as past medical history and history of present illnesses. The interview process generally consists of a series of questions and answers so that doctors can obtain sufficient information to make their judgments. Hence, the ability to effectively communicate personal health information is closely associated with the quality of personal healthcare. Previous studies [9, 10] show that patient-provider communication may be hindered by the ineffective information reported by patients, especially those who have low health literacy. Similar observations happened in our study where patients frequently faltered and had difficulty answering questions, even when the questions were regarding their own experiences. Many of these moments of communication breakdowns were followed by a medical records sharing session where patients took out written documents that helped facilitate the expression of their thoughts. These documents were mostly the medical records that were not turned in at the beginning of the consultation. Xiaoyi is a local patient who came in to see Dr. Yang. During the consultation, Dr. Yang routinely asked what medications and lab tests she had recently. Xiaoyi pondered for a while and started complaining:

"These pill names are just too hard to remember, I think I will never remember them. You know, I have diabetes, hypertension and heart diseases. I need to take more than 10 types of medications everyday. I am 74 years old and I don't have lots of medical knowledge. How could possibly that I can remember these names myself"

However, after a few seconds of thinking, Xiaoyi took out a small medical records book in which her past medical visits had been documented. She passed this record to Dr. Yang and pointed to a few prescriptions she is now taking. Sharing medical records allows Xiaoyi to report her medical information to the doctors quickly without taking too much effort to remember it. This sharing process is especially beneficial for older patients who might have memory loss and limited medical knowledge. It also saves valuable consulting time in such an under resourced healthcare setting.

Making Decisions

Not only do physicians look to past diagnoses and prescriptions to substitute some oral communication, they also check other information such as radiology images or laboratory tests when it is available to them. To physicians, this information demonstrates a disease's progress from earlier onset to the various treatments already used. It also helps physicians to eliminate their initial hypothesis about an illness. And as physicians almost inevitably request lab and radiology images from patients when reading their basic medical records, medical records help to exclude previously tried medical procedures.

A young man came in with his mother to see Dr. Jiang – a well-known eye specialist. The young man reported a recent loss of vision on his left eye. The loss was getting worse and they suspected that it might be related to an injury that happened seven years ago. Dr. Jiang's first inquiry was about the seven year old injury. The mother took out the records they had received 7 years ago from her purse. Even though the paper records were a bit torn, Dr. Jiang could still get a pretty good sense of what the medical condition was when the injury happened.

After viewing the records, Dr. Jiang did a simple ophthalmoscope check and told the patient:

"Ok, I think you should only take a retinal photograph. You should be able to get results this afternoon. Your precious radiology images seem clear that the lost vision has nothing to do with your injury. You know, it could have cost you weeks to get CT tests here."

Here the personally maintained medical records changed the medical decision making process. Medical decision-making is essentially a hypothetical-deductive process. With more clinical evidence available at the point of care, physicians can eliminate unrelated hypotheses during the initial medical decision-making process. Narrowing down initial hypotheses saves patients from doing unnecessary tests and shortens the overall

diagnosis time. As shown in our observation, for the patients who travel to consult second opinions in the Eye or ENT departments, medical records may save weeks from the waiting time.

Discussion

In this study, we found that personal health records have been used as a means to transmit an individual's professional health information among their various healthcare providers. These medical records are brought to a consulting room and shared with the physician during the consulting process. Patients then add the newly received records to their personal health information repositories. In this section, we discuss the implications of this medical records usage patterns to clinical practice.

Patient-centric Record Keeping

Fragmentation is a term that has often been associated with the current healthcare practice [11, 12]. Fragmentation refers to the fact that an individual's healthcare information may reside in various healthcare organizations that they visited previously. As has been observed in this study, chronic care patients may have routine medical visits with both their primary care physicians and various specialists. Patients who have severe diseases tend to consult multiple experts to pursue the best treatment or obtain second opinions constantly. Many times, past medical records are not accessible at the point of care. Even though we advocate universal Healthcare IT solutions to interoperate different systems in different healthcare organizations, many technical, financial, organizational and political barriers remain in constructing such a universal accessible record-keeping system.

In the current study, the patients' self-maintained medical records shifted record management from provider-centric to patient-centric. The records are no longer kept at a single healthcare organization, but are organized by an individual patient across various healthcare organizations. This individual-based management allows patients to process their life-long medical records and keep information with them conveniently. This concept is much like the integrated online PHR system that incorporates patients' life-long medical records in a safe and secure place [4]. However, the integrated PHR requires huge input from both the providers' side and the patients' side. It requires go-live EMR systems that store patients' information at the providers' side and also Internet access and computer literacy at the patients' side. This study was conducted in an under resourced healthcare settings with many patients who are uninsured and suffering from poverty, yet even in this setting, the patients were capable of managing their own healthcare records. This study proves the values of personal records management from the individual patients' perspective.

Patient-provider Communication

Patient-provider communication is the basis for outpatient practices. In common occasions, patients have to verbally report their symptoms and other medical histories to doctors and continue answering questions that doctors raise. Thus, the quality of the healthcare relies on whether patients can accu-

rately express their needs and answer questions. This, however, may be challenging for those who have low health literacy and educations [9, 10].

Many patients in this study were elderly and suffering from memory loss, and may not have been able to understand what the doctors asked them. In turn, most of times, what they communicated to doctors was generic information about their health. Such as the example showed in the previous section, even though the patient and his mother described the injury incident to the doctor, the information they reported used lay words and may not have satisfied a physician's professional needs. The inaccuracy of self-reported information may be error-prone and lead to medical mistakes.

This verbal communication has been replaced by sharing medical records in this study. Patients always submit their recent medical records book for review before they enter the consulting room. The initial inquiry has changed to a records review session where records from different organizations and time spans are read by doctors. During the medical interview, patients always refer back to their previous records to help answer questions. We have observed many occasions where patients facilitate doctors to locate specific information in the record books, such as one individual lab test result or a particular medical visit. Patients may even bring in records that were obtained many years ago in case it is needed in the consulting process, though this is most often seen when patient present with serious diseases.

This information sharing differs from patients' verbal conversation since medical records are documented by healthcare professionals. In this way, a patient's healthcare information is transmitted among healthcare providers without any alteration. This fosters invisible collaborations among various doctors, across different times and locations. Even though these doctors may never meet, they can use the shared records to collaboratively make their judgment and speculate about earlier disease situations in a way that would otherwise be unavailable to them.

Patient-Provider Collaboration

The shift to a medical records system also affects how physician and patients communicate. Patients often stay passive in the healthcare process. They wait passively for healthcare professionals to collect and review their healthcare information and make their decisions. By managing their own medical records, patients are taking more responsibility since the goal of obtaining good health now requires their involvements. They have to transmit appropriate medical records to their providers in order to guarantee quality healthcare. In this sense, a simple task of carrying medical records to the hospital is participating in one's own health.

By transmitting medical records to healthcare providers, patients start forming a collaborative relationship with their doctors as how they manage their records affects their own health outcomes. Accordingly, the job of organizing pieces of information in the thick medical records is also shifted from the providers' side to patients'. Many patients in our study took the effort to reorganize the scattered information into a mean-

ingful arrangement so that it was easy for physicians to check during the consultation. Patients not only facilitate the timely access to medically relevant information in a time-constrained situation, but also ensure the all the necessary medical information is checked to avoid confusion. These involvements enable patients to be engaged in their own healthcare by supplying medical information at the point of care to ease the information flow in medical interviews.

Control of Personal Health Information

Self-maintained medical records also provide patients with a strong sense of control over their own health information. Patients can choose to show or not show certain records to their physicians. For example, one observation in the study showed that a patient hid some records at the beginning of the consultation and showed it later on. This was because the patient was obtaining a second opinion. He hid previous records so that the doctor could provide him with fresh insight.

Patients also have control over how they keep their records. As some observations described earlier, some patients prefer to have recent records in their purse at all times in the case of impromptu medical visits. Many others keep their records in separate piles, for serious and mild diseases, organizing which records to bring to which providers. Patients also integrate health information that is generated from home with the information they obtain from the hospital, such as organizing home glucose readings with clinics results chronically, or associating lab results with a food diary that account for activities in the same time period. Hence, the full access of medical records enables patients to engage more fully in using their health information, and eventually in their own health.

Conclusion

This paper explores how patients' self-maintained medical records affect clinical practice in consulting rooms. We conducted an observational field study at an urban Chinese hospital to examine how personal health records are shared and used during medical interviews. The observations reveal that self-maintained records are largely used as a transitional tool for patients to share information with healthcare providers. This sharing process allowed patients to integrate their health information in a patient-centric way and provide them with a strong sense of ownership and control over their own health information. Self-managed medical records changed error-prone verbal reports into professional documentations collaborated among providers. Most importantly, this study shows that patients, even those who have low health care literacy in under resourced healthcare settings, can be effective contributors to their own health. Researchers ought to rethink the patient-provider relationship in designing new interactive health systems that force patients to take more responsibilities in the healthcare process.

References

[1] Markle Foundation: Working Group on Policies for Electronic Information Sharing Between Doctors and Patients: Final Report: Connecting Americans To Their Healthcare. 2004.

[2] Halasyamani L, et.al. Transition of care for hospitalized elderly patients--development of a discharge checklist for hospitalists. J Hosp Med. 2006:1 (6): 354-60.

[3] Parry C, Kramer HM, Coleman EA. A qualitative exploration of a patient-centered coaching intervention to improve care transitions in chronically ill older adults. Home Health Care Serv Q. 2006: 25 (3-4): 39-53.

[4] Tang PC, Ash JS, Bates DW, Overhage JM and Sands, DZ Personal Health Records: Definition, Benefits, and Strategies for Overcoming Barriers to Adoption. JAMIA, 2006: 12 (2): 121 - 126.

[5] Bronson DL and K OM. The impact of shared medical records on smoking awareness and behavior in ambulatory care. J Gen Intern Med, 1986: (1-2): 34-37.

[6] Cimino J J, Li J, Mendonca E.A, Sengupta S, Patel VL, and Kushniruk AW. An evaluation of patient access to their electronic medical records via the World Wide Web. Proc AMIA Symp. 2000: 151 - 155.

[7] Earnest MA, Ross SE, Wittevrongel L., Moore LA, and Lin CT. Use of a patient-accessible electronic medical record in a practice for congestive heart failure: patient and physician experiences. JAMIA, 2004: (9-10): 410 - 417.

[8] Glaser BG and Strauss AL. The discovery of grounded theory: Strategies for qualitative research. Aldine de Gruyter. , Hawthorne, NY, 1967.

[9] Williams MV, Davis T, Parker RM, Weiss BD. The role of health literacy in patient-physician communication. Fam Med. 2002: 34(5): 383-9.

[10] Schillinger D, Bindman A, Wang F, Stewart A, Piette J. Functional health literacy and the quality of physician-patient communication among diabetes patients. Patient Educ Couns. 2004: 52(3): 315-23.

[11] Pham HH., O'Malley AS, Bach PB., Saiontz-Martinez C, and Schrag D. Primary Care Physicians' Links to Other Physicians Through Medicare Patients: The Scope of Care Coordination. Ann Intern Med. 2009: 150 (4): 236-242.

[12] Pratt W, Unruh K, Civan A, and Skeels MM. Personal health information management. Commun. ACM, 2006: 49 (1): 51-55.