When Medical Expertise Meets Record Expertise: The Practices of Patient Accessible Medical Records in China

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Abstract Recent consumer, private sector, and governmental health informatics initiatives outline patient accessible medical records (PAMR) as key for engaging patients and supporting patient-clinician communication. However, many challenges have been encountered in designing usable digital systems for patients to access and use their medical records. Barriers to such systems include social, cultural, and policy constraints in addition to usability problems. In particular, questions of expertise, responsibility, and ownership surrounding medical records are often hotly contested between medical professionals and healthcare organizations. In broaching the design challenge of PAMR, much can be learned from examining existing practices for patient carried and accessible records in contexts where these practices are well established. We examine practices surrounding PAMR in a setting where medical records have long been managed by patients: the Chinese healthcare system. Through close examination of managing medical records and sharing medical health information, we find that these personal record practices in China enable a two-way medical records sharing practice between patients and their providers, which fundamentally reconfigures the patient role in healthcare process, facilitates development of 'record expertise' on the part of patients, and joint responsibility for health management. We use these findings to illuminate the potential benefits of PAMR, and to offer design considerations to optimize future systems design and deployment efforts in other contexts.

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1 Introduction

Effective healthcare requires contributions from both healthcare providers and patients. However, patients' involvement has long been minimized in the health-care process. With limited health resources worldwide, the provider centric model is often less than optimal in treating patients. Thus, there is a call for innovative tools and methods to engage patients in their care, such as promoting patient awareness about their own health issues, educating them to have proper health knowledge, and supporting effective communication between patients and clini-cians. In particular, it is believed that "in order for patients to be true partners in the health care encounter, they must have access to their own personal clinical health information" [1].

Recent consumer and policy initiatives promote the role of digital tools in achieving these aims, and prioritize the development of such tools as a key to digital health development across the globe [2–4]. Patient Accessible Medical Record (PAMS) Systems are increasingly designed and deployed to enhancing patients' involvement in their own care, such as Personal Health Records (PHR) [3]. Accessing clinician-generated information is critical to shift the provider-centered paradigm to one of patient-provider collaboration. As Piras and Zanutto [5] describe it, such patient-centered information exchange aims to redefine the patient as "…not 'the object described in documents exchanged among doctors,' but rather 'the actor most concerned with the flow of information through the carers' network" (p. 589).

The shift to digital health records systems has created a potential to re-think current health record practices and create new inclusive systems that give patients increased access to their medical records. However, despite the potential advan-tages, PHR systems have not been widely embraced, and a number of technical and policy barriers to adoption have been outlined [6]. For example, the high profile failure of GoogleHealth, a tool with a huge investment of human and financial resources, has been attributed to lack of consumer knowledge about e-health, lack of organization and provider involvement and willingness to transfer data, and privacy concerns [7]. The systems that have come into use are largely designed as an individual portal which allows patients to access their information online but that bears limited impact on the collaborative nature of patient care. It is clear that much work is needed to understand how to best design and deploy PAMR systems in practice. Further, little empirical research on cooperative work in healthcare examines information work of patients and information sharing and collaboration between patients and clinicians, home and healthcare organization.

The goal of this study is to explore the practices of PAMR in practice, and to draw design insights for future digital records systems that can encourage and engage patients' involvement in their own information and care. This study is timely and important as allowing patients to access their medical records, and promoting patient engagement in healthcare through digital systems has been a new trend in many western countries. However, the use of such systems relies not

only on technological advancements, but also deep understandings about the records practices that patients engage in, which are inherently social and cultural. In this research we explore the design of PAMR systems through ethnographic research in a case where paper-based PAMR are in use. We conducted a field study in a large comprehensive hospital in China where patients are able to access, interact with, and manage their own paper-based medical records. In our study, the paper-based records resemble the concepts and goals that the digital systems, such as PHR, intend to achieve, and the potential such records practices afford for enhanced patient-provider collaborations.

This research makes multiple contributions to the ECSCW research tradition by examining medical record practices in a context in which little empirical research has been conducted (China), and through in-depth examination of collaborative information practices between clinicians and patients, thus bridging healthcare organizations and the domestic sphere of patient homes. Finally, this paper contributes by exploring patients' medical records management practices to inform future design and implementation of digital systems that support patient engagement and information sharing. Theoretically, we contribute an understanding of record expertise–a form of authoritative knowledge gained by patients through practices of managing records and collaboratively sharing medical information with clinicians.

2 Related Work

PAMR systems have been outlined as a major part of strategies to use health information technologies to improve the quality and efficiency of healthcare [8], and many initiatives in PAMR have been developed and led by industry and healthcare organizations. However, little research to date has been conducted on practices of using PAMR, such as PHR systems. Recent work in the Human-Computer Interaction and Computer Supported Cooperative Work areas has focused on developing methods to evaluate usability of PHR technology [9], the potential information needs and desires of intended PHR users [10], as well as the work of simply being a patient [11].

2.1 Benefits and Challenges of PAMR Systems

PAMR have long been in discussion in medical informatics and general medicine literatures worldwide. Multiple studies have found that access to one's medical record in either traditional paper format or electronically has the potential to enhance patients' understanding of their condition [12]; empower individuals to become active participants in their own care [13]; result in better medical management [14]; lead to more effective provider patient communication [12, 14];

improve electronic health record (EHR) accuracy and increasing compliance with health maintenance clinical guidelines [15]. Further, many studies demonstrate that access to one's health information using digital technologies is desired by majority of health care consumers.

On the other hand, although desirable by patients, there are multiple challenges to wide implementation and use of such systems. For instance, a national survey conducted with hospital CEOs in Canada indicates that patients experience low levels of accessibility to their medical records, with financial limitation to implement electronic records system and providers' unwillingness to provide access as two major barriers [16]. Similarly, research conducted in a hospital in Israel found 94 % of providers studied refused to give patients access to their records [4]. Physicians report worry about the negative impacts on sharing records to their own clinical practice and also cite fear of negative impacts on certain patients, for example, cancer patients, as reasons for refusing patient access to medical records [17]. Additionally, prior literature notes that health care consumers must understand and accept their roles and responsibilities related to their own health care [3, 18]. One previous study found that although patients were interested in enrolling in PHR when such a system was available to them, rarely had anyone requested a copy of their medical records previously [19]. Thus, motivating both clinicians and patients to accept and fully benefit from PAMR remains a significant topic in need of research. However, there is a lack of research on PAMR in general and particularly on how personal health information artifacts figure in relations between clinicians and patients.

2.2 Patient-Clinician Communication and Cooperative Work

Studying PAMR calls attention to the need to understand information sharing and collaboration between healthcare providers and consumers of healthcare, patients. Thus, PAMR provides an intriguing opportunity to examine cooperative work that extends between two different spheres, the organizational/institutional sphere of healthcare organizations and the domestic sphere of personal health [5]. Past research on cooperative work in healthcare focuses primarily on either the care coordination process among caregivers [20] or on the clinical collaboration process within healthcare settings [21, 22]. In the home setting, a rich body of research examines information sharing and collaboration between care supporters and care networks [20, 23]. However, little research to date examines the intersection of information practices of the home and healthcare organization, and fundamental tensions surrounding this intersection, such as knowledge, authority, and responsibility. Our research provides an initial attempt to address this gap through examining patient-provider communication and information sharing centered on medical record artifacts as a form of cooperative work.

Understanding opportunities and barriers for PAMR requires an understanding that designing such artifacts must take into account the inter-relation of these

artifacts with practices of patient-clinician communication and information exchange that are inherently social, cultural, and material. Further, we argue that in understanding opportunities and barriers to PAMR, we must understand the questions that these artifacts-in-use raise for authority, expertise, and responsibility between patients and clinicians in cooperative work process. Medical anthropology research has previously taken a critical perspective of patient-clinician interactions, pointing out that power imbalances often pervade interactions between doctors and patients. Authoritative knowledge studies in particular point to the role of technological artifacts in perpetuating medical-scientific knowledge as the dominant form of knowledge in patient provider interactions [24]. Patients do not have access to this knowledge nor to the artifacts that produce or contain it, thus are unable to access authoritative knowledge about their bodies and the conditions of care.

More broadly, Practice theory [25–27] has previously been described in the design and CSCW domain in the work of scholars such as Schmidt [28]. A practice perspective shifts the researcher's view of "knowledge;" knowing is seen as relational, emergent, embodied, inscribed in artifacts, and only partly articulated in discourse [29]. A practice perspective emphasizes power, politics, and conflict as constitutive of experienced reality. Practices make certain ways of acting or feeling available to some participants and not others; these asymmetries are perpetuated in space and time in large part through objects such as information technologies.

Using ethnographic data consisting of observations and interviews, we examine how Chinese patients manage their medical records using a variety of artifacts accumulated and created over a lifetime of healthcare interactions. Further, we examine collaborative practices of sharing personal health information using personal record archives maintained by patients and how practices of patient management and patient-clinician sharing of records relate to social and cultural understandings of patient knowledge and responsibility in the Chinese context. Finally, we offer design insights for future digital PAMR.

3 Methodology

We conducted a qualitative study consisting of semi-structured interviews and non-participant observation examining the practices of patients' self-managed medical records at outpatient departments of a Chinese health organization. We chose to conduct this study in China because the outpatient medical records (paper-based) produced by health providers are given and thus managed by individual patients. This provided a unique setting to understand PAMR in use and how it can inform the design of digital systems that aim to function similarly. We obtained ethical approval from the university the researchers are affiliated with, and the approval of the scientific review board of the hospital being studied.

3.1 Participants

The hospital where this study was carried out is a nationally known comprehensive health organization. Patients of this hospital include both local residents having routine medical visits, to patients who traveled from other cities seeking treatment or second opinions for illnesses that they have been unable to obtain proper diagnosis or treatment for elsewhere. These two patient populations present an interesting case to study self-accessible patients record use since we are able to study a diverse set of the medical records practices engaged by patients.

Two participant populations were included: clinicians and patients. To gain an understanding of patient-clinician communication centered on PAMR, we recruited a total of four doctors, and 17 health consumers, including 13 patients and 4 family members from our field site. Family members were interviewed either when patients were younger than 18 years old or when family members served as the main information gatekeeper for the household. We focused on data collection from patients with chronic health conditions because we observed that this population engaged in record keeping practices to a greater extent than those who did not suffer from chronic conditions, thus provided an ideal sample in which we could examine these practices in depth given limited time for the study.

3.2 Data Collection and Analysis

To understand how patients' self-maintained medical records were used during the consultation process, we conducted observations of patient-clinician interactions surrounding patient medical records that occurred during medical visits. Observations were conducted in the medical consultation rooms located in each department. A total of 40 h of observations were performed in the consulting room, consisting of 76 patient consultations in total. Each observation session lasted for 4–5 h. During the observation, the researcher sat in an unobtrusive location within the consulting room. 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 speaker and previously majored in medicine. This ensured proper understandings of the patient-physician interactions in the consulting room.

In addition to exam-room observations, we also studied patients' records management practices through patient interviews. We did not observe patients' record-keeping behaviors at home since these activities may occur at any time private settings. Observing these activities was impractical from a data collection standpoint and also raised ethical questions surrounding patients' privacy in home settings. Instead, we used semi-structured interviews to explore patients' behaviors, attitudes, and practices around keeping, using, organizing records. In the

study, we asked interviewees to show us the records they brought with them–this way we were able to see how records are organized and probed further to understand how patients prepared their records and managed their records at home. Interviews ranged from 25 to 60 min in length. 15 interviews were audio recorded and the rest were recorded with pen and paper [30]. Interview transcripts and observation notes were coded using an iterative open coding scheme to extract the medical records usage patterns in the consulting room.

4 Findings

In this section we describe two PARM practices. First, based on interviews with patients about their practices of managing records, we describe how they engaged in a series of record managing and organization activities outside of physician offices. Second, drawing on observations conducted in physician offices, we describe practices of exchanging patient carried records with health providers during medical visits. Through engaging in these two practices of managing and sharing records, patients were able to obtain familiarity with their own records and to provide necessary assistance to locate information for providers to use at the point of care.

4.1 Managing Records

Patients observed and interviewed in this study are able to fully access their outpatient medical records. The information patients can access includes medical history, diagnosis, prescriptions, lab results, radiology images and reports. At the study site, the chief complaint and medical history are handwritten on pocket-sized medical records book. Diagnosis and prescription information are entered into a hospital-wide information system first, then printed out and attached to the medical records book.

After the records are given to patients, they are responsible for taking care of their records on their own. Hence, the responsibility of keeping the medical records is shifted on to individual patients. It is the patients' responsibility to collect and maintain their records from different visits and manage them in a meaningful way for doctors to use. For instance, patients have to collect the test results from laboratory or radiology departments themselves and bring them back to physicians; patients also need to collect records they receive from different medical visits, or from different health organizations they choose to visit; eventually, patients are responsible to bring the records to their next medical visit for doctors to view their medical histories. This series of actions allows patients to be the owner and organizer of their own records. In the following, we describe a number of specific actions that are involved in the practice of managing records (Fig. 1).

Fig. 1 A physician
documents on small record.
Diagnosis and prescription
are printed out from the
information system are
attached on the *bottom* of the
page
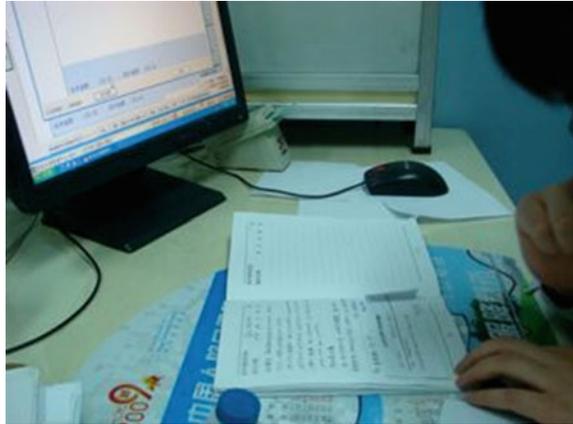
First, patients store their records. It is not unusual to see patients bring in years
of records during observation, or to learn they kept all their medical records
carefully at home during interviews. In interviewing subjects, we found that most
patients stored their records; there were no instances, in our study data, of patients
not placing a high value on storing records and bringing records with them each
time they came to a medical visit. The archive of personal records is extensive and
lifelong, with most patients maintaining original records from when they were first
diagnosed, along with all consequent visits for that particular disease. Each time a
patient receives any type medical records, in the form of physician notes in a
records book, x-rays, lab results, or other artifacts, the patient adds these records to
their personal archive of medical information. Storage of records is very important
to patients and this importance reflects the high degree of responsibility they feel
for archiving and managing medical records for oneself and for one's family
members. Most patients reported storing records in a single, valued location, either
a series of bags kept together (sometimes hanging from a hook on the wall), or in a
specified cabinet in the home. A husband of a 38-year-old tympanitis patient said:
"*We put all the important records in the big plastic bag for each hospital visit and
hang them on the wall in our bedroom.*" A mother of a congenital cataract patient
described "*These [medical records] are the most important things for my child. I
keep all the records for my child in a separate cabinet ever since he was born [the
child is five years old now] and will track them'til he grows up, maybe for his
whole life*." Some patients even stored their records with other most important
documents such as their ID and bank statements, indicating the importance of
these medical records for patients.

Second, we found that most chronic care patients engaged in some amount of
sorting of their personal records according to condition and importance. The
growing body of medical records that patients archive over time leads to the
development of sorting practices that allow people to keep their own and their
family's records sorted in meaningful ways that facilitate usage. We found that

patients suffering from chronic conditions that required ongoing care (or caring for household members with chronic conditions) tended to engage in more extensive sorting practices than patients who did not suffer from chronic conditions—this initial finding led us to conduct focused data collection with chronic disease patients. The high volume of medical records accumulated by those with chronic conditions made the need to sort records more pressing. Chronic sufferers were accustomed to frequent medical visits requiring well organized records, and dealing with the daily reality of chronic health problems made sorting records a high priority for these patients and their families.

Records were often separated and organized according to particular diseases and conditions and sometimes according to clinic. For chronic conditions, a separate subset of records was often created and maintained related solely to the trajectory of that condition. For example, one patient with diabetes (56 years old) described how she visits both a small clinic near her home for minor illnesses and the hospital where the study was carried out for diabetes care. Even though these two places use a unified record system where clinicians from different organizations can be unified in the same record book, she decided to have two books, one for each clinic, for the purposes of separating visits and more easily finding information. She said, "*Actually I could have had just one record book, but I am afraid that I cannot distinguish different medical visits…using two books is easier for me.*" Later she said "*I put my medical card, record book, and medications for each clinic in a separate bag. This way I can just grab it on my way out and I have everything I need.*" Similarly, another diabetes patient told us that she always pulls out blood test results and arranges them chronologically before going to the doctor, because this allows her to easily see and demonstrate how her diabetes is progressing over time. Patients arrange records both before storing them at home and in preparation for medical visits. Many patients interviewed reported reading through their records periodically at home as they arrange and re-arrange their archive of records, demonstrating that the patients in our sample actively engage with their medical information in the home and apart from interactions with clinicians.

Third, some of the patients in our study engaged in practices of annotating their records. This involves organizing their records in particular ways and marking, making notes, or creating new documents related to their records which are added to the patient's archive. For instance, one patient said, "*not only do I keep all my medical records and read them from time to time, I organize these [information] resources into a 'health information book'* (Fig. 2)." In showing the organized records to the researcher, he pointed out several sheets of lab results and said "*these red annotations indicate whether readings of lab results are increasing, or decreasing.*" He proudly said: "*I developed this system all by myself.*" Another common form of annotation reported by patients was creating their own typed record summary that synthesizes the lengthy health information into a brief summary. Typically, the summary lists records according to the dates of medical visits, and serves as an index page for patients to locate where the information for a particular visit was documented, and what was the key information generated in
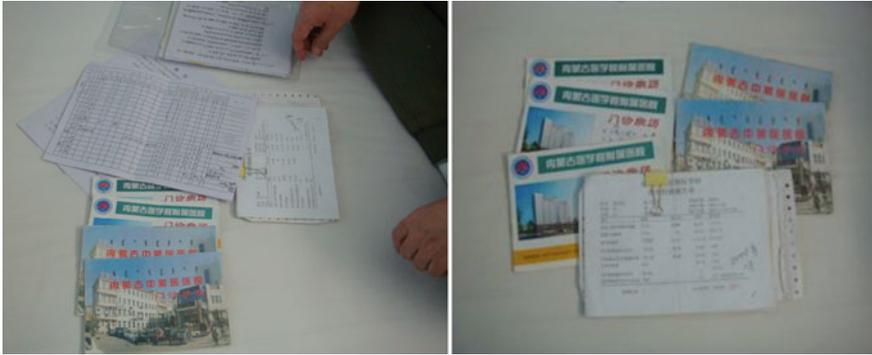
Fig. 2 Stored, sorted and annotated records by a chronic hyperthyroidism patient. *Left* sorted lab results. *Right* annotated summary page

each visit (Fig. 2). Again, intensive arranging and annotating of the personal record archive varied widely between patients and households, mostly following patients' and caregivers' own personal preferences and rules of using the records. Our interviews and observations revealed that the degree to which patients engaged in these practices varied such that that the more intense, long-term chronic disease sufferers had more elaborate systems for arranging and annotating that they had developed over time through managing archives and learning to organize records to facilitate communication with doctors through repeated visits.

4.2 Sharing Records

Demonstrating responsibility and involvement in one's own healthcare was the predominant reason patients reported for engaging in record management activities. The patients' self-managed records were brought back to medical visits and shared with clinicians, since patients felt that their own memory was inadequate in providing an accurate history to clinicians. Thus they believed that distributed, artifact-based memory of disease and treatment was crucial to receiving good care. Patient-clinician visits in our field site routinely involved detailed patient history based around the medical records that patients brought with them to visits.

Throughout the entire study, only a very few patients came back without their previous medical records. The shared medical information provided a basis for physicians to know the whole picture of patient's history and status so they could avoid possible overdose and drug interactions. In our sample of Chinese doctors, doing a thorough history was contingent on having access to patient-carried records. Clinicians felt that a verbal history was insufficient, as was a history based solely on their own clinic's records. Since patients are the owner and manager of their records in our field site, many of them were skilled at facilitating records

sharing through bringing the records to the medical visits, and providing necessary help for doctors to read the information when they needed it. Observations of patient-clinician interactions revealed that patients who engaged in active sorting and annotating of their records were particularly skilled in engaging with clinicians in dialogue about their conditions. While some patients simply brought in piles of records from past visits, others brought carefully sorted, arranged, and annotated records, and these patients were able to more quickly find information requested by clinicians and converse with physicians about their condition and their care. The following two observations illustrate the process of records sharing between patients and clinicians during a medical visit.

Case one: a patient with 20-year history of diabetes

The patient came in with his wife, who was a vocal participant in interactions with the doctor.

The first thing that happened after the doctor greeted the patient was that the patient showed the doctor a self-written glucose log he had recorded for the past two weeks.

Doctor (pointing to one number): "why this one was so low?"

Wife: "we heard from others that Douzha (a special tofu product) can lower the blood sugar, so we tried it out, we didn't expect it to be this low in the first day."

Doctor, "what medication you are on now?"

Instead of answering the question verbally, the wife took out a stack of medical records she brought into the visit. Other than a few medical record books, she also brought a self-annotated "medical visit history" log summarizing his past medical issues. This table-like log contains doctor's name, the prescription, medication, dosages, lab test results, and his personal notes. Soon she handed a medical record book with a few pieces of lab test results. The doctor started reading them.

Patient: "I've been on insulin for a month."

Doctor: "oh, so how many units is he on? Is it 302 or 502?

Wife (points to the record in the doctor's hand): Actually I don't really know.

Doctor (sees number he needs and turns to patient for next question): "how's your kidney function?"

Wife: "the urine test reports are attached at the back of the record book."

Patient: "you know, I now exercise a lot. I walk almost 10 kilometers a day."

Doctor (nodding, and looking at the urine test reports) "yes that's really good for you."

Wife: "he has stroke 7 years ago that almost killed him….it is really difficult for us now. The insulin – he needs 8 shots, and also needs to test the blood sugar 4 to 5 times a day. We simply cannot travel anywhere in this situation now."

Doctor "why he is on insulin?"

Wife: "that was from last July or August, there was a few days he got really hungry during night, and had some cookies and milk." She describes how his glucose got out of control, and they went to the local clinic but it was too late. Since his glucose was out of control for a while, they had to start insulin treatment.

The doctor nodded, and advised the wife: "it is really important to have regular meals. You cannot eat too much, or adjust your insulin intake too frequently."

The doctor started reading the glucose log again. He pointed to another number and asked "what you had on that day?" The wife began describing what they ate on that day, the portion etc. The wife replies that they are doing better with diet, they used to buy wheat bread at the store, but her husband realized there is lots of sugar in it. Now we they bake it themselves.

Doctor (pointing to the log): see you have 5.2, then 9.2 then 5.2 again here…

Patient: the 9.2 one was because I ate snacks during the night.

Doctor, if that's the case, you can take a little bit insulin in the middle of the night to lower the sugar level.

Next the doctor renewed the prescription and ended the medical visit.

As demonstrated by the case above, patient-clinician interactions in our field site involved conversations about patient history and disease in which the patient's self-carried, and often personally arranged and annotated, medical records played a key role. Instead of being verbally reported to physicians, information requested by doctors is often communicated through sharing documents from the archive of medical records carried by the patient. Sharing records during medical visits consists of a series of cooperative actions performed jointly by patients and clinicians. These include reviewing, locating, and pointing out relevant information in the records, such as when the doctor above points to a glucose reading and asks why it is so low, the patient's wife locates the requested information in a particular record book, or when the patient's wife directs the doctor to look at the urinalysis results attached to the back of the record. In the process of reviewing, locating, and pointing out relevant information, the clinician is able to ascertain a patient history in dialogue with the patient (and the patient's family, as the case may be). The history is articulated through dialogue between clinician and patients, and is constructed using a number of documents from within the patient's personal archive of records, both self-created (such as the diabetes patient's summary sheet) and collected from different clinics over time (such as past urine test results).

When patients and clinicians review, locate, and point out key information through dialogue, clinicians typically ask a number of clarifying questions. For example, the doctor in out last example asks about an unusually low glucose level, in the process receiving a response about a change in diet, and then asks the patient and his wife directly about the patient's current treatment regime. This questioning is centered on review of records, and often results in patients producing nuanced details about symptoms, treatment, and relevant lifestyle factors. It is crucial to note that this conversation is not one-sided. Patients and family members also ask questions, direct the clinician to information they think is important, and voice opinions about the information in the records they are sharing. The vignette below, in which a gastritis patient discusses the severity of his illness with a doctor, offers a good example.

Case two: recently diagnosed gastritis patient seeking second opinion

The patient came in with two prior medical diagnoses at two other hospitals. He had never seen this doctor before, but had received a recommendation from a friend.

After introductions, the first thing the patient started to was describe his conditions. He tells the doctor he is on three medications right now. He reads the names of these medications from a small post-it held in his hand. He then pulled out his pathology, gastroscopy,colonoscopy and ultrasound reports from the previous visits. The patient tells the doctor that he has gut edema.

Doctor: "why did you think so?"

Patient (pointing to the lab result) "it's right there."

Doctor looks at the lab results and asks him what medications he is on right now. The patient shows the post-it note to the doctor.

The doctor takes the ultrasound images from the patient and starts checking the images. After looking at the lab results and the images, he explains to the patient that certain images look very serious, but the condition is in the process of recovering.

The patient says "I thought my edema is really severe, isn't it? You see this is the picture."

The doctor says "well, doing the test will cause some edema itself. But it's not as serious as you thought to be."

They go on the discuss medications, with the patient requesting a certain medication, and the doctor telling him that he may already be on too many medications. They discussed the treatment plan and the doctor entered the prescriptions in the computer system, wrote down the assessment in the medical record book, then printed out the prescriptions from the system, and gave them all to the patient.

In case two, the doctor directly asks the patient why he feels that he has a certain condition based on his symptoms, and the patient refers to test results that he has brought with him as part of his personal record archive. The doctor and patient then discussed the severity of the condition, with the doctor modulating concerns raised by the patient based on the images provided by the patient. It is important to note that the patient is actively enrolled in expressing his opinion about his condition, and he has access to his own test images, which he refers to when questioning the doctor about his condition. As in the first case, the history proceeds through a process of patient sharing records with the clinician as the clinician asks the patient about his condition. Through locating and sharing information, communication takes place through the information contained in the medical records, which are handed back and forth as they are discussed. Through the course of the dialogue, the patient offers his own interpretations of his condition. While the clinician does not always agree, the patient's opinion is heard and acknowledged by the clinician, who responds directly using the patient's own medical information to convey an expert opinion.

Our findings demonstrate that chronic care patients actively deploy the records expertise that they gain from managing their personal records, and use this expertise to question and discuss their conditions with clinicians. Clinicians are still the authoritative actors in the interaction, and often respond to patient comments and beliefs about their condition with different opinions based on medical expertise in interpreting medical information. However, it is notable that this conversation occurs through mutually constructed dialogue. Patients respond to questions, ask their own questions, offer additional information, and offer opinions as they locate information in their medical records for clinicians. We feel that there is a large connection between the practices of managing records one's records—which enables a patient to become familiar with the structure and content of the records—and in developing facility at sharing records with clinicians. Sharing records is not simply a matter of handing over records for the clinician to review, but of engaging in collaborative dialogue into understand the patient's history and condition. Our data reveal that some patients are more skilled in managing their records, usually due to increased engagement with their records necessitated by a chronic condition and frequent interaction with medical professionals.

In examining the role of record expertise in shaping patient-clinician interaction, our data show that the nature of the PAMR in our Chinese sample is a crucial in promoting different configurations of knowledge and responsibility. Patients are well versed in their own medical information, and are figured in the relationships as "experts" with knowledge of their own records. Clinicians, when seeking information, accept the records provided by patients as factual. While this could seemingly rise questions of professional hegemony, in the Chinese case clinicians retain professional expertise and authority in interpreting medical information. We observed multiple instances in which clinicians corrected patients' own self assessments, such as that above; in another case, we observed a diabetes who was very worried about her lymph cell counts. Her doctor told her that lymph counts were better left to a doctor's interpretation. While the practice of sharing records configures patients as experts of their own data, doctors retain authority in authoritative interpretation of this data. However, doctors in our sample expected patients to be active partners in a dialogue about a patient's history. Further, they viewed this artifact-centered dialogue as key to doing a "good" history, thus key to their own medical practice. No clinicians in our sample raised concerns about patients carrying their own medical records; this practice is "business as usual" in our context of study.

5 Discussion

Our findings explore how Chinese patients engage in a practice of managing their medical record at home and collaboratively sharing medical information with clinicians to develop a complete medical history and optimize care plans. Taking a practice approach to examine the relationship between social practices and information technologies calls attention to knowledge and power dynamics embedded in use [31]. Our study unveils aspects of knowledge and power dynamics that emerge through the interaction of social practices and personal health information artifacts that, we argue, can inform our understanding of collaborative information work between patients and clinicians and inform future design of digital PAMR.

First, through the practice of managing records, patients and patient family members engage in a series of activities to store, sort, organize, annotate, and arrange their medical records. Through these activities, patients become familiar and comfortable with the content and structure of medical information and medical record artifacts. A useful concept here is that of authoritative knowledge, drawn from Jordan [24]. Jordan argues that in any particular domain several knowledge systems exist, some of which carry more weight than others- often because they are associated with a stronger power base. Authoritative knowledge is constituted and re-constituted through an ongoing social process that builds on and reflects power relationships. In the medical domain, formal medical knowledge is 'authoritative knowledge,' Jordan argues that, in the ecology of practice in many

healthcare organizations, access to information technologies systematically empowers clinicians and disempowers patients, who do not have access to technical systems and information that clinicians use in medical decision making. In many contexts, the medical record is inaccessible to patients and the information contained within it is impenetrable to patients; in contrast, Chinese patients gain both formal and tacit knowledge [32] of medical records through activities of engaging with their records over a lifetime. We refer to this knowledge as "record expertise" and see it as a different form of authoritative knowledge that patients obtained through practices of engaging with their medical records. In our definition, record expertise is an emergent quality of managing one's record over time that enables patients to move from passive receivers of information to active consumers and organizers of medical information.

Second, through gaining record expertise by managing records through the activities of storing, sorting, organizing, arranging and annotating, another key dynamic shifts, this time in the clinic at the site of care. Patients who are have record expertise engage in a practice of information sharing that leads to co-constructed plans and accounts of medical care. Take for the example the patient who insisted on showing the physician a key piece of information about past symptoms treated by a different physician. Knowledge structures provide the patient a key source of knowledge about their health and care, rather than a passive subject receiving treatment and information. In this way, the record expertise of the patient becomes an ongoing source of co-constructed knowledge. This results in more accurate information, particularly about medical history, while at the same time allowing potential for a more engaged patient in the care process.

Finally, the practice of sharing records reveals a sense of shared responsibility for medical care. Responsibility is shared between patients and clinicians, and between multiple clinicians who may see a patient over the course of a patient's lifetime, each contributing to the patient's archive of testing, diagnosis, and treatment records. It must be noted that an examination of malpractice and accountability for clinicians in the Chinese legal system is outside the scope of our study. Litigiousness is often cited as a reason for medical professional's concerns over sharing medical records with patients in other contexts. In our field site, it was apparent that there were no qualms with sharing records between clinics and clinicians- records are the property of the patient receiving care, not the clinic in which care is received. This places a large burden of responsibility on patients, but we found no patients who complained about the burden of managing records; on the contrary, patients in our sample put much time and energy into managing their record archive and that of their family members, in accordance with the importance they placed on these records as artifacts crucial to receiving good care.

In applying these insights to design of future digital PHR, some crucial considerations emerge. First, we find in the Chinese context that the practice of managing the record, through storing, sorting, arranging, and annotating their records. Technologies that allow patients to read their medical information will likely not engage patients to the same degree as a tool that promotes a practice of active record management in the home. Managing records promotes a sense of

ownership over records, and facilitates patient-clinician cooperative work; in giving patients the ability to manage the presentation of their health to some degree, patients can become active partners with clinicians in cooperative medical records work. Second, it is essential that digital PHR tools facilitate practices of sharing information during the clinical encounter. When patients and clinicians are able to directly engage with record artifacts and exchange these artifacts in the clinic, information quality is improved, care plans are optimized, and the potential for collaborative decision making which casts patients as authoritative interaction partners emerges.

6 Conclusion

Despite high expectations and large expenditures on certain PAMR tools, many PAMR systems have not delivered on their promise. To date, few studies provide in depth ethnographic accounts of PHR tools in use, particularly outside of the U.S. and Europe. More studies of existing digital PHR and paper-based PAMR are needed. In this paper, we make strides toward filling this gap by presenting findings from an in-depth ethnographic study of PAMR in China. Chinese patients gain record expertise though a practice of managing medical record artifacts in the home, thus facilitating cooperative work between patients and clinicians and changing the tenor of the patient-clinician relationship from one that casts patients as passive recipients of information to active co-constructors of medical plans and accounts. In designing future digital PAMR tools, designers could benefit from applying insights from the Chinese case by designing records that promote practices of managing records in the home and sharing medical information during clinical encounters. Furthermore, we feel that studies of PAMR tools taking a practice perspective and occurring over the lifecycle of design and deployment, from case studies exploring existing PAMR practices through design, deployment, and use of digital PAMR technologies, will greatly facilitate the design of effective tools and ecologies of medical record practice.

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