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C H A P T E R

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# The Recording and Reuse of Psychosocial Information in Care

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## 1. INTRODUCTION

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The strategic role that health information technology (HIT) plays in enabling the health care reform in the United States, combined with the ongoing national debate on how HIT should be used “meaningfully” to achieve the desirable transformative change, has created a critical need for research studies that contribute to a better understanding of how to utilize electronically available data for constructive, cooperative use and reuse. While electronic health record (EHR) systems provide tremendous promise for improving quality of care and controlling soaring costs, a large body of literature has noted the cumbersome usability of these systems, including numerous unintended adverse work-related and care-related consequences (e.g., [Heath and Luff, 1996](#)).

p0020

Furthermore, increasingly, doctors have to cope with patients’ chronic illnesses, which affect a patient personally and socially overtime beyond the disease-specific medical symptoms and treatments ([Kutner et al., 1999](#)). For example, there have been an increasing number of patients who demonstrate various kinds of pain issues, many of which are caused by, or contribute to, serious psychosocial problems they bear in life. This trend requires doctors to acquire a complete view of a patient’s history in order to make informed treatment decisions.

p0025

Unfortunately, it has been shown that a patient’s history can be poorly documented in an EHR system ([Heath and Luff, 1996](#)). Through this field-based study, we aimed to explore how information is used and documented to support medical work, how it is reused across a patient’s multiple care episodes, and how an improved understanding of doctors’ information practices could inform more accommodating and usable EHR designs. The findings explicate the dichotomized purpose of medical records, as both a representation of medical work to facilitate real-time activities (i.e., practice centered) and a representation of the

patient to support long-term information reuse (i.e., patient centered). In addition, this study contributes to health informatics research and practice by highlighting several key functionalities that have been missing from current designs.

p0030 This chapter is based on a 2-year field study at a large teaching hospital where the first author shadowed the routine patient care practice of over 24 physicians and residents. Data were collected in 2008–09, and reports on the use of e-Care, the system used at the time. Unless noted here, the findings still carry into current practice.

p0035 In this chapter, we examine how doctors acquire, document, and use information across multiple episodes of patient care with special attention paid to how they cope with a patient's psychosocial experience. In this study, we define psychosocial information as a patient's psychological and social issues in her illness experience. With this focus, we explored (1) under what circumstances doctors choose to document psychosocial information and what kinds of psychosocial information they choose to document and (2) how this information, or more likely its absence, affects a patient's treatment plan and subsequently the effectiveness of care. Too often the psychosocial information required to understand the patient's situation or motivations is not sufficiently documented in the EHR to be of subsequent use. This is not trivial. For instance, according to the US Substance Abuse and Mental Health Service Administration, nine percent of the US population aged 12 years or older, or 22.3 million people, were classified with substance dependence or abuse issues in 2007. Such issues could be more effectively treated by making full use of psychosocial information.

p0040 In the remaining sections of this chapter, we first review the relevant literature that serves as the guiding framework for our research. Next, we describe our field site and data collection, followed by several representative patient cases describing doctors' information practice. We conclude with a discussion of insights that this research helps generate into medical professionals' information behavior as well as the implications for improving the design of current HIT systems to support a better representation of medical work.

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## 2. LITERATURE REVIEW

p0045 A hallmark of HCI/CSCW and health informatics research has been the analysis of the [AU2] gap between representations of work and the work they represent (e.g., Reddy and Dourish, 2002). In health care, for example, Bossen (2006) studied a prototype EHR system constructed according to a Danish national EHR standard. The system was found to only partially support clinical work, which was largely attributable to the model used in the standard deviating from how clinical work is actually performed. Similarly, Niazkhani et al. (2009) reported that the overly simplistic representation models underlying current medication ordering systems led to severe interference with, rather than facilitation of, the actual medical work. Furthermore, Fitzpatrick (2004) showed that in reality, clinicians often tailor, re-present, and augment clinical information according to their roles and preferences, which is not adequately supported in the current EHR design. Finally, researchers have demonstrated that the flexibility that allows patient records to be provisional, informal, or private could facilitate care delivery (Hardstone et al., 2004) and patient hand-off processes (Engesmo and Tjora, 2006; Zhou et al., 2009). Such "informality" of documentation is generally not available in the HIT systems seen to date.

p0050 A separate but related stream of HCI/CSCW research attempts to understand the function of medical records in supporting medical work. Berg (1997) referred to medical records as a formal tool or system that embed representations describing medical workplace and activities. He argued that through clinicians' reading and writing in their patient care activities, medical records play a fundamental and constitutive role in supporting medical practice (Berg, 1996). In studying e-prescribing applications, Gorman et al. (2003) argued that HIT systems are useful only when their designs accommodate and facilitate clinical activities as a multidisciplinary collaboration effort and fit better into the larger system of patient care.

p0055 Part of this stream concerns the question whether medical records should be conceptualized as process centered (i.e., organized around a medical facility's work processes) or as patient centered (i.e., organized around the patient's disease descriptors and health conditions). For instance, Østerlund (2004) depicted medical records acting like a "map and itinerary to guide clinicians' work," and thus he favored the process centered organization. As we will see, this distinction is critical to the design of medical record systems.

p0060 Finally, to examine the appropriateness (accuracy and comprehensiveness) of representations of medical work in the context of medical records design, we found the concept of *trajectory*, a term that Strauss and colleagues (Glaser and Strauss, 1967; Strauss, 1993; Strauss et al., 1997) first coined, useful in our analysis. According to Strauss, a "clinical course" differs from an "illness trajectory." The clinical course describes what has happened since the patient's admission, such as reasons for the admission, medically meaningful symptoms, and diagnostic results and treatment plans; whereas an illness trajectory refers "not only to the physiological unfolding of a patient's disease but also to the total organization of work done over the course, plus the impact on those involved with that work and its organization" (Strauss et al., 1997, p. 8). The difference between a specific clinical course and an illness trajectory, as we show in the later sections of this chapter, is useful in understanding doctors' information practices and the role of medical records in supporting (or hindering) such practices.

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### 3. ABOUT THE STUDY

p0065 We collected the field data by observing a general internal medicine team. This team was selected because its work is in line with our primary research interest, long-term use of medical information. The team provides service to patients who often have chronic episodes of their illness across their adult lifespan and come to the hospital when they experience a flare-up or other acute situations. Observing this service's work would thus provide rich data on information reuse issues from a long-term perspective.

#### s0025 3.1 Participants

p0070 The team, called the Medicine Howard (MH) service, is one of four general medicine services in the department of internal medicine. It usually consists of one attending physician (referred to as an *attending* in this chapter), one or two second-year residents (*residents*), and two first-year residents (*interns*). Occasionally the team hosts one medical school student. Each month, one of the four senior physicians who belong to the MH service supervises the

residents and interns, who also rotate through the service. During our 9 months of observation, three attendings, nine residents, twelve interns, and two medical students participated in our study. In addition, we observed the work of another team periodically in order to gain a broader understanding of doctors' work.

### s0030 3.2 Data and Data Collection

p0075 This study consists of largely field-based observations augmented by the examination of patients' medical records in the EHR system, in this context, e-Care. The first author performed the field observations. She shadowed doctors' overall work, typically from 3 to 5h each time. On two occasions, she shadowed the team throughout their on-call day, that is, 30 consecutive hours in the hospital. The observational activities involved following the teams' patient care activities, asking clarification questions, tracking critical incidents, and taking field notes. Between observations, the researcher reviewed patient records and working documents. In addition, whenever appropriate, the researcher also asked to look at personal rounding sheets in order to understand how the attendings, residents, and interns assembled information. She also attended the educational meetings and lectures organized by the attendings. She was even invited to the team social events, such as the dinner party when a rotation ended.

p0080 The first author was also granted access to the e-Care system, so she could conduct an in-depth analysis of relevant research issues captured in the medical records. The e-Care system, used at the time of the study, was a web-based medical records application providing authorized users real-time access to patient data. It integrated, to a limited extent, information residing in other electronic systems of the hospital, such as Emergency Department (ED) diary notes, medication orders, laboratory work, and data from radiology, cardiology, neurology, registration, and other special care units. It included clinical notes from doctors, nurses, and other clinical personnel (e.g., admission notes, progress notes, nursing notes, discharge summaries, and social worker notes).

p0085 Our investigation began with an examination of the overall work of the MH team, which spans a wide range of activities including patient admission, initial diagnostic interviews, morning rounds, post-rounds group discussions, generating notes, providing medications, team meetings, sign-out process, and so on. Our attention was soon attracted to the information assembling process, particularly when the team admitted new patients, and to the morning rounds immediately after an on-call day, when diagnoses and treatments were intensively discussed among the team members. The first author observed a total of 260 patient room visits during morning rounds, among which 104 were the first visit after the patients were admitted. Additionally, over 70 patients' records (30 with substantial psychosocial issues) were reviewed with a special focus on the doctors' comprehensive assessments of each of the patient cases.

p0090 For the study reported in this paper, we extracted the portions from our field observational notes related to information seeking and assembling activities that occurred immediately following patient admission. We identified information use issues from a social/symbolic interactionism perspective (Glaser and Strauss, 1967; Strauss, 1993) and paid close attention to the occurrence of psychosocial issues in the work of care. We then investigated whether

the psychosocial information was, or was not, documented in e-Care by reviewing the corresponding patient records. Field notes and medical records were used to corroborate one another during the data analysis process.

p0095 Any cases described in this chapter are summarized from the field notes and examination of patient records retrieved from the EHR. All data, including names and the site's name, have been anonymized.

s0035

#### 4. DOCTORS' WORK

p0100 Over 80% of the patients on the MH service are transferred from the ED at the hospital. The remaining patients are referred from ambulatory care. Patients usually stay on this service for 3–4 days on average, with a wide range from a 1-day stay to over a month-long hospitalization. MH takes patients whose symptoms do not fit into any of the clearly defined special service teams (e.g., cardiovascular, gastroenterology, hematology, and oncology); thus, the MH patient pool covers a range of profiles including arthritis, asthma, diabetes, hypertension, and heart disease. Many patients who have chronic nonmalignant pain issues are also often assigned to this service.

p0105 This situation requires the MH team to deal with a mixture of complicated issues. The residents of this team usually arrive at the hospital early enough to conduct individual visits with their patients and prepare for the morning rounds. Morning rounds start between 7 and 8 a.m., and they usually last 2 to 3 h depending on how many new patients have been admitted. After morning rounds, the residents always talk with each intern again in order to make sure that the treatment and entire care plan will be carried out and done on schedule. Doctors then spend the rest of the day working on their own, although interacting (via phone) with specialty teams, family members, primary care doctors, social workers, discharge planners, and nurses also constitutes a large part of their work.

p0110 The MH team admits eight new patients during their on-call day, which occurs on every fourth day. In the meantime, they still need to take care of three to five remaining patients from previous on-call days. The morning rounds on post on-call days are the most intensive work activity because the team has to discuss each new patient in great detail and come up with a treatment and care plan.

[AU3] p0115 In the remaining part of this section, we use illness trajectory as a guiding analytical concept to describe and interpret our findings along two major lines: *information use* and *documentation*. First, we present briefly how medical information is acquired, assembled, and used in a general illness trajectory (case 1). Then, we describe how doctors process psychosocial information with three illustrative cases: (1) where a psychosocial issue occurred in a trajectory but was not documented by doctors (case 2); (2) where a psychosocial issue, supported by definitive evidence, was communicated among doctors (and with other medical professionals) and was subsequently documented in e-Care (case 3); and (3) where in certain circumstances psychosocial information was judiciously documented and used (case 4). While presenting these cases, we highlight how the absence of psychosocial information (i.e., the missing representation) may have had an impact on quality of patient care and costs.



s0040 **4.1 Information Acquiring and Assembling**

p0120 Information seeking and assembling takes place simultaneously in the process when MH admits new patients, conducts diagnostic interviews, and evaluates a patient during morning rounds. The most intensive information seeking and assembling occurs right after admitting a patient.

p0125 The work starts with a paging text from the ED or the admitting unit to the resident, which includes a possible diagnosis. The resident immediately makes a quick assessment based on the ED diary notes in e-Care to decide whether this patient is appropriate for the MH service. Next, the resident may briefly talk with the ED doctor and then assign this patient to one of the interns. When a patient is referred to the hospital, the resident often expects a primary care physician's note in the e-Care system. Both the attending and the resident(s) supervise the interns, but ultimately it is the interns who are responsible for generating the medical records (admission notes, progress notes, treatment plan, discharge document, and so on), which will be subsequently reviewed by the residents and revised (if necessary) and signed by the attending doctor.

p0130 A doctor rarely goes to see a patient for a diagnostic interview without careful preparation. She needs to have a relatively convincing idea of what is going on (e.g., several possible causes) with this patient. In some cases, a patient comes to the hospital for a chronic illness flare-up that has been treated before in this hospital. If the laboratory results, vital signs, and other measures are very consistent with what has been observed before, the anticipated trajectory can be very routine and predictable. For other patients, however, the resident and interns may not be able to make sense of the case based on the patient's symptoms and performance and their possible causes. In such cases, the doctors use additional information sources. The following case demonstrates this.

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b0010 **CASE 1**

A patient was transferred from another hospital as an emergency case. He has past medical history with post kidney transplant and hypertension. Recently he took a vacation to Honduras for a scuba diving trip. After he flew back, he developed nausea with vomiting. In another hospital, his situation improved, but he was found to be hypoxic (i.e., low oxygen in his blood). Based on a concern for him as a kidney transplant patient, the patient was transferred to this hospital for further evaluation.

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p0135 The intern reviewed the ED diary notes, laboratory test results, and the medical records sent from the outside hospital in order to prepare for meeting with the patient. She could not understand why the patient had developed decreased oxygen saturation with all vital signs and other descriptors appearing fine. After searching an online clinical information database for "hypoxic" causes, she started to examine this patient's previous records one by one in e-Care. Eventually, the intern discovered that the patient had experienced a similar condition 2 years ago but later recovered without further medical intervention. After this effort,



the intern conducted the diagnostic interview. This case highlights the intense informational activities during the preparation for a diagnostic interview.

p0140 Diagnostic interviews often take place shortly after a patient is admitted to the MH service. The resident and the intern conduct independent interviews with the patient. During an interview, 14 categories of questions will be asked, each relating to one part of the human body system. The interview usually goes in a matter-of-fact style, Q&A fashion, and at fast speed. However, because the doctors want to investigate information about not only symptoms but also about the patient's past medical history, family and social history, and lifestyle (i.e., the entire context of the illness experience, which often includes sensitive psychosocial information), a diagnostic interview may lead to a very emotional reaction. For instance, when one female patient was asked about her pregnancy history, a previous miscarriage caused her to burst into tears.

p0145 Doctors often have to learn skills to deal with patients who present with problematic behaviors. For instance, the interns and residents often share tricks, which they name "distractable components," to discover whether a patient is truly suffering pain or just demanding a controlled substance. Patients with substance abuse histories often present at the ED complaining of severe "abdominal pain," since it is expensive to screen out all potential causes. Inconsistent reactions to each physical assessment are considered to be faking the symptoms. The team members often share information among themselves verbally about those patients who are likely to fake their symptoms. This observation is similar to that by [Strauss et al. \(1997\)](#) that moral judgments are very frequent and severe in emergency rooms.

p0150 Finding out about a patient is a process of information sharing, sense-making, decision-making, education, and training. For instance, patients often tell different doctors different stories or stories of more or less depth about their illness experience, particularly about the psychosocial issues in their lives. Morning rounds provide an opportunity for the team to piece together the information and gain a better understanding of their patients. In a patient's room during morning rounds, psychosocial information is often acquired through talking with family members individually and with other caregivers, such as home visiting nurses.

p0155 As searching and acquiring information develops along a trajectory, assembling the information takes place simultaneously. Each doctor has her version of the rounding sheet, whether a structured template or a piece of blank paper. Each patient gets one sheet. This rounding sheet appears to be the most important working document for doctors to carry around in their pockets. The rounding sheet will be manually filled in with a patient's demographic information, emergency contact, history of present illness, past medical/surgery history, ongoing medication, family/social history, newest radiology/laboratory results, and so on.

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## 5. DOCUMENTING HEALTH CARE INFORMATION

p0160 A great deal of information is generated during the process of a developing trajectory. What information do doctors document? How do they write a patient's information, especially psychosocial, into the medical records?

- p0165 The e-Care electronic patient records system used in the study hospital is a Web-based application that allows doctors, nurses, and other clinicians to generate free-text notes, including admission notes, progress notes, discharge documents, nursing notes, social worker notes, and special consulting notes. All documents are arranged chronologically; and at the time of the study, there was no keyword search.
- p0170 An admission note includes predefined categories of information including a patient's chief complaint, detailed history of present illness, past medical and surgery history, family and social history, and the assessment and plan. Among the various notes, the admission note contains the most comprehensive information about a patient and is the first document that the service team provides. It is used throughout the trajectory not only by the team itself but also by nurses and other clinicians as both a source of baseline information and a guide for the work of care.
- p0175 Among various categories of information in an admission note, several are matter-of-fact and straightforward, but others can be questionable and sometimes require careful wording (see later cases in this chapter). For instance, "family history" usually records whether family members have a similar or related disease; "social history" should include any information about the patient's living situation, occupation, or any other aspects of the patient's life that may be clinically significant to the patient's problem. "Social history" is supposed to contain information such as where and with whom the patient lives, employment, social support, activities, habits, insurance coverage, feelings of anxiety or depression, visits to psychiatry or social workers, and ability to care for oneself (if elderly). All of this information will tell a doctor how a patient manages her illness in her social situation. However, according to one attending doctor, in practice, the "social history" has deteriorated to include only habits such as smoking, drinking, and illegal drug use.
- p0180 In the "history of present illness" section, doctors write in free-text how a patient presents at the hospital, various symptoms, and other phenomena they observed or stories they investigated via a diagnostic interview with the patient and discussion with her family members. At the end of an admission note, the "assessment and plan" should document a doctor's rational thinking, that is, their interpretation of the patient case and why this patient should receive this particular treatment. A good admission note should address the issues clearly and provide a convincing rationale for the treatment plan. However, the critical thinking or supporting evidence is often missing, leaving later doctors to wonder why the patient received an intervention during the previous episode. Psychosocial issues (if documented) often appear in the "history of present illness" and the "assessment and plan" sections.
- p0185 As psychosocial information is often considered to be subjective and is often vaguely defined or perceived differently by different care providers, the handling of such information magnifies the gap between the work, the patient, and the representation (i.e., medical record). In the following sections, we describe three cases that illustrate how doctors cope with patients' psychosocial issues; how they interpret, use, and document psychosocial information; and, how the breakdown in the representation can potentially affect clinician performance, quality of care, and costs.

s0050 **5.1 Psychosocial Information, but Only in “Talk”**

p0190 Consider the following example:

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b0015 **CASE 2**

A 36-year-old female patient with history of hypertension and anxiety disorder presented at the ED with the complaint of chest pain. She was assigned to MH and was waiting for a bed. Upon arriving at the ED, Kristine, the MH resident, overheard a nurse say that this patient showed up at the ED every few days. Often, the patient received an intravenous (IV) infusion (with a controlled substance) and then was discharged. On several occasions, she was hospitalized for further evaluation, so she could get more pain medications. The laboratory/radiological data did not reveal anything clinically significant. When Kristine communicated this case to her attending, the attending became outraged and immediately led the entire team to the ED. The attending speculated that the patient was manipulating her symptoms to gain access to a controlled substance. The attending confronted the ED doctor. Eventually, the patient was discharged from the ED as requested by the MH service.

[AU4]

p0195 This was a problematic care trajectory, which ended with the attending’s interaction with the ED doctor. However, the record did not document the conflicting understandings of the attending and the ED doctor nor any of the patient’s problematic behavior. It may be speculated that when this patient arrives at the hospital again, she may be admitted to a different service or even to the same service when the attending, residents, and interns are different (due to periodical rotations). For this case, although the psychosocial issue emerged as a main concern, it still did not seem legitimate enough to be documented in the record. As one resident stated, “You never know for sure.”

p0200 Patients demonstrating pain symptoms are prevalent in this study site. Yet, e-Care did not provide a systematic means for the medical teams to formally capture this information as part of a patient’s record or perhaps better, in informal documentation (as noted in [Hardstone et al., 2004](#)), so that this information can be noted down and shared across care episodes. This points to missing technical capability for supporting this type of long-term information reuse. Whether or not to record this sensitive information and how to record it is largely left up to each individual doctor. Many other psychosocial issues critical to understanding a patient’s needs and motives are also shared only verbally. This leaves the next care team in an information vacuum and requires the repetition of time-consuming investigations in complicated patient conditions.

s0055 **5.2 Psychosocial Information in the Record, but When?**

p0205 Under certain circumstances, psychosocial information may be documented in the formal representation. However, its importance may not be immediately recognized by every

member of the medical team. The psychosocial information is largely passed along orally in the beginning of a patient's illness. Perhaps it will be eventually captured in e-Care, but this may not occur for a long time. In the following case, it happens a patient resorts to violent behavior, and doctors have "hard evidence" to note in the record.

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b0020 **CASE 3**

(All quotes are from doctors' notes in e-Care.) A 23-year-old woman with a history of sickle cell disease comes to the hospital ED every few days complaining of chest pain. During the last hospitalization, the patient had "significant issues with behavior." When she was told she could not have IV Benadryl (an abusable substance), "she became quite frustrated and ripped up all of her paperwork. ...She physically threatened numerous staff members and required security presence on more than one occasion." The MH service ordered full tests, then noted, "there was no evidence of acute chest syndrome demonstrated. ...It was not felt that the patient was exhibiting evidence of serious sequelae of sickle cell crisis."

The attending talked with the patient's primary care physician to put her on a chronic pain management program, which might eventually help the patient stop the drug abuse. They jointly made it very clear in the patient's discharge notes, she "should no longer get IV Benadryl and she was abusing this."

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p0210 Although this case was of a similar nature to case 2, details were recorded in the e-Care system to inform others about this patient's conditions, which, if used properly, could prevent these issues from happening again.

p0215 As an aside, there is no guarantee that such information would be re-examined, since reuse is subject to visibility, incentives, and the power relationships between doctors. The next ED doctor missed the information written in the discharge notes in e-Care.

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b0025 After only a few days, the patient showed up at the ED complaining of nausea, vomiting, and severe pain in her legs and back. She again demonstrated questionable behavior, refusing a chest X-ray when she did not receive IV narcotics. Then the ED doctor gave her one dose of IV Benadryl, which violated her ongoing pain management program that the attending and her primary care physician setup.

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p0220 The ED routinely uses another electronic system, which records a patient's vital signs and other medically critical information but does not have a patient's detailed past medical history. If the ED doctors want, they can login to e-Care to find out a patient's past episodes, but this requires extra effort. As well, there are distinct differences in the priorities between ED doctors and floor doctors (those doctors such as the MH team). ED doctors' priorities are in treating the immediate symptoms and moving patients to floor units as quickly as possible. Floor doctors, on the other hand, not only deal with acute conditions but also need to plan for long-term care. It is not necessarily in an ED doctor's interest to face down drug abuse, as this could considerably slow down the interaction with a patient. Floor doctors, on the other hand, must do a great deal of unnecessary work for patients seeking drugs. Accordingly,

there is a tension between floor doctors' desire to have ED doctors to carefully read patients' prior records and the ED doctors' incentives to ignore prior information. The lack of visibility does not help. We will return to this issue below.

p0225 So far, we have described cases where the psychosocial information was never recorded and where it was recorded late in a patient's history. Next, we examine a case where it was recorded appropriately.

### s0060 5.3 Detailing Psychosocial Information in the Record

p0230 Some trajectories may be dominated by the psychosocial factors to such an extent that without those issues being in the patient's record, the necessary work cannot be accomplished. Below is a case that illustrates psychosocial information being systematically captured in the medical records from the very beginning of a trajectory (as compared to case 2 and case 3, where the psychosocial issue was never recorded or recorded only after severe events had occurred).

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#### b0030 CASE 4 (ALL QUOTES ARE FROM THE RECORDS IN E-CARE)

**Day 1:** Mrs. Smith, an 81-year-old patient with a history of dementia, anemia, depression, and hypertension, presented at the ED with multiple falls. ED doctors noted the patient "had some ecchymosis (skin discoloration caused by blood) over the right side of her face.... The number of falls the patient has had over the last several days is concerning, especially given her living situation." The MH team resident Nancy and the intern John conducted diagnostic interviews separately and examined the patient carefully. They had serious concerns.

**Day 2:** Nancy and John reported to the attending that they called the home visiting nurse, who reported that the patient's son who lives nearby said, "Dad beats Mom." After the attending carefully examined the patient, he noted in the admission note, "It is unclear how one discrete fall could cause the variety of bruises on the patient, including the ... edema, arm bruises, and side bruises. This may be consistent with multiple falls over time because of dementia, however abuse should be considered in this case as well..." The attending pushed for a meeting with the family and to include a social worker.

**Day 3–5:** Various personnel were called to evaluate Mrs. Smith. Her primary physician was also informed. Diane, a practice management coordinator, phoned Adult Protective Service (APS) and the visiting nurse organization (VNO). She noted in the records that the VNO expressed "their concerns of the safety in the home due to Mr. Smith's sexual advances toward the home visiting nurse." Soon, APS became involved in the case.

Surprisingly, Mrs. Smith, who was believed to be non-conversant, became more verbal, mumbling "they are mad at me" and "everyone is yelling and asking me what I am trying to do."

**Day 6:** A progress note noted "significant bruising over her body, concern for elder abuse. Adult protective services has been contacted, are currently investigating her case. Unsafe to go home."

**Day 7–12:** While all parties worked hard to investigate the problem, the family was trying to have the patient discharged to her home. Nurses noted in records that the patient had a "crying episode overnight for 5 hours".

**Day 13:** The meeting of all parties took place. The APS representative "discussed with the family legal actions against them for their noncooperation."

**Day 16:** Mrs. Smith was discharged to a nursing facility. Family may not take the patient from the nursing facility without discussing their plan first with the APS agency.

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- p0235 The hint of elder abuse, the psychosocial information, was noted in the records from the very first day. Along the development of the trajectory, details of elder abuse and complicated troublesome family dynamics were increasingly discovered and documented in the records. Compared to other trajectories, in which the explicitness and accountability of the psychosocial issues in the records were limited, psychosocial issues were at the core of this trajectory and this was reflected in the records.
- p0240 This is a very special trajectory that highlights the complexity of the emotional work in some cases of medical care. Several issues are of note. First, it is stunning that how many details related to psychosocial issues that the MH team investigated and documented in the record. Furthermore, the attending pushed very hard on this case to get all parties involved; otherwise, Mrs. Smith might have been just treated as a normal “dementia patient fall” case.
- p0245 Second, as described in the story, there are many clinical personnel (e.g., ED doctors, MH team, nurses, social workers, practice management coordinators, and the primary care physician) and several social services (e.g., APS, county sheriff, and nursing home) involved in this trajectory. Each of them had their specific role in solving medical issues (perhaps simple in this case) and social issues (extremely complicated). The hospital clinicians described their work and their understanding of the case in e-Care in real time. Information sharing was very intensive, as a coordination to collectively investigate the issue and solve the problem. In this case, the medical work of care was marginal (i.e., treating bruises), but the information work was at the very core of the entire trajectory.
- p0250 Third, the patient and family members, who were fighting among themselves, were non-cooperative with doctors and social services, and they complicated the trajectory by not being able to provide or by attempting to hide information. However, the information was pieced together collectively, and the doctors tried to write the consequences of each step in the records. In this case, e-Care was able to satisfy the needs of the clinical workflow and work representations in this case.
- p0255 This case showed how the medical team, when they felt it appropriate, would document the psychosocial information for a patient. Clearly, this case was unusual. It highlights, nonetheless, the emphasis on the doctors’ sense of “appropriateness” in determining when to document. We turn to a discussion of this next, as well as design implications from our study.

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## 6. DISCUSSION

- p0260 Our field observations reveal the need for additional consideration of psychosocial issues in medical practice. This is partially due to complicated patient profiles, chronic illnesses throughout patients’ lifetimes, or poorly controlled pain issues.
- p0265 There are three important findings from this study for medical information systems design. The first is that doctors will detail psychosocial information; however, they do not *always* document this information, as demonstrated through the differentiated handling of such information in case 2 and case 4. Why might this be the case?
- p0270 We believe this is a result of the way that doctors are trained to use their documentation. Doctors are trained to look for *symptoms* first, then they think about the *causes* (based on their medical knowledge and their experiences). This is the sense-making stage and also the



medical reasoning process that leads to diagnostic judgments. Finally, they need to come up with a *treatment plan*. Therefore, symptoms, possible causes, and treatment and care plans are perhaps the most important three categories of information in medical records to represent their work. These categories of information also constitute valuable information for future reuse when a patient is readmitted to the hospital.

p0275 If suspected “causes” match “symptoms” well, a trajectory will be straightforward, even though achieving it may not always be uneventful (as in case 1). In an internal medicine unit, most patients are admitted because of acute events due to chronic illness, so the “cause” is easily assumed to be medical. In case 4, the symptoms were bruises, and the cause was a “fall” (according to the family members’ report). However, a single fall was not likely to cause so many bruises on her body (as the attending noted in the records), and if the bruises were caused by multiple falls, how did these falls happen? Doctors needed to provide a convincing diagnosis, so they went further. In this case, the “cause” was psychosocial, but the symptoms were medical. This was reflected in the records, where a great deal of psychosocial information was documented. In addition, the treatment could not address just medical issues. The doctors needed to prevent the abuse from happening again, so they pulled together all sources to find a suitable treatment plan.

p0280 In case 3 however, the pain drug-seeking patient had a medical issue, that is, sickle cell disease. Although she was admitted to the hospital frequently, the doctors still first looked for symptoms. The symptoms were documented in the records as “questionable behaviors” because they did not match sickle cell disease (i.e., the cause). The doctors speculated that the patient was faking the symptoms. In this scenario, the “symptoms” became psychosocial, or at least a mix of medical and psychosocial. In reviewing previous records of this patient, the doctors did not put appropriate information in her records until the most recent episode in which the patient became violent and threatened others. This became the triggering incident that provided evidence for the doctors’ speculation. Lacking definitive evidence, doctors may hesitate to document such suspicions of “faked symptom” in the medical record. This is reflected in case 2, where the doctors speculated that the patient was seeking drugs but did not explicate this in the records. This missing representation of psychosocial information may eventually create severe problems, such as the incident described in case 3, where the psychosocial issue was finally brought to the medical team’s attention and documented in writing. However, it may have been too late for the patient.

p0285 Indeed, this story is not extraordinary: Over the past several decades, there has been a tendency to view *all* patient-presented complaints and symptoms as curable diseases that can and should be treated within the purview of medical professionals (Gallagher and Ferrante, 2005). This view, however, often leads to an overly narrow, “medicalized” lens of health and illness that largely ignores psychosocial causes and other contributing social and economic factors. Smoking and obesity, for example, can be viewed merely as diagnosable and curable diseases and treated with nicotine substitutes and obesity drugs; however, this defocuses their behavioral and socioeconomic root causes (Lantz et al., 2006).

p0290 Medicalization is defined as “the expansion of medicine as an institution and the use of a medical lens to view human processes and behavior” (Zola, 1972). We believe it is largely this medicalized view, not the sensitivity of information, that sets the boundary of what information to be documented and what not to be. It is also this medicalized view that determines the reuse value of information in subsequent care episodes. Medicalization implies



clear diagnostic tests and evidence. Oftentimes certain psychosocial information gets lost, as in case 2, because such information is not yet formally defined in medicalized terms and encompassed in the medicalization view. Such information is relegated to the “subjective”, becoming less than a “medical fact”.

p0295 Case 4 illustrates a rather unique case where the medical team transcended the boundary set by the medicalized view to actively seek help from other parties including social services. In this case, the symptom, “bruise,” was clearly disconnected from the suspected medically relevant cause, “fall,” which obliged the medical team to think out of the box to find nonmedical evidence and seek nonmedical interventions. This endeavor, however, does not always take place because such a disconnection is not always readily discernable.

p0300 Second, our findings point once again toward the need for considering the broader context of medical information systems. The information models underlying current EHR systems are mainly organized around storing and managing symptoms and treatments. For example, the Certification Commission for Health Information Technology, the accreditation body for commercial EHR products, places an exclusive emphasis in their certification criteria on whether an EHR system has the capability of capturing and managing discrete, process-oriented, and medicalized data, rather than on the meaningfulness (and cognitively coherent representations) of the data to clinicians in their patient care activities. Our study shows the need to gain legitimization for psychosocial issues in system construction and include appropriate representations in the record formats.

p0305 Third, and most importantly, as we have shown, there exists a gap between the work, the patient, and the representation, which may account for the suboptimal outcomes or adverse consequences observed such as repetitive investigations, delayed diagnoses, inappropriate treatments, unnecessary hospitalizations, and increased cost burdens for the hospital.

p0310 This broader implication raises the need to reconceptualize medical records adaptively as both a representation of medical processes and of the patient. An extensive body of literature in HCI/CSCW has been devoted to studying the issues related to the representations of work, recognizing the inherent gap between representation and the real world, and how systems should be designed to support ongoing work activities (e.g., [Bossen, 2006](#); [Schmidt, 1997](#)). Our study points to a new perspective that representation of information may need to be constructed in adaptive forms when a singular form cannot adequately support a multiplicity of purposes, changing demands across time, and distinct priorities of the information consumers. In the medical context, while the information representation that supports medical processes—routines and procedures in day-to-day care—remains critical, what needs to be shared across multiple patient care episodes is not only the process-oriented information but also information centered around the patient’s life long illness trajectory ([Strauss et al., 1997](#))—her medical conditions and other associated psychological and social experiences. As shown in this paper, the conceptual models underlying current medical records are largely process centered, which do not accommodate this multifaceted need and hence may adversely affect medical practice and diminish the reuse value of documented patient care information. Our study represents an attempt to examine whether focusing on one model may lead to the missing of critical functionalities for the continuity of care when a patient comes back.

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## 7. DESIGN IMPLICATIONS

p0315 Our findings provide several insights into redesigning medical information systems from a socio-technical perspective. First, it shows it is necessary to consider the organizational incentives for all of the stakeholders. In this setting, it was clear that pain medicine abuse is exacerbated by the ED doctors' tendency to move patients through as quickly as possible. Technically, providing all doctors convenient access to critical information about patients is also important. For example, many US states have now implemented patient registry systems that maintain a comprehensive list of patients' prescriptions. This list is accessible to licensed physicians free of charge; integrating such information directly into EHRs could help address the issue of information visibility.

p0320 Second, this study highlights the need for a technical capability of documenting psychosocial information—this would allow clinicians to consider the “whole” of a patient. This psychosocial information is often perceived as “informal” when definitive evidence is not yet available. EHR systems, such as e-Care, are not only designed to support care processes but also to focus on the capture of billable, “medicalized” information. As we have seen, EHR systems lack the ability to document and use “informal” and provisional information, as argued in [Hardstone et al. \(2004\)](#), particularly the information that sheds important light on patients' psychosocial issues. In our site, such information was then communicated only verbally and therefore not communicated to the next team effectively.

p0325 Third, our study also suggests the importance of considering information's long-term use more broadly. At this site, understanding the patient from a long-term perspective is far too difficult due in part to the technical difficulties of reusing patients' medical records across multiple episodes. When information reuse occurs within an episode, clinicians need explanatory details to help them understand the current trajectory; when it occurs across episodes, they need to know key issues about the patient. This was reflected in case 1 when the doctor had to read an immense volume of past records, line by line, in order to identify the information she needed. This reiterates the need for mindful consideration when constructing medical records for multiple purposes. An EHR system should be designed to facilitate the clinical work in a nuanced way (i.e., process-centered representation) while *simultaneously* preparing information of high value about the patient for long-term reuse (i.e., patient-centered representation).

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## 8. CONCLUSIONS

p0330 This field-based study describes doctors' use and documentation of medical information, in particular, psychosocial information. We found that doctors documented a considerable amount of psychosocial information in the EHR. Yet, we also noted that such information was only recorded selectively, with a “medicalized” view of appropriate information being a key contributing factor. As well, our study showed how problematic and missing representations of a patient seriously affect work activities for the medical team and for a patient's care, especially for chronic conditions. We accordingly suggest that electronic systems in health care should be designed to support both representations of medical processes and of the patient.

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# ACKERMAN: 08

## Non-Print Items

### **Abstract**

We conducted a field-based, ethnographic study at a large teaching hospital to examine doctors' use and documentation of patient care information, with a special focus on a patient's psychosocial information. We were particularly interested in the gaps between the medical work and representations of the patient. This chapter describes how doctors record this information for immediate and long-term use. We found that doctors documented a considerable amount of psychosocial information in their electronic health record systems; however, we also observed that such information was often recorded too selectively to be reused later. Our study shows how missing or problematic representations of a patient's motivations or social setting affect clinical work activities and patient care. We accordingly suggest that medical systems can be made more useful in the long run by supporting representations of both medical processes and patients.

**Keywords:** CSCW; EHR; Electronic patient records; Health informatics; Medical records; Organizational memory; Physician information needs; Psychosocial information.