Facilitating Patients’ Safe Access to Electronic Health Records: A Proposed Cognitive Framework

Vimla L. Patel*1 Sahiti Myneni*1

*1Center for Cognitive Informatics and Decision Making, School of Health Information Sciences, The University of Texas Health Science Center, Houston, TX, USA

Correspondence: vimla.patel@uth.tmc.edu

Patients’ access to and use of personal health data are important aspects of patient care, which could result in greater patient empowerment and would also contribute to the overall improvement in health outcomes. Given the limitations of the existing health records, such doctor-patient information sharing with proper data partition can lead the patients to misconstrue doctors’ diagnostic and therapeutic decisions. Mental health introduces additional challenges, namely issues concerning privacy and risks associated with providing patients with access to sensitive evaluative information. In particular, adolescent patients’ access to their mental health records (MHRs) raises more concerns about the appropriateness of allowing the patients to view their complete medical part of records. We propose a formative research design framework that has implications for developing information architecture (IA) for improving the comprehensibility of patient health records, in the context of adolescent depression, such that patients can access “appropriate” versions of their records. Such an empirical framework based on cognitive methods and consumer health informatics will help in abstracting culturally sensitive health information from physicians’ versions of patients’ MHRs and can aid in thoughtful design of patient health records. This approach can reduce the probability of misinterpretations caused by the information embodied in MHRs by providing patients with access to an alternative version of their own MHRs, which can be accessed by their physicians.

Key words: EHR Information architecture, Doctor-patient communication, Cognition, Privacy

1. Introduction

Evidence-based medicine coupled with emerging information technologies represents an unprecedented opportunity to greatly improve the health care delivery. Both technological advances and legal provisions propel patients’ access to their health records electronically1,2). However, health data security, privacy, confidentiality, and comprehensibility are some critical aspects that play an important role for facilitating patients with safe access to their records. This paper focuses on methods to improve privacy and comprehensibility of electronic health records. Comprehensibility of medical records is vital to consider for various reasons such as: (1) Patients’ sensitivity may generate misunderstanding about the meaning of the content in their records, and may hinder effective processing of the presented data; and (2) Patients’ lack of knowledge of medical terminology may also lead to misconceptions and misinterpretations of the data, which may have potentially deleterious consequences. The proba-
bility of misinterpretation is often higher for mental health records (MHRs) because of the sensitive and complex nature of psychological data. This highlights the need to investigate ways to redesign electronic health record systems that are more comprehensible and offer patients safe access to their health records. This paper proposes a methodological framework that can contribute to the design of Electronic Medical Records (EMRs) and Patient Health Records (PHRs) that may promote patients’ safe access to their health information.

2. Patients’ Access to Electronic Health Information

Rapid growth in communication technologies and the Internet have created new possibilities for individuals to assume a more prominent role in their own health and health care. Reasons for increasing reliance on e-health applications, such as EMRs and PHRs, include the following: (1) easier access by a more diverse group of users to more powerful technologies, (2) the development of participative health care models, (3) the growth of health information that makes it difficult for any one physician to keep pace, and (4) cost containment efforts that significantly curtail physicians’ time with patients. It is essential to understand how these records can enhance overall improvement in health outcomes when patients are provided with access to their health information.

2.1 Role of Electronic Medical Records

EMRs are typically modeled after the physicians’ work process and the language of these records provides a medium for health professionals to communicate. There have been several studies that document the utility of these records for patients suffering from chronic illnesses. For example, the perceived usefulness of online EMRs by patients living with chronic inflammatory bowel disease centers on the themes of illness ownership, patient-driven communication, personalized support, and mutual trust between physicians and patients. Several studies have suggested that patient access to medical records may enhance doctor-patient communication. Some studies have shown better patients’ adherence to treatment, whereas others have shown no difference. In order for patients to be able to understand and appreciate the significance of their personal data and supportive information stored in these records, methods to enhance active learning in patients need to be incorporated into the EMRs. EMRs also need to be goal-oriented and directed toward the patients’ needs. Without a clear purpose, patients will derive little benefit from access to their records and may even discontinue use. Thus, the ability of electronic medical records to address dynamic and manifold needs of patients is vital to maximize the benefit of patients’ access to their health information.

2.2 Role of Patient Health Records

PHRs are patient-centered systems that allow people to access and coordinate their lifelong health information. These systems make appropriate parts of patients’ health information available to those who need them. These are different from EMRs, which are limited to use by the healthcare provider and the information cannot be transferred to other providers. PHRs have the potential to transform the healthcare system by empowering patients to become active, informed participants in managing their health. However, there is compelling evidence to suggest that lay people have difficulty retrieving, evaluating and productively using knowledge from electronic medical sources. Without comprehensible and usable information, patients may feel overwhelmed, disaffected or even disempowered. Similar problems are exhibited in doctor-patient communication. A significant gulf exists between the language of clinical medicine and the
lay language(s) expressed by patients. Research has shown that patient-physician language mis-
matches occur at multiple levels from surface lev-
el to the underlying deeper mental models. This study shows that clinicians’ understandings of
patients’ problems are supported by a disease model whereas patients employ an illness ex-
planatory model that is framed in narrative rather than causal terms. Therefore, PHRs need to
bridge the barrier between clinical descriptions of illness as understood by medical professionals and
patients’ conceptual models of their illness. Design-
ers of PHRs should take into account informa-
tion relevant to the patient comprehension of medical problems, which will influence their com-
pliance. As discussed, misunderstanding doctors’ therapeutic and diagnostic decisions pose serious
challenges when sharing mental health information with patients. The sensitive nature of mental
health data demands carefully tailored strategies to incorporate certain characteristics into elec-
tronic health care technologies to distinguish men-
tal health problems from general illness.

3. Patients’ Access to Mental Health
Records

The domain of mental health introduces addi-
tional challenges, most notably issues concerning privacy and risks associated with providing
patients with access to sensitive information. Patients’ access to their mental health records
(MHRs) raises further concerns as to whether it is appropriate or detrimental to allow patients to
view their records. Both practitioners and patients have found psychiatric case notes to be poten-
tially confusing, offensive, and / or alarming. Mental health information and ter-
minology may be inherently more sensitive and stigmatized than general medical information
(Cline et al., 2001). Hence, it is essential to de-
vote special attention to develop PHRs that are
efficient, effective and also safe for patient access.

Increasing the comprehensibility of mental health records and encouraging patient input will likely
increase the benefits (and diminish the negative ramifications) of patients’ access to their MHRs.
Given the prevalent nature of adolescent depression worldwide, we chose it as an example to elu-
cidate the concepts of the proposed cognitive framework.

3.1 Facilitating Adolescents’ Safe Access
to MHRs

Although adolescent patients’ access to their
MHRs may empower them to be more actively
engaged in their healthcare and result in sound indi-
vidualized treatment decisions, enhanced patient-clinician relationships, and increased
patient adherence to regimens, there are few
methods to frame the information in MHRs so it is
comprehensible to lay adolescents. Without
proper understanding of content within their
MHRs, including doctors’ evaluations and sug-
gested interventions, patients may experience deleterious outcomes from access to their MHRs.

Figure 1 presents an investigative cognitive
framework to help redesign a MHR and promote
safe access of mental health data. The basic steps
involved in this framework are as follows:
1) Compile adolescent vocabulary of depression
to create a comprehensible MHR,
2) Characterize adolescents’ organization of con-
ceptual knowledge to form more coherent infor-
mation architecture,
3) Explore adolescents’ comprehension of their
own web-based electronic mental health records
in two different versions: (a) summary from the
electronic medical record by psychiatrist and a
(b) summary created based on vocabulary ob-
tained in step 1, and
4) Design a mockup interface for PHRs based on
steps 1–3.
3.2 Extracting Adolescent Vocabularies

A significant gulf exists between the language of clinical medicine and the lay language(s) expressed by patients. Medical concepts and terminology used by healthcare professionals are largely inaccessible to most lay people. The healthcare field contains numerous technical terms for describing anatomical parts, biological systems, bodily functions, symptoms, diseases and drugs. The terms are either unfamiliar or have different referents in the lay and technical language(s). A layperson may know a form but may not understand the technical concept (e.g., asthma may be associated with severe gasping for air). Conversely, when a concept is understood, but the technical form is not known, a layperson may fill in the blank by using less precise general language expressions. Recent work on consumer health vocabularies (CHVs) represents a novel approach to bridging the gap between professional and lay language. Informally (as they occur in everyday language), CHV refers to a collection of expressions, concepts, attitudes and beliefs held by most members of a consumer discourse group to communicate about health-related issues. In order to be effective, a standardized CHV will need to consist of normal standard ways of expressing things and informal terminology. There have been several approaches to elicit and structure a CHV. They typically involve eliciting discourse from natural sources or through interviews and mapping it to other clinical or professional
vocabularies. To accomplish this task, researchers often employ the Unified Medical Language System® (UMLS®) Metathesaurus developed by the National Library of Medicine. Previous studies have used different techniques for collecting and mapping lay terms\(^{11,18,19}\). And, it was shown that adolescents used very similar language to explain their understanding and experience of depression\(^{20}\). Therefore, it should be possible to use consumer health informatics to create a summary of the information in MHRs using adolescents’ vocabulary. This terminology can be obtained by conducting interviews with the end user community, in this case, adolescents with depression. These extracted expressions can be mapped to other similar concepts using the UMLS Metathesaurus. This can be done by using manual or automated mechanisms\(^{18}\). The created forms can then be compared with professional vocabulary for consistency. Thus, adolescents can possibly be provided with access to a more comprehensible version of their own MHRs.

### 3.3 Improving the Coherence of Information Architecture in a Mental Health Record

Capturing adolescent’s conceptual knowledge as it pertains to mental health and depression is vital in this process. Alongside assessing conceptual knowledge of individuals, gauging their ability to categorize knowledge chunks plays a great deal role in understanding and designing information technology systems. There is an enormous extensive literature in psychology and related disciplines characterizing the nature of the human conceptual system as realized in terms of categorical knowledge\(^{21−24}\). Previous research demonstrated the use of cognitive methods (e.g., representation of natural language processing (propositional analysis), think aloud protocol) in understanding reasoning strategies and knowledge organization of physicians and patients. Findings of these studies helped in the design and customization of information structure in EMRs\(^{13,25}\). This knowledge about adolescents’ reasoning, beliefs and mental models can be transformed and used in the design of patient-centered MHRs. Methods such as categorical card sorting can also be used to gain insight on how users mentally categorize information and to discern the degree of agreement within a given population. In recent years, card sorting tasks have been used to guide the development of information architectures and websites in particular\(^{26}\).

### 3.4 Exploring Comprehension of Summarized Electronic Health Records

A clinical summary and patient-centered summary could be used to evaluate the adolescents’ comprehension of mental health information. The clinical summary may be developed from the patient’s electronic medical record, while the patient-centered summary could be compiled essentially from the same information, the language should employ terms derived from the consumer health vocabulary described in section 3.1 1). In addition, the information in the patient-centered summary may be organized based on the additional knowledge gained from section 3.1 2). However, it may be essential to match the two summaries for length and semantic density. Based on the recall and accuracy exhibited by the patients with the two summaries, a safer patient health record could be proposed.

### 3.5 Developing an Information Architecture

In addition to comprehension, adolescent privacy is identified as a key issue to be considered during the implementation of an electronic medical record\(^{27}\). A thoughtful design and implementation of PHRs, EMRs, and other patient portals is necessary to facilitate effective communication between patients and clinicians, and improve
health outcomes\textsuperscript{28}. Several studies proposed designs of clever health records that can dynamically customize the information presented to its users depending upon their personal privacy needs\textsuperscript{29,30}. Similar methods can be adopted for designing adolescent patients’ PHRs with appropriate access controls. Such health records can be designed with the help of information architecture (IA) that allows adolescent patients to access a modified comprehensible summary of test results and physicians’ notes in their PHRs. An IA is the structure of an information space designed to facilitate intuitive access to content and task completion\textsuperscript{31}. It complements the privacy and confidentiality necessities that frequently arise during adolescent patients’ mental health care. Accuracy of encoding, efficiency as measured by the time needed to complete the task and user satisfaction are the measures that one might need to consider when designing an IA for any PHR. The empirical design framework described above attempts to improve comprehensibility PHRs based on a comparative evaluation of two versions of electronic health records. The proposed framework could result in better patient-centered PHRs as a result of the adoption of methods from cognitive science and consumer health informatics. The more the system matches to the mental models of the users, the better the comprehensibility of content, page labels, and links of the PHR will be\textsuperscript{32}. However, systems like MHRs and PHRs that serve both patients and health care professionals will need to address differing expectations regarding security and ease of use\textsuperscript{33}.

4. Conclusions

There is a general agreement that contents of health records should be accessible to patients, because informed patients tend to be better equipped to participate in their health care decisions with their health care providers in a partnership manner. Studies show that providing patients with access to their own health records can result in smooth doctor-patient communication, better adherence to treatment and patient empowerment. Comprehensibility, security, privacy, and confidentiality are most challenging issues that should be addressed by the informatics research community to minimize the risks when patients are given access to their own health records. In this information age, electronic health records may become more common for patients to review their records routinely. Hence it is necessary to incorporate specific features into EMRs and PHRs that allow patients to have safe access to their health records.

This paper describes a cognitive framework that can improve comprehensibility of electronic health records and reduce probability of misinterpretation among adolescent patients. Patient health records are packed with jargon, acronyms and medical terms that health care professionals know and understand. Often there is a learning curve before patients become familiar with medical terminology associated with their illnesses. Consequently, they may require more familiar words and phrases to describe medical concepts in an accessible form. Our framework draws ideas from cognitive science and consumer health informatics to design patient-centered MHRs. It includes the examination of mental models of the target patient community, the development of a consumer (patient) health vocabulary, and the construction of intuitive information architecture (IA). Such a user-centered system can possibly increase comprehension of medical and mental health information presented to patients and relieve concerns of confidentiality and privacy.

References

1) Ross SE, Lin CT. The effects of promoting patient access to medical records: A review. Journal of the American Medical Informatics Association 2003; 10:


27) Spooner SA, Council on Clinical Information Tech-


