Towards Consumer-Friendly PHRs: Patients' Experience with Reviewing Their Health Records

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Abstract

Consumer-friendly Personal Health Records (PHRs) have the potential of providing patients with the basis for taking an active role in their healthcare. However, few studies focused on the features that make health records comprehensible for lay audiences. This paper presents a survey of patients' experience with reviewing their health records, in order to identify barriers to optimal record use. The data are analyzed via descriptive statistical and thematic analysis. The results point to providers' notes, laboratory test results and radiology reports as the most difficult records sections for lay reviewers. Professional medical terminology, lack of explanations of complex concepts (e.g., lab test ranges) and suboptimal data ordering emerge as the most common comprehension barriers. While most patients today access their records in paper format, electronic PHRs present much more opportunities for providing comprehension support.

Introduction

Patients are increasingly encouraged to take an active role in their health care [1], often by accessing and contributing to their health records. Records need to be easily understood by lay readers in order to provide them with optimal decision support. However, health records are complex documents created by health care professionals for medical, legal, financial and administrative purposes. They employ professional medical terminology and contain codes and abbreviations that are likely to be unfamiliar to most health consumers.

Personal health records (PHRs) are electronic records, specifically designed for patient audiences. Proponents of PHRs view them as a potential solution to the problem of "consumer-unfriendliness" in professional records. Limited research has been done on what features would make PHR easy to understand by lay audiences. Most PHR systems today rely heavily on institutional electronic health records (EHRs) as their data source, and often incorporate sections of EHRs [2,3]. Efforts to make PHRs "consumer-friendly" have generally focused on issues of user interface design [4] and the links to educational materials (i.e. infobuttons [5]). Less attention has been given to the underlying logic of information organization and content selection.

Despite these efforts, PHRs continue to pose a challenge to lay users [2,3]. The need to make PHRs and EHRs "consumer-friendly" will grow as more consumers with varying levels of health literacy gain access to increasingly comprehensive records. A prominent panel of fellows of the American College of Medical Informatics recently published a white paper stating "In order to be useful to the patient, the PHR must present data … in ways that enable the individual to understand and to act on the information contained in the record."[6] Developing consumer-friendly PHRs requires comprehensive knowledge of 1) what kinds of questions patients hope to answer when they access their health records and 2) what characteristics of information content and presentation affect record comprehension. Such knowledge can then inform the design of new PHR systems. While multiple studies focused on users' experience with specific PHR products, we present a general survey of patients' information and comprehension needs related to medical records.

Methods

Instrument and procedure: a 25-item survey instrument developed by a multidisciplinary team included the following sections: Background; Information Seeking Behavior; Comprehension and Satisfaction; Decisions, Actions and Outcome; and Recommendations. Twenty three of the questions were multiple choice; two were open ended ("What could make your medical records easier to understand?" and "How can records be improved to be more useful to patients?"). Survey coverage was based on a PHR literature review [6] and consultations with clinical experts. As the data were collected and maintained by a federal agency (NLM), IRB approval was not required. To comply with the Paperwork Reduction Act, the protocol was approved by the Office of Management and Budget of the National Institutes of Health.

Participants: As we were interested in general record comprehension problems regardless of the format, individuals who viewed their paper or electronic health records within the past year were eligible to participate. The link to the online survey was posted to twenty high-traffic google and yahoo news groups on a range of health-related topics. A convenience sample of 104 unpaid volunteers completed the survey between Dec 19, 2006 and Feb 1, 2007 (see demographics in Table 1).

Of the 103 participants who answered the question about their health status, 93% suffered from a chronic disease; 72% required daily medication; 29% have been hospitalized. Of those with a chronic condition, 83% rated their knowledge about their condition as good or excellent. Our self-selected sample was comprised of educated individuals with extensive health knowledge, and is minimally representative of minorities and individuals with low health literacy. Prevalence of females in the sample was unexpected.

Table 1. Sample's Demographics (the numbers do not always add to 104, due to some missing answers)

Characteristic	Sample Distribution
Gender	Male: 14; Female: 89
Race	White: 95; Asian: 2; "Other": 5
Ethnicity	Non-Hisp: 98; Hisp: 2
Education	HS: 9; College: 48; Grad school: 39; "Other": 5
Age	30-39yo : 11; 40-49yo: 19; 50-59 yo: 41; 60 and over: 32

Analysis: Forced-choice questions were analyzed via descriptive statistical analysis. Open ended comments about barriers and ways to improve comprehension were combined so as to create one note per participant (N-83), and analyzed via data-driven thematic content coding [7]. One coder segmented narrative responses into sentences or clauses, with each segment representing one idea. This coder then read the responses, assigning each a descriptive label. Whenever possible, the label was selected from those already existing; otherwise, a new label was created. The labels were then arranged into a hierarchical scheme with the following branches, indicating problem areas that could benefit from support:

1. Language
2. Conceptual Knowledge
3. Record Structure and Organization
4. Data Quality
5. Record Clarity
6. Record Access
7. Data Standardization
8. Support from Health Care Professionals

The following is an example of the Language code branch hierarchy:

1. Language
    1.1 "Plain English" codes
        1.1.1 Lay terminology
        1.1.2 Narrative structure
        1.1.3 Code and abbreviation support
    1.2 Clear section heading titles

Codes were assigned at the finest possible level of granularity. To assess inter-rater reliability, the coding scheme was collapsed to 10 categories (at the top- and second-to-top levels). A second rater, blind to the first rater's assignments, coded the data for 25 participants using the same scheme. The Kappa coefficient of .85 indicated very good agreement at this level. Kappa assessment at a finer-grained level was not possible, due to the scarcity of some codes.

Results: Descriptive Statistics

Background: The background questions asked participants about the number of times they had viewed their records in the past year, the number of facilities from which the records were requested, the records' format and the time spent on the last review. Twenty six percent of the respondents viewed their records only once in the past year; 43 % viewed them between two and five times; 13 % - more than five times; 18% – following each visit. Most participants had viewed the record from more than one health facility. Typed paper records were the most frequently viewed format (by 79% of participants), followed by handwritten paper records (viewed by 54%) and professional EMRs (by 43%). Patient-oriented electronic PHRs were the least common (viewed by 20%). The mean amount of time spent per record review was 24 minutes (STD=23).

Information Seeking Behavior: These questions tallied participants' reasons for looking at the records, specific information they wanted to find, and sections they viewed. Any number of answers could be chosen for each of the three questions. Table 2 presents participants' reasons for requesting their record. Table 3 presents types of information that patients hoped to address through the record review. Most frequently viewed parts of the record included lab test results (85% of participants), radiology reports

(63%), physicians' notes (58%) and diagnostic images (52%).

Table 2 (N=104). Reasons for Accessing Records

Reason Accessed	#
To have detailed info about one's health	81%
To take more active role manag. own health	81%
To have a copy for one's own record	80%
To confirm record's accuracy	55%
To explain situation to someone else	42%
To check if best possible care was provided	32%
To request a second opinion	27%
To check for negative comments	24%
"Other"	11%

Table 3 (N=104). Specific Information Desired

Information Desired	#
Tests being done / tests that have been done	81%
Details of the diagnosis	64%
Treatment plan	49%
Probable disease course and outcome	44%
Complications (side effects) ; qual of life	31%
General overview, nothing specific	24%
Details of hospital stay	23%
Administrative and insurance aspects	12%
"Other"	6%

Comprehension and satisfaction: Participants were asked to rate the ease of locating needed information within the record on the scale from 1 (difficult) to 5 (easy). Forty eight percent of respondents felt that finding the information was "easy" or "somewhat easy", 33% were neutral on the subject, and 19% felt that it was "somewhat difficult" or "difficult".

Table 4 (N=104). Comprehension Ease by Section

Record section	Easy	Neut	Dff
Lab test results (out of 87)	51%	26%	23%
Radiology reports (64)	45%	28%	27%
Physician's notes (59)	36%	30%	34%
Discharge summary (30)	63%	27%	10%
Medications list (25)	80%	16%	4%
Nurses' notes (19)	47%	21%	32%
Immunization record (7)	71%	29%	0%

Table 4 presents percentages of participants finding a particular record section as easy or difficult to comprehend, out of all participants viewing that section. The original 1-5 scale was collapsed in the following way: 4-5 = "easy", 3 = "neutral", 1-2= "difficult". Sections that were perceived as most difficult are physicians' and nurses notes, radiology reports and lab test results.

Most participants utilized various resources in order to understand and interpret their medical records. Table 5 presents the list of the resources, in descending frequency order. The most commonly consulted resource is the Internet, followed by conversation with health care providers.

Table 5 (N=104). Comprehension Aid Resources

Resource used	#
Internet search	84%
Talking to doctor / nurse	59%
Medical dictionary	39%
More knowledgeable friends	32%
Library	14%
"Other"	14%
None	9%

Decisions, outcomes, actions: Table 6 describes participants' actions with respect to sharing the information in their record: discussing the record and showing copies of the record. Not surprisingly, individuals most frequently share their records with physicians and family members.

Table 6 (N=104). Records' Sharing Patterns

Individual(s)	Discussed	Showed
Family members	70%	52%
Friends	45%	14%
Doctor	77%	51%
Nurse	36%	17%
Other provider	18%	17%
"Other"	14%	10%
Noone	4%	24%

For 76% of the participants, records viewing translated into some decisions that affected their care. Table 7 outlines actions, most frequently undertaken by the participants as a result of their record review.

Table 7 (N=102). Records' Sharing Patterns

Action	#
Request certain care	42%
Change self-care	37%
Agree to certain care	33%
Request a second opinion	32%
Nothing	24%
Refuse certain care	19%
Other	13%

Results: Qualitative Analysis

Eighty three participants provided narrative comments about barriers to positive record review experience and ways to improve it (Table 8).

In the Record Access coding category (#6), the most frequent code was Ease of Access (#6.1). Seventeen participants commented on the difficulty of obtaining their records from health care facilities, eg, "Doctors don't respond to requests for records as though I had nobusiness seeing my own records." Five noted a generally long wait to obtain the record. Six suggested that records' review should routinely follow or precede each visit (#6.4 Routine Access).

Table 8 (N=83). Narrative Comments by Category

Comment area	#
Record Access	63
Conceptual knowledge	44
Language	38
Data quality	33
Structure and organization	20
Support from health professionals /advocates	15
Record standardization	7

Seventeen participants suggested that records should be kept in electronic format (#6.3 Access Mode code), often pointing that a secure online view option would make access easier (eg, "have them available online so one doesn't feel like a nuisance asking for them.") Seven participants mentioned privacy / security / confidentiality issues in connection with electronic access (#6.5 Privacy, Security, Confidentiality). Most felt that the problem could be resolved, eg, "secure electronic access via Internet, it can be done without violating anything in HIPAA."

Forty four participants made comments that pointed to records comprehension barriers that were related to insufficient conceptual knowledge (category #2). Twenty seven of these were related to problems that could be ameliorated by pointers to general reference-type support (#2.1 Reference type support), while 17 would require individualized decision support. Concepts related to lab tests seemed to require the most support: 15 participants asked for reference support with understanding test purposes (#2.1.2), results ranges (#2.1.5) and measurement units (#2.1.6), while 9 asked for help with interpreting their individual results and data trends across time (#2.2.1 and #2.2.4).

Thirty eight participants commented on professional language as a barrier to record comprehension. Across all coding categories, medical terminology (#1.1.1 Lay Terminology) was the most frequently cited difficulty area (comments by 24 participants). The need for terminology support was often expressed as a preference for "simpler words" or "laymen's terms" in place of "medical terms", "as if they were written for non medical degreed person." Some participants also noted that electronic record format would make providing terminology resources (eg, online dictionaries) easier. A significant proportion of language-related comments (9) also had to do with the use of abbreviations and special codes in the records (#1.2.3 Abbreviation and Codes Understanding Support). One of the participants expressed her frustration by writing, "The abbreviations, acronyms and symbols doctors use are a mini-foreign-language to most of us."

Thirty three participants commented on some problems with the quality of the records' data. Of these, fourteen had to do with problematic legibility of handwritten comments (#4.4 Handwriting Legibility); ten mentioned problems with the records' completeness (#4.2 Completeness of Documentation) and seven pointed to inaccuracies (#4.1 Accuracy).

Twenty participants commented on the record structure as a factor contributing to comprehension difficulty. Eleven of these comments concerned data ordering (#3.5 Data Ordering): some participants felt that topical organization was preferable to temporal, or vice versa, others asked for topical categories arranged within temporal ones (eg, "Put them in a structured document so I can compare apples to apples over the course of the longitudinal record.")

Finally, fifteen participants commented on the role that health professionals and advocates should play in the process of record comprehension. These participants often felt that no matter how much comprehension support is provided within the record, interpretation of this professional document requires medical expertise. They, therefore, felt that records should be jointly reviewed and discussed by patients and health professionals (eg, "Review and discuss reports (especially lab) with a healthcare provider.")

Discussion and Conclusions

This paper presents a survey of patient information needs and experiences with reviewing their health records, which can provide insight for optimal "patient-friendly" PHR design. The following four key points emerge from the findings:

1. *Health records are a valuable resource for enabling patients' participation in their health care.* Participants' interest in their records was often prompted by their desire to play an active, collaborative role in their care and share the information with family and friends. Records review as an indicator of conflict and dissatisfaction with care was less common: participants were more likely to view their records in order to have detailed information about their health than to check adequacy of care and seek out second opinion. The survey also suggests that for many people, viewing their record translates into care-related decisions and actions, be it requesting specific care or changing self-care.

Unfortunately, gaining access to the records was often a challenge.

2. *Most notable specific comprehension barriers include professional terms and abbreviations, difficult concepts (particularly in the areas related to lab testing and radiology) and data ordering.* Our results suggest that even for actively involved, highly educated individuals, understanding their records is not always easy. Many participants who reviewed physicians' and nurses' notes, lab test results and radiology reports found them somewhat difficult or quite difficult. As these sections contain the information described as most needed, this is a reason for concern. Analysis of narrative comments points to several aspects that may impede comprehension. Some involve data quality issues that are common to professional and patient versions of the record, but others are unique to lay readers and require special supports oriented towards consumers.

3. *Many of the above comprehension barriers can be effectively addressed in carefully designed PHRs.* Records viewed by patients today are most likely to be in paper format, which provides limited opportunity for comprehension support. Many participants noted that electronic format could ease record access and eliminate the problem of indecipherable handwriting. Beyond that, PHRs could provide terminology support in the form of online dictionaries and automated translators [8], infobutton-types links to the information on difficult concepts [5] and decision support tools. They could also allow switching between chronological and topical views, provide summaries and chart data trends. Finally, PHRs could allow electronic sharing of information with friends and family members.

4. *For maximum usefulness to patients, PHRs data may need to be comprehensive.* Radiology reports, physicians' notes and diagnostic images were among the most frequently requested records sections in our survey. However, many existing PHRs do not presently include these sections.

One of the limitations of the study is a non-random, self-selected, predominantly White, educated and mainly female sample. While the sample may be representative of patients used to requesting their records [9], it is not representative of the general patient population of the country, so statistical results should be interpreted with caution. At the same time, findings on the basis of our sample are likely to underestimate rather than overestimate potential barriers to health records comprehension, which can be exacerbate by inadequate health literacy. Therefore, while this survey cannot comment on the extent of health records use difficulties in the general population, addressing problems identified here could benefit many users.

Additional research will provide us with the information about ways to optimize PHR experience for populations with limited health literacy and understanding of their conditions. The present study suggests that work in the area of machine translation into consumer friendly forms, user-friendly presentation of difficult concepts and multiple-view representation have the promise of improving health records review experience for lay readers.

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