The urban underserved: attitudes towards gaining full access to electronic medical records

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Abstract

Background As the use of electronic medical records (EMRs) spreads, health-care organizations are increasingly offering patients online access to their medical records. Studies evaluating patient attitudes towards viewing elements of their records through secure, electronic patient portals have generally not included medically underserved patients or those with HIV/AIDS. The goal of this study was to gain insight into such patients' attitudes towards online access to their medical records, including their doctors' visit notes.

Methods Qualitative study of four focus groups with adult patients in general adult medicine and HIV clinics at a large county hospital. Transcripts were analysed for themes using an immersion/crystallization approach.

Results Patients' baseline understanding of the health record was limited. Perceived benefits of online access were improved patient understanding of health and disease, convenience, empowerment and a stronger relationship with their provider. Concerns included threats to privacy, worries about being unable to understand their record, fear that the computer would replace direct provider contact and hesitancy about potential demands on a provider's time. Patients also recommended providing online visit reminders, links to credible health information and assistance for paying bills.

Conclusion Despite their initial lack of knowledge of the health record, focus group participants were overwhelmingly positive about the prospect of online access to medical records. However, they worried about potential loss of privacy and interference with the patient–provider relationship. As EMRs increasingly offer patients open access to their medical records, vulnerable patient groups will likely join others in desiring and adopting such change, but may need targeted support during times of transition.

Introduction

With the use of electronic medical records (EMRs) spreading rapidly and growing interest in greater transparency in health care, more and more health-care organizations are offering patients online access to variable aspects of their medical records.[1–4] Several studies indicate that consumers are enthusiastic about gaining and profiting from such access,[5–7] but research has focused largely on those with computers and routine Internet access. Few investigations have examined the perspective of patients from vulnerable populations, with the exception of one telephone interview study of 31 Medicaid beneficiaries suggesting that the interest of these patients was not different from those with private insurance[8,9] and a mailed survey study of a predominately well-educated, middle-class Midwestern population reporting that women and non-whites were more interested in accessing personal health information online.[10]

The OpenNotes project involves more than 100 primary care physicians (PCPs) and 20 000 patients in Boston, rural Pennsylvania and at Harborview Medical Center (HMC)[1] where we are now piloting a secure website portal that allows online EMR access for selected patients in our HIV clinic and an adult medicine clinic. HMC, managed by the University of Washington in Seattle, began using electronic medical records in 1995.[11] The hospital's mission is to serve a broad population, including medically underserved patients, uninsured and underinsured populations, and homeless and incarcerated patients.[12] Many patients have complicated medical conditions that co-exist with substance abuse or psychiatric illness.

In addition to their primary care visit notes, patients at HMC may now view laboratory, cardiology, radiology and pathology results. Many of our patients are marginally housed or homeless, without regular access to computers at home, and we were particularly interested in their views towards online access to their records. Would they be interested in seeing their records online and reading their doctors' visit notes? Do they have access to computers to do so? Do they have particular concerns about online access that we might need to address as we refine the portal? To gain further insight and to develop hypotheses for future evaluations, we invited HMC patients to join us in a qualitative study of their views on such issues.

Methods

We conducted four focus group discussions with HMC patients in November and December 2009. Each group consisted of five to nine participants with diverse backgrounds (total $N = 30$). The discussions lasted approximately two hours, and we audio- and/or video-taped and transcribed each. We informed participants verbally of the recordings during the recruitment process and again before the start of each group. Participants signed informed consent prior to the discussion and received 50-dollar grocery store gift cards and reimbursement for parking or bus tickets at the end of the session. The study was approved by the University of Washington Institutional Review Board.

Recruitment

We recruited a diverse group of patients from two clinics: one that manages patients with HIV/AIDS and a general medicine, primary care clinic for adults. The HIV/AIDS clinic, affiliated with the University of Washington Center for AIDS Research (CFAR) and one of 20 AIDS research centres funded by the National Institutes of Health, maintains a registry with contact information and 'consent for contact' for all patients who wish to be considered for research studies. The clinic's research nurse developed a list of approximately 30 patients from the registry who were considered physically and mentally able to participate in focus groups. Of the 21 patients contacted, 19 agreed to attend the meetings, and all but two participated.

Four primary care providers from the general medicine, primary care clinic suggested a total of 83 patients from their patient rosters, who they judged both appropriate candidates

for focus groups and likely amenable to being approached about research. The research staff reached 41 of these candidates by telephone and spoke with them using a recruitment script. Eighteen agreed in principle, and 13 participated.

Participant questionnaire

Before the discussions, participants completed a brief questionnaire (available from the first author) that included demographic items (gender, age, education, ethnicity, presence of chronic disease) and Likert scale questions that gauged their knowledge and interest in the discussion topic: for example, 'I would be interested in having access to my medical records electronically;' 'Learning how to access and navigate my medical records electronically would be …' (rated from 'very easy' to 'very difficult'). Following the discussion, they completed the same questionnaire, minus the demographic questions.

Discussion guide

Following a discussion guide developed by the authors, two investigators (LR, NVO) facilitated each of the four groups. We described EMRs and the planned patient portal and then asked participants to discuss the pros and cons of patient access to EMRs, how likely they would be to seek out medical information online, what aspects of records would be most beneficial to them and how they thought access to their medical records might affect communication with their doctors. The discussions also offered ample opportunities for participants to provide unstructured feedback.

Analysis

Using transcripts of the meetings, we conducted iterative rounds of analysis using immersion–crystallization techniques to come to joint agreement on key themes.[13] Initially, four investigators (SD, NVO, LR, KF) independently reviewed the transcripts to develop a list of key themes from the discussions. Next, they met to compare their interpretations and discuss and resolve differences of opinion about the meaning of specific passages. Only those themes that recurred in all four groups are presented herein, and evaluation of the transcripts revealed that thematic saturation had been achieved by the third group. Finally, two investigators (NVO, LR) re-read the transcripts to identify quotations exemplifying the themes that had emerged.

Results

Demographic characteristics of the 30 patients who participated are shown in Table 1.

Paired *t*-tests of patients' questionnaire responses revealed that participating patients were more interested in having electronic access to medical records post-discussion ($M = 4.59$ on a five-point scale) than pre-discussion

Table 1 Characteristics of participants from four focus groups

Characteristic	Number ($n = 30$)	Percentage
Gender		
Female	9	30
Male	21	70
Age (in years)		
18–40	5	16.7
40 or 41–60	19	63.3
60+	4	13.3
Missing data	2	6.7
Ethnic background		
African American	9	30
Hispanic/Latino	2	6.7
White/Caucasian	16	53.3
Other	3	10
Education level		
High school or less	10	33.3
At least some college	16	53.3
Post graduate	2	6.7
Missing data	2	6.7
Chronic illness		
Yes	24	80
No	4	13.3
Missing data	2	6.7
Clinic		
Adult medicine	13	43.3
HIV/AIDS	17	56.7

($M = 4.07$, $t = 3.17$, $P < 0.01$). No significant differences in reported interest in having electronic access to medical records were found by gender, age, ethnicity, education level, chronic illness or clinic.

Baseline perceptions and knowledge of EMRs

Only one participant had seen his medical record, some did not realize that they had a legal right to see their records and some were not aware that providers write notes documenting patient visits. Despite this lack of knowledge, patients predicted that learning how to navigate their online medical records would be easy. One participant believed that a process exists for automatically correcting errors in the record.

Participants raised a number of themes listed in Table 2 and described in detail below:

Incomplete transparency

'…what's the point of (being) able to access our file if (doctors) have private notes sitting on the side somewhere? We want to know what the private ones are too!'

Many participants expressed the need for full transparency of the record and worried that providers would be able to limit access to some records or portions thereof. These patients had a strong desire to know everything about their medical and health conditions and wanted nothing hidden from them: 'I want to see everything. *I want to know that nothing's being left out*.'

Privacy and security

'That would be my only concern … is someone outside of me and my doctor accessing that information?'

A large number of patients at this county hospital are marginally housed or homeless and use public spaces, such as libraries, to access the Internet. Patients in the groups expressed concern about login security, worrying that their medical records could be viewed by others in such public spaces. They also wondered about deliberate break-ins by computer hackers or by hospital employees developing the website. And some feared that having medical information online would help insurance companies deny medical claims.

After some discussion, participants seemed convinced that the hospital had an interest in guaranteeing security for this process, and most appeared reassured that security measures would be in place, frequently citing online banking as proof that customer data could be secure. Nevertheless, they wanted a way to determine who had accessed their records.

Stress from medical knowledge

'…it was like the way doctors speak … I had no clue what I was reading half the time.' (Quote from the only focus group patient who had seen his own medical records).

Many participants expressed concern about not being able to understand medical language in their records, and a few did not want to read them, noting that written information could make diseases too 'real' to them, might remind them of health problems and could result in a poorer quality of life. Two thought that seeing their diagnoses in writing would be stressful enough to '…*put me over the top*.' Several felt that too much knowledge would lead to progression of their medical problems as a 'self-fulfilling prophecy'. One noted,

Table 2 Themes/hypothesis of patients related to open access to electronic medical records (EMRs)

Perception/knowledge of EMR
Negative themes
Transparency
Privacy and security
Medical knowledge and stress
Technology replacing individual contact
Increasing the clinician's workload
Positive themes
Enhanced understanding of health
Empowerment
Relationship with provider
Convenience

'*What you don't know won't hurt you. I found out people be living and doing good and just happy-go-lucky. Soon as they find out they got some kind of disease, they go right downhill.*'

Technology replacing individual contact

'Do not substitute access to these medical records for physician care.'

Some patients expressed concern that web access to records would change and potentially harm their relationships with their doctors. Most were fond of their providers and did not want their role to diminish. They worried that care would be increasingly delivered online, eventually replacing face-to-face interactions with their providers. Indeed, one patient questioned the medical centre's motives in offering patients online access to medical records, suspecting that '*...somebody's trying to save some money.*'

Patients worried also that access might replace verbal communication and were nervous about finding information in their record that had not been conveyed verbally by their provider: '*I don't want any major surprises... As long as you or I have talked about it in our session and then you put it online, then I'm fine with that. I just wouldn't want to be, like, totally shocked and be alone, or if I'm feeling down and depressed, have to deal with that on my own. Because at least here [in the clinic] if I get bad news, I can deal with it...*'

Increasing the clinician's workload

'...it could be a nightmare for them.' Participants were mindful of their providers' workloads and worried that patients who read their records would flood clinicians with messages and questions.

Enhanced understanding

'They're always talking about wanting the patient to take control or care of their own health – well, this is a tool to make them do it!'

Most patients felt that access to their records would improve their understanding of the plan of care, clarify verbal messages from providers and remind them of what had been communicated during the visit. They were particularly interested in being able to review medications and laboratory results after the visit. A few, however, doubted that they would access the record. They felt confident in their understanding of plans communicated during the visit. But many patients felt that reading their medical records would reinforce their knowledge of their health and illness and lead to beneficial outcomes.

Empowerment

'I think it's very important in a system that takes away your power at every turn to give people back that power.'

Participants noted that access was a means to empowerment that would allow self-management of disease and enable them to be more proactive about their health. They thought that written recommendations from their providers regarding behaviour modification, such as smoking cessation, would have an impact beyond verbal messages given during the visit. They also felt that having access to a previous visit note would allow them to have more meaningful and interactive conversations with their providers in upcoming visits: '*I think that access is very, very critical to understanding exactly what's expected of me, what my doctor expects of me, so that when I come to the office I'm ready to talk with her, too. Not only should I remember, but I want to remember what's supposed to be happening.*'

Relationships

'*I personally think it would strengthen the relationship, because I would be able to question more about what is this, what is that.*' Patients noted that open medical records could strengthen their relationship with their primary care physician and, in particular, that increased

education about their health would strengthen the provider–patient relationship.

Convenience

'*And it would have been so easy just to... pull it up... instead of somebody starting from scratch with your health history*.' Group participants noted the convenience of being able to access records online, especially when travelling.

Wish lists

Many patients shared opinions regarding their 'wish list' for open medical records (Table 3). At our hospital, the study allows patients to view provider notes and, also for the first time, results of radiology, pathology, laboratory and cardiology tests. Patients also expressed interest in being able to link to a web-based search engine, such as Google or Bing, in order to understand and explore terms or conditions in the medical record. Others preferred to receive their medical education from the hospital as a trusted resource, rather than an outside web source, and suggested that terms in the medical record be linked to a hospital-specific education site, which would include topics such as diabetes education, drug interaction information and lifestyle modification (i.e. diet and exercise).

Participants also wished to be able to pay bills through the portal, request refills from their pharmacy and receive reminders of upcoming physician visits and screening/

Table 3 Wish list from patients: features they would like to see related to electronic medical records

The visit notes

Communication with provider (web-messaging, email)

Pharmacy link for refills and questions regarding medications

Direct link to accurate and trustworthy health information (via search engine or hospital-based website)

Pay bills and obtain financial assistance

Routine email visit reminders

Annual health-care maintenance reminders (i.e. vaccine schedules, Pap smears)

Integrated patient health diary – ability of patient to integrate own health diary into EMR

vaccination schedules. One remarked excitedly, '*...if I could just punch a little button and get all my prescriptions renewed!*' Another exclaimed, '*There's been times when I've needed my prescriptions, my list of prescriptions. I can't remember them all...all those weird names. I'd be able to go in and print out my pharmacy!*'

Some wanted to be able to view the names of all health-care providers who had accessed their medical records and also to correct errors in the medical record. One participant stated, 'At least you have access to it, you know. Like right now I don't even know what's in my chart. At least to know what my doctor types in after I leave. But if it was online, I could go online to get it. Then I'd be able to say, you know, wait a minute – we didn't talk about this or whatever. Maybe he makes a mistake, you know? Maybe I made a mistake. It could be corrected.'

Patients wanted also to be able to communicate with their providers after reviewing the record, either via email, phone or face-to-face interaction. Patients also envisioned being able to conveniently 'chat' with other patients with similar diagnoses, using patient support groups through the portal. Many patients discussed the idea of personalized, age- and gender-based health recommendations (e-mail reminders to women to have a mammogram, get a booster shot for tetanus, etc.).

And finally, patients expressed interest in being able to make personal notes that would serve as reminders in a personal 'health diary' portion of the record. They pointed out that if patients had non-urgent questions that they wished to have addressed at an upcoming visit, they should be able to write themselves a brief online note so that they would remember.

The overall tenor of the focus groups was that the public is ready for online medical records. One participant summed it up, stating: 'It's in everything and just life and everything...and there's people that hack computers, and it's all going to go on and keep happening. But if we see something that's good, does that mean you just stalemate and stop and freeze up because, you know, oh, something can

happen to that? I think the motives of this are genuine and good. And I think it would help people. So does that mean we just don't do it because, uh oh, somebody could do this or that? I don't think so. Does that mean we stop? I don't think so.'

Discussion

Taken as a whole, the vulnerable urban patients in these focus groups were enthusiastic about gaining comprehensive online access to their medical records. They felt that such access would enhance understanding of their health, improve relationships with their providers and both allow and stimulate them to become more active participants in their care. While some described gaining access to computers as a challenge, they offered diverse options, such as using computers in public libraries, homeless shelters, coffee shops and the hospital health education centres.

In general, compared to patients in studies focusing on less-vulnerable populations, these inner-city patients seeking care at a county hospital had similar interest in accessing their medical records and strikingly similar thoughts about the opportunities such transparency might engender. The patients assumed ease of use with the technology and were under the impression that navigating through their online medical records would be a simple task, fulfilling one of the core determinants of user acceptance models to explain intentions to use new technology.[14]

In contrast to previous work on general patient populations,[6,15] some of these patients were not aware that providers wrote notes after each clinic visit. In addition, many did not know of their legal right to access their medical records. Moreover, many expressed worries about threats to privacy and specific concerns about who *else* would be able to see their records. Part of their speculation may have stemmed from neither having seen a secure web-based portal nor having accessed one using a personal identifier and password. In addition, the concerns of our participants may also have been heightened by mental health

issues, immigration status or other issues of special concern to vulnerable populations. Such fears accompanied the desire expressed by *all* patients for easy access to an audit function wherein they could ascertain exactly who had looked at their records.

Patients also reminded us in several contexts of the importance of open communication with providers and not wanting to be 'shocked' by something they read in the record. Mistrust has been cited as a reason that patients may request access to medical records, and discrepancies between verbal communication and written documentation can result in resentment towards the health-care team.[16] This might prove even more important when patients are able to access their records readily.

For varying reasons, some patients did not want to read their records, which is in contrast to other studies.[8–10] They are often worried about what they will find there,[6] and some with whom we spoke took the 'I don't want to know' concept a step further, believing that too much knowledge could contribute to self-fulfilling prophesies of worsening disease. Even when EMRs are broadly available to patients, some, almost surely, will not use them. On the other hand, the conversations appeared to increase participants' interest in accessing their records, suggesting that reaching out to patients with information about the potential benefits of viewing their medical records may motivate some to turn towards using them.

Our study is the first to ask individuals with HIV about their perspective on access to their medical records. We noted no difference between the patients from the HIV clinic and the general medicine clinic, except that the HIV-positive patients were more enthusiastic about having open access to their laboratory test results.

That our participants wanted access to their complete record is consistent with earlier findings from general patient populations. Some have suggested that materials such as documentation of mental health issues, differential diagnoses and varied social factors be withheld from patients.[17] One of the tasks on the road to transparency is to define such potential bound-

aries, and it will be important for patients as well as providers to consider possible limits. Further research could elucidate patient preferences using specific case examples.

Our focus group patients worried also about how patient access would affect their providers, fearing that it could increase the number of messages and amount of uncompensated time spent communicating with patients. This concern over burdening the provider has not been previously described in this patient population. While they echo the concerns of many clinicians, published studies have yielded mixed results regarding increased physician workload,[18,19] and we hope that what we learn from the broader OpenNotes study will shed further light on this important issue.

These patients raised several themes of broad interest that should become hypotheses for further study. Perhaps, the thorniest matter relates to whether certain parts of the medical record should or should not be 'open'. We need next to bring together clinicians and patients to discuss the limits, if any, on the transparency that 'open' medical records exemplify.

A strength of our study is the use of qualitative research methods that rely on anthropological techniques. This approach seeks to listen to the participants without introducing our own bias as we gather data. Patterns in the data are then identified. Results from qualitative research are often invaluable for informing and making sense of quantitative results and providing greater insights into clinical questions and public health problems.

As with most qualitative research, however, our study is limited by its small size. It involved a single location, and our findings may not be generalizable to other vulnerable patient groups, such as those from diverse cultures and traditions regarding health care. Although our intent was to reach vulnerable populations, we excluded patients we thought incapable of participating, and we were unable to recruit those patients without access to phones or email. As a result, we may have excluded some particularly vulnerable patients. Moreover, while an important study finding is the fact that partici-

pants had little knowledge of the content of medical records, of EMRs or of how web-based patient portals worked, this can also be seen as a limitation when reviewing their comments about potential risks and benefits.

Conclusion

Vulnerable patients, including those with chronic diseases such as HIV, were overall enthusiastic about the prospect of gaining ready access to their medical records based on our findings. Lack of knowledge of EMRs and concerns of privacy still exist in this population and will need to be addressed to avoid introducing a new element into the health-care 'digital divide'.[20] Safety net institutions will need to provide targeted support to help their patients benefit maximally from what appears to be a rapid and inevitable movement towards the technologies we describe.

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