

The Electronic Health Record and Patient Portals in HIV Medicine

Pushing the Boundaries of Current Ethics and Stigma

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Abstract: The electronic medical record provides an exciting opportunity to support the coordination of care by medical and social providers. Many of these systems include patient portals that allow providers to share clinical information with patients in real time. These “patient portals” provide a unique opportunity for clients and patients to access and use HIV and sexually transmitted infection information for communication with healthcare providers, with potential or actual sex partners, and for tracking their own clinical course and progress. A concerted effort to develop these should include a high level of transparency and adequate support for both patient and provider.

Keywords: HIV; sexually transmitted infections; patient portal; electronic medical record

HIV medicine in 2014 was marked by the personalized nature of the medical management of this now-chronic condition. With a very broad repertoire of antiretroviral medications to treat this once untreatable infection, clinical trials data are contextualized to the exact viral genome that infects each patient. Guidelines indicate appropriate use of these medications; but ultimately, viral genetic information is used to select what medications will suppress viral replication in a patient, taking HIV from modern plague to a manageable chronic disease. HIV is the infectious disease version of diabetes or hypertension, a treatable condition that when controlled, decreases the risk of life-threatening complications.

HIV patients, like their medical providers, are influenced by their clinical data. Shortly after diagnosis, many people living with HIV develop both an understanding of and compulsive need to have the status of their “numbers,” such as their T cell count and their HIV viral load. In living with HIV, patients become de facto molecular biologists.

They develop at least a superficial understanding of polymerase chain reaction to measure the amount or “load” of virus in their blood and flow cytometry to quantify the number of CD4-positive T cells circulating in their system to protect them from infection. Patients are focused on having undetectable viral loads, which is evidence of the efficacy of their antiretroviral cocktail and successful adherence to these medications. This focus on “undetectability” is the cornerstone of HIV medicine, and the primary way in which the quality of HIV care is measured. In addition to the information about their viral load, most patients closely track their T cell counts, a number that indicates the relative health of their immune system, the stage of their disease, and their risk for a host of opportunistic conditions and infections. High T cells and low viral load are the central goal of HIV therapeutics, and, debatably, of HIV care.

In addition to its being a measure of personal health, the scientific community, people living with HIV and those at risk for HIV have accepted the HIV

viral load as a measure of how infectious someone with the virus may be. With studies such as HIV Prevention Trials Network (HPTN) 052 and the Conference on Retroviruses and Opportunistic Infections (CROI) PARTNER Study,¹ indicating that individuals with suppressed HIV viral loads are very unlikely to transmit HIV, undetectability is often information used in negotiating condom use and safety in sexual relationships. The focus on laboratory parameters as well as detailed discussions about other laboratory-based testing is the cornerstone of the interaction between people with HIV and their providers.

Patient Portals and the Electronic Health Record (EHR)

Some EHRs allow patients to enter a portal that permits them to see their laboratory results and communicate with their providers through secure communication. Patient portals provide an opportunity for clinicians to share a high level of data with their patients, because patients are able to directly access laboratory results and to discuss them with healthcare providers. Patient portals create a high level of efficient information exchange critical to the patient's self-management of disease. Information on the patient portal can be accessed using handheld devices, making the portal a moveable medical record that patients may use to share their data with medical providers and other significant individuals in their life. Several practical examples occur in practice.

Sharing HIV and Sexually Transmitted Infection (STI) Testing Results with Sex Partners

Mobile applications of the patient portal allow both people living with HIV and those at risk for HIV to show potential

partners test results that may be used in negotiating safety in sexual encounters. HIV-negative individuals may share their up-to-date HIV and sexually transmitted disease (STD) test results to demonstrate the lack of infection. Similarly, people with HIV may share data about their undetectable viral load to demonstrate that they are less likely to transmit HIV. Although this data sharing may lead to unprotected sex, it facilitates sharing HIV status information with sex partners and might help reduce the risk of transmission.

Provision of Real-Time Data to Non-Primary Healthcare Providers

Despite the efforts of HIV care providers to teach patients to remember their "HIV vitals" such as T cells, viral load, and medication lists, these details are often forgotten by many patients. The mobile portal allows patients to share their medical information when they seek care in clinics, emergency rooms, or urgent care centers outside of their primary care venue.

Many patients will log into their portal to share their most recent laboratory test results and medications. The benefit of such data to an outside provider is significant. T cells results allow providers to stratify the risk of the patient for acquiring opportunistic conditions. For example, pneumonia in a patient with 100 T cells may be caused by significantly more pathogens than a clinically identical pneumonia in someone with 500 T cells. Correct medication lists also prevent interruptions in therapy as well as inadvertent medication errors, which may occur with the very complex medication interactions associated with common antiretroviral treatment.

As a provider of HIV care to many people living with HIV, I have learned that there are many benefits to patients using such an interface; however, I have

also been taught about some of the limits of this technology in the context of a disease that is still stigmatized. The patient portal allows a clinician to release results and, often, explanations of these results to their patient. Given the data-driven nature of HIV medicine, this provides a clear benefit to the provider and a willing patient. In a typical visit, patients will have a significant number of laboratory tests to monitor the progress of their disease, the efficacy of their treatments, and the potential medication- and disease-related complications. In the past, patients were often scheduled to return after their laboratory testing to review all of the results in great detail, often limited by the often-overbooked schedules of urban HIV medicine providers. With patient portals, such as Epic MyChart, the patient's laboratory test results can be released once they are reviewed by the clinician with an explanation of the meaning of these values.

It has become routine for me to release reports of undetectable viral loads with a brief message encouraging a patient to continue adherence to medication and commending the patient with a gold star on a viral load report card. The portal also provides a highly efficient way to report results and formulate a plan for follow-up. An example is when a patient has a detectable viral load after it had been suppressed on medication. This can represent a probably meaningless and transient increase in virus or can herald the failure of an antiretroviral regimen. Releasing a detectable viral load via the patient portal to a patient who had previously had no evidence of viral replication can cause significant stress. Coupling these data with a message from the clinician that explains the meaning of the result and maps a path back to the clinic for a repeat check may lessen the blow and provide an action plan for patients

to be aggressive about managing their HIV.

Another important use of the portal that is often critical to the timely management of disease is in the realm of HIV and sexually transmitted infection prevention. People living with HIV and those at risk for infection need up-to-date information about sexually transmitted infections, given the nature of their sexual lives. The patient portal allows clinicians to communicate both positive and negative results to help patients formulate a plan for prevention or treatment. These are three very common examples in my practice.

Pre-exposure prophylaxis (PrEP) initiation or continuation. PrEP is the Food and Drug Administration (FDA) approved use of HIV medication in HIV-negative individuals at risk for infection, to prevent HIV seroconversion. To start this intervention, an HIV-negative test needs to be documented in the her, and kidney function needs to be measured to initiate and to continue this highly efficacious medication. The patient portal may be used to inform patients that their test result is negative, and it can be used for electronic prescription of PrEP medications. These patients are also instructed to use the portal to discuss side effects and potential symptoms of acute HIV infection that may indicate the need for urgent discontinuation of PrEP.

STI treatment and prevention. The patient portal also allows providers to release the results of STI testing. This allows for communication of these results in a timely manner that eases anxiety, accelerates treatment, and allows for expedited partner management.

HIV exposure management. The patient portal is also a very important tool in post-exposure prophylaxis (PEP). Patients can be instructed to use the

portal after a potential HIV exposure to contact their provider to be started on preventive medicines. Appropriate exposures can trigger e-scripts of PEP medications and subsequent expedited HIV and STI testing.

Patient Portals, Confidentiality, and Stigmatization

To many people living with HIV and at risk for infection, confidentiality and the discretion of their medical care establishment are central to their care alliance with their physicians. Therefore, the benefit of an electronic patient portal for that population is limited by the perception that the use of this technology may lead to potential infringements on confidentiality and result in stigmatization. Although data empower people to continue managing their disease and engage with the details of their infection, accessibility of the data may also be viewed as a step toward disclosure of their medical information. Despite assurances that the interaction using the portal is secure and password protected, and that confidentiality is maintained, some of my patients decline enrollment in the patient portal citing mistrust of this technology.

To providers who take care of the often-marginalized population of individuals living with or at risk for HIV, the importance of confidentiality does not come as a surprise. Despite significant strides in reducing stigma, HIV remains shrouded in shame and internalized feelings of self-hate. In the daily lives of people living with HIV, stigma leads to secrecy and, ultimately, to denial. For some individuals, any document, digital or real, that reveals HIV-related information, provides an unwelcome opportunity of disclosure, alienation, and hate. Optimistically, one could hope that fear of stigmatization and other potential social harms of disclosure are

more perceived than real, but in some communities, disclosure of HIV risk or positive status could result in estrangement from family, community, and other personal support structures. A further most serious concern about disclosure is that it could lead to physical or mental abuse from partners or family members.

An example of how good intentions may lead to significant patient discomfort relates to the guidelines for the meaningful use of the EHR.² Meaningful use is defined as using certified EHR technology to improve quality, safety and efficiency, and reduce health disparities. It should also improve engagement with patients and family. The EHR ought to improve coordination of care as well as improving population and public health.

The guidelines specifying the meaningful use of the EHR include the recommendation to provide patients with a written care plan on discharge from a clinic. For many patients, this is a useful tool that might help them adhere to treatment and encourage self-care. For example, individuals with diabetes, hypertension, and other less-stigmatized chronic conditions can benefit from having a written and printed care plan. For individuals with HIV, however, a document listing laboratory results, health problems, and medications can be the equivalent of a public announcement of their disease. Many of my patients refuse to accept this printed form and some are offended that they are offered such a document.

Conclusion

The increase in accessibility of medical information stored in the EHR by the patient has in many ways been a great fit for the modern management of HIV disease. The emerging epidemic of HIV among technology-savvy youth means that patient access to EHR data is a natural extension of social media and other

applications used constantly by these individuals, but despite the security of such portals and the good intentions behind the technological developments that enable patients to access personal data about their disease, patient portals are in many ways ahead of the social normalization of HIV. It is important to remember that for some individuals, HIV-related information, or potential evidence of HIV care, threatens perceived or actual security. Like so many other aspects of HIV medicine, use of

patient portals requires sensitive personalization of the technology to the individual patient.

Notes

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2. Blumenthal D, Marilyn T. The “meaningful use” regulation for electronic health records. *New England Journal of Medicine* 2010;363(6): 501–4.