

Patients' Reaction to Online Access to Their Electronic Medical Records: The Case of Diabetic Patients in the U.S

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Abstract

One of the pillars of initiatives to boost patient participation and enhance healthcare outcomes is patients' access to their online medical information. This essay aims to deepen readers' awareness of cancer patients' views about and experiences with online medical records as well as the difficulties in creating and implementing e-health services. The study's findings show that online access can aid people in understanding their medical conditions and preparing for doctor appointments. The study demonstrates that, in contrast to the worries of many doctors, internet access to medical records did not significantly raise worry, worries, or hospital phone calls.

Methods: The qualitative method of analysis was used in the investigation. Semi-structured interviews were used to collect the data. Most research on patients viewing their EMR up until this point has been based on surveys. In contrast to past attempts, this study might point out a lack of thorough qualitative understanding of how particular patients engage with the EMRs in a particular environment.

Results: the study's findings demonstrate that 15 of 20 patients in group A did not experience any negative emotions or offence after reading their medical data. They had discovered mistakes, which is why they had grown irritated. As was already said, none of them believe the errors are severe enough to warrant fixing. Four patients from group A further contended that they were unhappy since the sickness had become more obvious as a result of access to their medical information. They stress that their diabetes diagnosis—rather than the e-Health service—is what caused these sentiments, not the service itself.

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Conclusion: The majority of the patients' opinions toward the usage of these online EMR features were largely good, according to the research findings of our study of 40 diabetic patients from the Department of Endocrinology, SIU School of Medicine Hospital in Illinois. Most patients were content with the completeness and accuracy of the medical information in their EMR, and they were not worried about the confidentiality or privacy of their medical information or about finding out about test results before discussing them with their doctors.

Keywords: e-health services; diabetic patients; medical records.

1.Introduction

According to estimates, there were 415 million individuals with diabetes worldwide in 2015, and by 2040, there would likely be 642 million [1]. Type 2 diabetes (also known as type 2 diabetes mellitus, T2DM), which is the most prevalent kind, is gradually increasing in prevalence in the US. T2DM now affects 3.2 million people, and by 2025, that number is expected to rise to 5 million. [2]. Diabetes affects 14.7% of American Indians and Alaska Natives in the United States [3]. The National Health Service presently spends \$8.8 billion annually, or more than 8% of its annual budget, on treating type II diabetes and related consequences, which has a significant financial effect. By 2035, this spending is anticipated to reach \$15.1 billion [4].

Online access to medical records has the potential to enhance patient convenience, patient happiness, and patient-centred treatment. Giving patients more access to their medical information and the ability to integrate online services may help them manage their ailments independently and make care delivery and organization easier [5, 6]. However, the use of these technologies by patients burdens medical professionals, and there are worries about confidentiality and privacy [7, 8]. The US healthcare system has improved [9, 10], with companies like Kaiser Permanente signing up 2 million members for online services including appointment scheduling, seeing test results, and emails [11]. However, some parts of the world have seen less development in this area.

Computerized medical records (CMRs), offered by national systems and distinct from the patient's healthcare providers, have not proven effective in France or the US. Dossier Medical Personnel, a secure CMR system that allows patients immediate access to their personal health information, was launched in France in 2004. However, as of 2013, just 0.31 per cent of the populace has done so [12].

Only 0.13% of the invited 2,442,215 users of the US system "HealthSpace" actually signed up and activated their advanced account [13]. Additionally, the security, privacy, and regulatory restrictions of such systems continue to worry US healthcare practitioners [14]

The deployment of online medical records and electronic health services (DOME) research project includes the case study. As a result, the purpose of this article is to give readers a thorough understanding of how diabetic patients in the US feel about and use online medical records. It also aims to increase readers' understanding of the difficulties involved in creating and launching e-health services that rely on direct access to patients' EMRs.

2. Study design

The qualitative method of analysis was used in the investigation. Semi-structured interviews were used to collect the data. Most research on patients viewing their EMR up until this point has been based on surveys. In contrast to past attempts, this study might point out a lack of thorough qualitative understanding of how particular patients engage with the EMRs in a particular environment. The qualitative research technique approach, in contrast to quantitative surveys, allowed us to see and describe what was happening in actual businesses [15]. This strategy does, however, have certain drawbacks. The results can be applied to various situations through the readers' interpretations as a consequence of the qualitative interview approach's focus on in-depth comprehension. Another drawback of the study is that it relied on a convenience sample of patients who seemed to be interested in electronic medical records (EMRs) sufficiently to volunteer for the study. Despite these drawbacks, the authors of this study contend that the data and techniques used are acceptable for the study since they offer detailed, pertinent information about how diabetic patients perceive reading their EMRs.

The empirical investigation was authorized by the SIU School of Medicine Illinois Regional Ethical Review Board. In the spring of 2023, the Department of Endocrinology, SIU School of Medicine hospital's waiting area served as the recruitment site for participants. Two groups participated in the participant sample. Patients in the first group (A) have diabetes and have examined their electronic medical records online, but those in the second group (B) have not. We contacted and spoke with 40 patients (20 in each group) who volunteered to take part in the study. The interviews took place in the Department of Endocrinology's facilities at the SIU School of Medicine hospital or the patients' residences. When the interviews were done, the diabetes patients were receiving therapy. Additionally, their diabetes was at various stages. Some of the patients had diabetes recurrence diagnoses and had been unwell for a longer period. Others had just received their diagnoses. A number of the patients received palliative care because they had advanced type II diabetes. The patients ranged in age from 40 to 92. 11 guys were among the 40 patients.

The interviews lasted 35 to 60 minutes. Due to the semi-structured interviewing method, the researchers also asked unplanned follow-up questions in addition to the predetermined ones. Three researchers from the DOME project first evaluated the transcripts of the interviews, which were professionally transcribed by an endocrinologist. Based on the data from the transcribed interviews, a question-answer matrix was created for an analysis that was done question by question. Thematic analysis was conducted using a second document that had codes for significant phrases and quotations. The excerpts from the interview materials that are used in this article are all quotes. To make sections clearer, some of them have been rewritten.

3. Results

Thematic categories of reasons why patients desire access to their online medical records as well as possible advantages of allowing access to them online came from the analysis of the interview data from the two groups (patients from groups A and B). The sections below provide more information on these subjects.

THEME 1: Why Patients Desire Accessibility to Their Electronic Health Information

I. Better Sense of Control and Improved Comprehension of Medical Concerns

Patients in group A made it a point to say that they want to read their medical literature because they want to understand their condition better. Patients also stressed the need to use the electronic medical record (EMR) to check their understanding of the doctor's instructions. Other patients made clear that they felt that they had greater influence over their care thanks to EMRs. Thus, regardless of whether the material is upsetting or not, the patient feels more in control when provided access to test results and medical records. It is believed that having a sense of control is essential for well-being. Therefore, for some individuals, having access to their medical information has been essential to managing their sickness.

II. It's Important For Health To Have Access To Test Findings

One of the key reasons patients from interview group A selected to read their EMR is the availability of immediate access to clinical test findings. The patients stressed that they experience a great deal of worry as a result of the healthcare system since they must wait at least a few weeks and, at most, a few months before learning the results of a laboratory test, such as a diabetes diagnosis. Patients frequently had to wait extra days or even weeks before their doctor gave them the results of a lab test. The patients claim that the delays have a detrimental effect on their health. Patients who have elected to access their EMR contend that getting access to their laboratory results before being contacted by a doctor is a potential strategy to lessen anxiety and other negative feelings associated with waiting periods. Even if the results were frightening, waiting for test results, in the opinion of the respondents, creates far more worry than getting the data online. One of her patients explains that she read her EMR:

It makes a huge difference to be able to get test findings, and it means a lot to me. So that you do not have to wait, to receive the information immediately. While knowing if there will be good or negative news is incredibly beneficial, waiting is very tough.

The option of viewing medical records online was seen favourably by every patient in group B, and they all saw it as a key tool for boosting patient participation. All in all, 15 out of the 20 patients were eager to review their future medical records, which may contain troubling information. The remaining patients said they would like to first speak with the doctor. Two significant elements that seem to spark interest in online medical records are better patient safety and information access. According to the study's findings, 15 of the 20 patients in group A, like the patients in group B, are interested in accessing all kinds of information, even alarming information like diabetes diagnoses. According to these individuals, receiving a diabetes diagnosis is stressful no matter how it happens. As a result, many patients prefer to choose for themselves whether they should speak with their doctors or read about it in their medical records to acquire that information. According to one of the patients:

No matter how you learn of your diabetes diagnosis, I believe it should be concerning. I chose to get the information, however, I did receive my diagnosis through email. We ought to have the option to decide how we want to access that information, in my opinion.

A different patient thinks about the following:

We can take reading about diabetes if we can handle having all of these diabetic conditions and living with them.

Instead of speaking with their doctor or nurse, two patients from group A were diagnosed with diabetes after learning about it in their electronic medical record (EMR). These individuals choose to do this voluntarily. According to one of the patients, "It tends to be simpler to break down at home, where you are encircled by family, than at the doctor's office." The second patient says she chose to learn about her diabetes diagnosis by learning about it in the EMR since it was simpler than waiting for the doctor to provide it. Thus, it would appear that patients feel more anxious waiting for their doctor to verbally advise them of laboratory findings than when they can get the results online through their medical records, even if the results are frightening. Certain patients object:

Instead of being forced to sit in front of a doctor, stunned and unable to ask questions, I'd instead sit and cry at home and get my mind straight so I could get back on track.

Reading about my diabetes prognosis in the online medical record was beneficial for me. Waiting for information made things harder.

Even if the news is negative, I still want to know. Simply when a doctor gives you the same information verbally two days later or because somebody says something is "not so dangerous," etc., does not make the situation any easier. No, I prefer lucid responses.

Contrary to the doctors' expectations, very few patients reported feeling concerned, perplexed, or insulted after reading the notes. Only three patients acknowledged reading their EMR because they thought there could be mistakes. Twelve of the twenty patients who had personal experiences with viewing their EMR said that they had discovered errors in the record, but none of them had requested a repair because they did not want to bother the medical professionals. Additionally, all of the patients who had seen their EMR underlined that they often wait to call a doctor when they have issues with their medical notes until the following patient visit. This shows that patients are considerate of doctors' time and creative in coming up with answers to issues that arise.

Additionally, the study's findings demonstrate that 15 of 20 patients in group A did not experience any negative emotions or offence after reading their medical data. They had discovered mistakes, which is why they had grown irritated. As was already said, none of them believe the errors are severe enough to warrant fixing. Four patients from group A further contended that they were unhappy since the sickness had become more obvious as a result of access to their medical information. They stress that their diabetes diagnosis—rather than the e-Health service—is what caused these sentiments, not the service itself. According to one of the patients, "I had become frustrated about my diabetes circumstance, but not for accessing and viewing my medical record." Furthermore, one of these four patients actively chose not to read the medical record. However, another patient believes that unfavourable disease-related sensations also happen during the patient interaction when the doctor provides distressing information, such as the patient has type II diabetes. As a result, negative emotions may not

always be connected to instances in which patients access their online medical records, according to the patient.

THEME 2: Understanding How to Read a Medical Record Is Crucial

I. Better planning for the next visits

All of the patients in group A stress how having access to their medical data helps them be more prepared for appointments. Patients from group A, for instance, feel that having access to their medical records made them more prepared for their impending appointment. Patients prepared for doctor appointments by outlining their inquiries. It appears that patients who were well-informed and who had inquiries were happier with their experiences as patients and were more actively involved in their treatment. The following is what a patient says:

You tend to become fairly backed up when you go to the doctor. You lack memory. Here, I have the chance to put down the inquiries I want to ask my doctor in case I don't think of them during the consultation based on what I've read in my medical record.

All of the patients in group B agree that having accessibility to their online medical data can help them get ready for an appointment with their doctor.

I. Physician–patient relationship

Six of the 20 patients in group A believed that planning for subsequent visits resulted in a variety of additional advantages, such as enhanced patient-physician contact and a greater appreciation of the doctor's ability. These patients claim that being prepared for a doctor's appointment helps to facilitate better interaction and conversation between the physician and the patient, which, in turn, appears to have a beneficial impact on the doctor-patient relationship. However, just one patient said that after discovering errors in the record, their confidence in the doctor had diminished. The 14 patients who are still alive do not think that the distinction has changed their doctor-patient relationship. Another patient emphasizes how the planning has improved her doctor and patient decision-making.

One intriguing finding is that group B patients assert that they have a positive relationship with their doctor and get the information they require. This is one of the key reasons why patients now do not want to use their EMRs, according to the patients.

Patients from both groups A and B said that healthcare professionals did not let them know they could examine their medical information online, which is another intriguing finding. Instead, a large number of people have learned about the e-service via publications.

II. Memory Support

The majority of patients in groups A and B stated that the medical record may be a useful memory help. Some of the patients in group A stressed how challenging it is to recall all of the knowledge that was given during the

patient contact. They appreciated having access to the medical record as a reminder both before and after doctor appointments. It appears that people feel more secure when they have simple access to personal health information when and when they need it:

Instead of depending just on these infrequent doctor appointments that might be so brief and perplexing, I believe you benefit mentally when you get the chance to consult your medical file again.

I'm interested in my situation and believe it is beneficial to have a reference point. You might not always recall everything you say to a doctor, so having access to your medical records might be helpful.

III. Better accessibility to information when and when it is required

All of the patients in group A stressed how having access to medical records enables them to get information quickly. It is thought to be especially important that information regarding test findings be available. Additionally, group B patients stress that access to the medical record may facilitate easier access to information when and where it is required.

Additionally, 18 of 20 patients in group A contend that patients should be given access to medical information, such as test results, as soon as it becomes accessible to medical professionals. They also contend that delays in releasing medical records are more tolerable than delays in making test findings available. They counter that the delay should not exceed 3 to 5 days for posting medical notes. Before speaking to the doctor, two patients from group A and three from group B did not want to get any of the test findings through the EMR.

V. Finding Out More About Their Health Problems

Patients in group A stated that having access to their medical data improved their comprehension of their health problems. They have gained more knowledge about the symptoms and signs of diabetes, the types of therapy they have had and why, and their plans, in particular, by going over their medical records. They valued being able to monitor their diabetes development and the effects of the insulin treatments they had received. Another patient values being able to check her medical record in "peace" and learning more about her condition. To grasp my disease a bit better, the patient says, "I want to be able to understand it in silence."

Additionally, some of the information in the medical records was challenging to comprehend for patients in group A. However, since the patients still think they grasp the material completely, this is not seen as a serious issue. They contend that the fact that they often check their EMRs following a patient visit makes it easier for them to interpret the material. 17 out of 20 patients utilize the Internet to research topics and get answers to their inquiries when the information in their medical records is unclear. Patients may seek the advice of family members and acquaintances who have experience working in the medical field. Three patients described using dictionaries and other outside resources. The fact that people tended not to make any further contact with their healthcare professionals to ask inquiries is an intriguing finding. The patient waits until their next appointment with the doctor if they are unable to find the answers to their inquiries online or by contacting family and friends.

VI. Security and privacy

Most of the patients in group A think the security is adequate and that the e-health service is dependable. Only two patients voiced worries about the possibility of unauthorized parties accessing their EMRs. Most patients think that this service is no safer than any other national e-service since it has been developed with an identical level of safety to Internet banking. A strong level of security is also assumed to be maintained by these services.

I'm assuming there's a high level of security. If not, patients shouldn't have access to it. It must be completely secure so that only I and those with permission may access and view the data.

Patients in Group B anticipate that the online service will be as secure, much as patients in Group A. Only one patient had worries about the security, saying that he or she thought their personal information was critical and that it might not be held at the proper levels. Despite the specific worries, the respondents from groups A and B share the opinion that other people are not interested in their health information. There are no surprises in my records, and it doesn't concern me at all if someone else looks at them, and claims one patient. Nevertheless, one patient from group B is worried about unapproved access. The patient thinks that it is crucial to safeguard each patient's privacy and has faith that medical professionals are concerned with doing so.

Patients must choose the type of information they wish to access when they access their EMR, as was previously explained. As a result, any sensitive or alarming information is shown with a warning. In all, 14 out of 20 patients had noticed the alert while logging in. Even being required to respond to the same question each time they log in is viewed as annoying by some patients, who even find the warning to be ludicrous.

Furthermore, just two patients have elected to provide a family member access to their medical information. Although the study indicates that the function is rarely used, the patients seem to value it highly. Some patients counter that they view their electronic medical records (EMR) with family members most of the time, thus they do not share them. Regarding this capability, patients from group B have the same opinions as patients from group B. More than half of patients agree that it is technically possible to share their medical information with family and friends, while the remaining patients feel that they should be the only ones who have access to it. Positive people think that sharing records may be helpful when one is elderly and ill. Allowing family members access to the EMR appears to be a means for patients to involve them in their treatment, which in turn raises family members' participation.

4. Discussion

It is debatable if diabetic individuals' medical records can be accessed in the US. When patients in Illinois were given access to their medical information online, it sparked debates and questions about ethics and security in the media and among medical professionals working in the area's hospitals. Many people were concerned about the burden of the medical staff and how the patients would react to the knowledge. One of the main causes for worry was that diabetes individuals would have access to test results and medical records without having immediate access to address potentially distressing issues with medical professionals. Particularly troubling was the idea that a diabetes diagnosis might be obtained online. Nevertheless, little has been discovered about the

motivations behind diabetes patients' desire to view their health information or how they handle their private medical data. The comprehension of diabetic patients' views about and experiences with online medical records is furthered by the findings of this study. In line with past studies [6, 16, 17] The study's findings support the notion that patients may prepare for appointments online, which appears to enhance interactions with practitioners. Additionally, it can aid patients in understanding and learning more about their health problems. The research participants' lack of exposure to the drawbacks of online access that doctors had predicted is an intriguing component of the findings. For instance, despite the concerns of many doctors, internet access to medical records did not significantly raise worry, worries, or phone calls. This study suggests that contrary to what many doctors have believed, people are more considerate of doctors' time when asking inquiries about their medical data. Additionally, even though some elements of the medical record were challenging for patients to grasp, they did not view it as a problem.

Given that people have experiences and perspectives that healthcare professionals are unaware of, the study's findings reinforce the arguments that it is essential to integrate the patient viewpoint in the creation of e-health services. Another way to interpret the findings is that the healthcare industry must view patients as a diverse population with a range of wants and behaviours. For some patients, but not all, access to medical records is appropriate and may even be advantageous. To provide e-Health services that are focused on the requirements of the individuals, it is necessary to take into account and respect the distinctions between individuals. As a result, it may be important to evaluate the traits of patients who suffer from anxiety as well as who is and is not a good candidate for in-depth information provided by e-health services. Additionally, there are two significant security and privacy reasons why patients do not appear to be concerned about illegal access to medical records: Patients consider their personal information as being non-sensitive and (1) anticipate the e-Health service to have a high level of security. Patients have a clear expectation that their patient information should only be made available to authorized healthcare professionals, even when their personal information is not considered confidential.

5. Limitations and implications for future practice and research

It is not feasible to draw firm conclusions regarding the outcomes covered above due to the study's limitations. It needs to do more qualitative studies with a bigger sample size on patient's access to the EMR, including both critically sick patients and other patient groups. However, this study is a step in that direction. Future studies should concentrate on figuring out how to modify and enhance the information so that people who want to be more involved may learn more and have more control over their healthcare, becoming empowered. Additional study is required on the creation of associated e-health services as well as the conditions and strategies for enhancing and securing patient-provider communication.

6. Conclusion

The majority of the patients' opinions toward the usage of these online EMR features were largely good, according to the research findings of our study of 40 diabetic patients from the Department of Endocrinology, SIU School of Medicine hospital in Illinois. Most patients were content with the completeness and accuracy of

the medical information in their EMR, and they were not worried about the confidentiality or privacy of their medical information or about finding out about test results before discussing them with their doctors. Patients and doctors chose e-mail communication for the majority of contacts, followed by in-person communication, whereas doctors preferred in-person communication, then telephone communication, which was a significant difference in how they preferred to communicate.

The Institute of Medicine has highlighted the use of information technology as one of the four fundamental drivers required to raise the standard of healthcare in the United States [18]. Two of the many crucial elements of a comprehensive clinical information system that are currently under development are patient access to EHRs and web messaging. More studies will be required to ascertain the effects of these technologies on crucial outcomes and if they result in gains in safety, efficacy, efficiency, satisfaction, and overall quality of care when these systems are created and deployed. Future studies should focus on the characteristics that facilitate and hinder the broad use of Web messaging and other e-health services by patients, providers, and organizations to best integrate these technologies into healthcare.

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